Social Indicators Research Series 61

Barbara M. Altman *Editor*

International Measurement of Disability

Purpose, Method and Application
The Work of the Washington Group

Springer

Social Indicators Research Series

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Howard Meltzer
22 March 1951–23 January 2013

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Professor Howard Meltzer was an outstanding social researcher in the field of disability and an expert in the design, implementation, and analysis of national health surveys. As a charter member of the Washington Group on Disability Statistics representing the Office of National Statistics of England, he contributed enthusiastically and tirelessly to the improvement of disability statistics for international use. Born in Manchester, England, he was educated at North Manchester Grammar

School, North East London Polytechnic (BSc Psychology), London School of Economics (MSc Sociology), and Hull University (PhD). In 1979 he was appointed principal social survey officer, Social Survey Division, Office of Population, Censuses and Surveys (later becoming the Office for National Statistics), and promoted in 2004 to deputy divisional director, Health and Care Division. During his time at OPCS/ONS, he masterminded the national survey of disability in the late 1980s. Thanks to Howard's survey design skills Britain now has a unique mental health survey program which no other country has surpassed. This program of national mental health surveys of adults, children, carers, prisoners, and homeless people (www.mentalhealthsurveys.co.uk/) has made major contributions to the improved understanding of prevalence, risk, and protective factors for different illnesses and has been used to inform national policy on mental health and disability. The standards he set for survey design have had a major international influence.

In 1991 Howard began development and pilot work in Leicestershire on survey methods for measuring the prevalence of psychosis in adults. This work which was implemented in a general survey of Great Britain in 1993, with repeat surveys in 2000 and 2007, made possible the first and only survey of autism in adults in the general population in 2007. In 2006 Howard left the civil service and took up his academic chair as professor of mental health and disability in the Department of Health Sciences, University of Leicester.

Internationally, Howard made substantial contributions to the work of the Washington Group. He presented ideas, wrote papers, and often played devil's advocate in the discussions and decision-making processes that accompanied the development of survey modules on disability. He was particularly concerned with the measurement of disability among children and actively participated in the workgroup on child functioning and disability. The results of that work are included in this volume. While his contributions to our work are sorely missed, his spirit lingers as we continue to consider "what Howard would have said" in our ongoing deliberations. We are fortunate to be able to publish one of his last papers in this volume.

After work was done, Howard, the consummate gentleman, was a bon vivant of sorts enjoying the wine, cuisine, and shopping opportunities offered by the countries hosting the Washington Group meetings. He joined in spirited conversation on a wide range of topics with his colleagues. Howard always was well read and witty with a warm heart and a twinkle in his eye. We will miss all this as much as we feel the loss of his intellectual contributions. He is survived by his wife, Sylvie, two stepdaughters, Sophie and Claire, of whom he was immensely proud, and his brother, Edwin.

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Biography

Barbara M. Altman is a sociologist with a PhD from the University of Maryland. Retired from the National Center for Health Statistics, CDC, where she served as Special Assistant on Disability Statistics to the Office of the Director, she also worked at the Agency for Healthcare Research and Quality on the Medical Expenditure Panel Survey. She currently serves as a consultant on disability statistics issues. She has been involved with the work of the Washington Group, an international group working under the auspices of the United Nations, since its inception. She was also co-leader of the interagency committee which developed the questions on disability currently used in the American Community Survey which have also been adopted by other agencies such as the Bureau of Labor Statistics and the Justice Department. Her disability research interests focus primarily on disability definition and measurement, access and utilization of health-care services by persons with disabilities, and disability among minority groups, particularly Native Americans. She is the author of numerous articles and book chapters on disability topics including the recent *Disability and Health in the United States Chartbook* and currently is coeditor of the series *Research in Social Science and Disability*.

Sathi Alur is a development economist with professional qualifications in finance and management, accounting, and jurisprudence. He has worked with multinational corporations in Sweden and India, with many governments and in the international social development sectors—education, health, water, and disability—and international development agencies such as the World Bank and UNICEF. He was among the early pioneers in India (late 1970s) bringing professionalism into the finance and project management areas of NGO operations and service delivery in India. His work has focused on addressing sustainable, scalable, and replicable initiatives particularly in the context of restricted public finances, the absence of universal entitlements, and lack of social protection. Currently in India his work examines improved methodologies of data collection and analysis as a basis for more efficient and cost-effective ways of organizing and delivery of vital services for persons with disabilities particularly and of social services generally. He is also a member of the World Cerebral Palsy Initiative and of international professional management institutions.

He received his academic degrees from the University of Mumbai and professional qualifications from management institutes in India.

Alessandra Battisti is researcher at ISTAT (Italian Institute of Statistics) since 2000. Alessandra has a degree in Demography and Statistics Sciences from the University of Rome "La Sapienza," 1998. Alessandra has collaborated on the project "Information System on Disability," and she has developed considerable expertise in the management of surveys on different issues. Alessandra has also developed considerable expertise in the analysis of health data and indicators. At the international level, she has participated in many groups aimed to harmonize health statistics at the European level and in many international projects on disability (Washington Group on Disability Statistics, Budapest Initiative).

Alicia Bercovich is a demographer with a PhD in social sciences and MSc in mathematics. She was the coordinator of the Population Census Committee at the Brazilian Bureau of the Census (IBGE) for 13 years. She also coordinated the participation of Brazil in the Joint Population Census for the Mercosur countries, Bolivia and Chile. She was head of the Population Division in the 1990s and head of the Research and Data Preparation Division of the Census in the 1980s. She was a member of the Planning and Organization Commission for the Brazilian Census. She is a member of the Washington Group on Disability Statistics since its creation in 2001. Currently, she is an associate member of the Institute for Studies on Labor and Society (IETS). She has a wide experience in population censuses and large-scale surveys. She has published several papers, chapters, and reports on demographic topics: demographic discontinuities, disability, population structure, the youth wave and its impact on the labor market, and the demography of violence.

Emmanuelle Cambois is a senior researcher at the French demographic institute INED (Institut national d'études démographiques) and member of the research unit on "mortality, health, and epidemiology." Her research is in the field of public health and the population health measurement, with a specific interest to disparities, more particularly looking at social/gender health and mortality inequalities. Her current research is on the disablement process to identify mechanisms and factors leading from chronic diseases to functional limitation and activity restrictions, with national and European databases, on gender and health differentials and educational gaps in disability across Europe. She is in charge of the health expectancy indicators for France. She is involved in various working groups on measurement of health and disability on population-based survey and contribute to effort for an international harmonization of population health information.

Mary Chamie, Ph.D. private consultant with Population Associates, Inc., is the former assistant director of the United Nations Statistics Division and Chief of Branch of Demographic and Social Statistics. She coordinated the development of internationally agreed standards and methods for the collection of official demographic and social statistics through the use of population and housing censuses, national household surveys, and civil registration systems. She has worked extensively in the area of statistical classifications, with special attention to human functioning and disability. Dr. Chamie developed the international statistical program on disability for the United Nations Statistics Division and since her retirement from the United Nations continues to lecture and consult on this subject matter. She has published numerous reports and articles on disability in scientific journals under her own name and has also prepared a series of books and reports on human functioning and disability under the authorship of the United Nations.

Roberta Crialesi is the director of research (dirigente di ricerca) for Health and Social Care Statistics at ISTAT, the National Institute of Statistics in Italy. Roberta has a bachelor's degree in demography and statistics sciences (with focus on methodology and epidemiology) from the Università degli Studi di Roma "La Sapienza," 1987. She has extensive experience in the development of social statistics involving research, analysis, survey methodology, and data collection in the main domains of health, disability, and health care. Roberta is a member of several national and international working groups (socioeconomic inequalities in morbidity and mortality: a comparative study; EURO REVES; European Disability Measurements (EDM) di Eurostat; Washington Group on Disability Measurement (WG); Eurostat Working Group on Public Health; Eurostat Morbidity Statistics Development Group (MSDG); OECD Project "Costs of care for elderly populations"). Roberta is the author of several publications in a variety of fields including social care, health and disability, hospitalization, and cause of death.

Mary Crock is professor of public law at the University of Sydney. She has worked in the area of immigration and refugee law since 1985. An accredited specialist in immigration law, she has been chief examiner/head assessor in various specialist accreditation programs in immigration law across Australia since 1994. In 1989, she helped to establish a community legal center, known now as the Refugee and Immigration Law Centre Inc. (Vic). Author of 11 books and reports and over 60 articles, she has made issues around vulnerable migrants (especially children and persons with disabilities) a special focus in her research. Mary was the lead investigator in the AusAID-funded "Protection of Refugees with Disabilities" Project (2012–2015). Her projects on refugee children include the *Seeking Asylum Alone* and *Small Mercies, Big Futures* projects funded through the Australian Research Council and the MacArthur Foundation.

Elena De Palma is senior researcher at ISTAT (Italian Institute of Statistics) since 2001. She is currently working at the implementation of a "Statistical Information System on Disability," whose main aim is to set up a comprehensive statistical database, to be used for planning and monitoring of policies on disability. Elena has also experience in survey design on disability, cognitive tests (conducted for Washington Group, Eurostat, Task Force WHO/Eurostat/UNECE), and international projects on disability (European Disability Measurement (EDM) Project, Washington Group on Disability Statistics, Budapest Initiative). Elena has a degree in psychology (1989) and a master's degree in "data sources, methods and tools for social research" (2005)—both from the University of Rome "La Sapienza"—plus a master's degree in "human resources management" (2006) from the Third University of Rome. She has been a junior fellow within the "International Philanthropy Fellowship Program" at the Johns Hopkins University (USA, 1995–1996), where she completed also the "training of trainers for non-profit organizations" program (1996–1997).

Jessamyn O. Encarnacion is the interim assistant national statistician of the social sector statistics services of the Philippine Statistics Authority. She completed her bachelor's degree in statistics at the University of the Philippines and master's degree in public policy at Hitotsubashi University in Japan. She has earlier served as director of the Social Statistics Office of the Philippines National Statistical Coordination Board. She also served as temporary regional advisor on Statistics at the United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP) from 2013 to 2014. She has written/presented/published more than 70 papers/articles and has served as resource person/speaker in various local and international seminars/workshops, trainings, and forums on poverty statistics, gender statistics, millennium development goals (MDG) indicators, happiness index, child development index, and middle-income class. She is also a member of various statistical interagency and technical committees (IACs/TCs) in the Philippine statistical system and at the international level. In the Philippines, she served as member of IACs/TCs on population and housing, health and nutrition, education, poverty, gender and development, and labor and productivity statistics. At the international level, she serves as a member of the UNESCAP technical advisory group on population and social statistics. She has also participated in various international expert group meetings such as the U.N. Interagency and Expert Group on Gender Statistics and the U.N. Expert Group Meetings on the MDG Indicators.

Cordell Golden is a health statistician at the National Center for Health Statistics (NCHS). He earned his degree in sociology from the University of Maryland at College Park. His career at the NCHS began as a student intern in 1995. Since then, he has worked on an array of projects related to the collection and dissemination of NCHS's data products. He currently works in the Special Projects Branch linking NCHS survey data with administrative records, specializing in Medicare and Medicaid enrollment and claims data. In addition to his role with the NCHS Record Linkage Program, he also serves as the primary point of contact for the Secretariat of the Washington Group (WG), an international group working on disability measurement under the auspices of the United Nations (UN). The WG Secretariat serves as the central communications contact for the full WG membership and subcommittees representing nearly 120 national statistical offices, and collaborators from U.N. agencies, international disability, and other organizations.

Judith Heumann is an internationally recognized leader in the disability community and a lifelong civil rights advocate for disadvantaged people. In June 2010, she was appointed to her current position as the special advisor for International

Disability Rights at the US Department of State. As the special advisor, Heumann leads the department efforts to encourage and assist foreign governments and civil society organizations to increase their commitment and capacity to protect the rights, and ensure the inclusion and full participation of, persons with disabilities. She served as the World Bank's first advisor on Disability and Development and served in the Clinton Administration as the assistant secretary for the Office of Special Education and Rehabilitative Services in the Department of Education from 1993 to 2001. She previously worked with numerous disability rights organizations including co-founding the World Institute on Disability and the Center for Independent Living in Berkeley, California.

Carol Jagger is the AXA Professor of Epidemiology of Ageing at Newcastle University. Her research spans demography and epidemiology with a focus on mental and physical functioning in aging, and she is the leading UK researcher on healthy life expectancy. Carol has been involved in the design or analysis of most major UK cohort studies of aging, in particular the MRC Cognitive Function and Ageing Study and the Newcastle 85+ study. Within Europe she sits on the Scientific Advisory Board of the Joint Programming Initiative “More Years, Better Lives” and the EU Task Force to improve the Healthy Life Years indicator. She sits on the Steering Group of REVES, the International Network on Health Expectancy and the Disability Process, and has been co-investigator on the majority of Euro-REVES projects including the European Health Expectancy Monitoring Unit (EHEMU) and the Joint Action Healthy Life Years (JA EHLEIS). Nationally she has advised the Office for National Statistics and the Scottish Public Health Observatory on Healthy Life Expectancy and has provided evidence to the House of Lords report “Ready for Ageing,” government Works and Pensions Committee, the Health Committee, and the Scottish Finance Committee. Carol is a chartered scientist, a fellow of the Faculty of Public Health, and an honorary fellow of the Institute and Faculty of Actuaries on whose Mortality Research Steering Committee she sits.

Mitchell Loeb is a health scientist in the Office of Analysis and Epidemiology at the National Center for Health Statistics, Centers for Disease Control and Prevention. In addition to his work in the U.S.A., he has carried out epidemiologic research in Canada, Norway, and several developing countries in sub-Saharan Africa and Southeast Asia. He is currently concentrating on the analysis of disability data from various U.S. health surveys and continues his international commitment to the development of culturally comparable disability measures through his work with the Washington Group on Disability Statistics (WG). He routinely trains statisticians from National Statistical Offices around the word in understanding and adapting the WG approach to disability measurement for use in their own national censuses and surveys.

Jennifer H. Madans, Ph.D. has been the associate director for science, National Center for Health Statistics, since May 1996, and is responsible for the overall plan and development of NCHS's data collection and analysis programs. Since Dr.

Madans joined the center, she has concentrated her research efforts on data collection methodology, measurement of health and functioning, and health services research. She has directed two national longitudinal studies (NHANES I Epidemiologic Follow-up Study and the National Nursing Home Follow-up Study) as well as the redesign of the National Health Interview Survey questionnaire, and she was one of the designers of the DHHS Survey Integration Plan. She is a founding member of two U.N.-sponsored initiatives to develop internationally comparable measures of disability and health, the Washington Group on Disability Statistics and the Budapest Initiative on the Measurement of Health Status, and has chaired the steering committee of both groups since their inception. Dr. Madans is a graduate of Bard College (BA) and the University of Michigan (MA and PhD in Sociology). She completed a postdoctoral fellowship in the Department of Epidemiology and Public Health at Yale University. She has served as an adjunct associate professor in the Division of Biostatistics and Epidemiology, Department of Community and Family Medicine, Georgetown University School of Medicine and in the Department of Demography at Georgetown. She is a fellow of the American Statistical Association and an elected member of the International Statistical Institute and served as a vice-president of the International Association of Official Statistics.

Howard Meltzer was professor of Mental Health and Disability at the Department of Health Sciences, University of Leicester from 2006 to 2013. Previously, he spent over 25 years at the Office for National Statistics (ONS) in the UK specializing in epidemiological surveys of disability and mental health among adults and children and latterly as Deputy Divisional Director of the Health and Care Division at ONS. He also acted as a consultant to various international and supranational organizations on the collection of disability and mental health statistics.

Kristen Miller, Ph.D. senior methodologist, directs the Question Design Research Laboratory within the National Center for Health Statistics (NCHS), CDC. Her writings have focused on question comparability, including question design and equivalence for lower SES respondents and the improvement of evaluation methods for cross-cultural and cross-national testing studies. Dr. Miller holds a PhD in Sociology from the University of Delaware.

Daniel Mont is an international expert in disability and development, specializing in disability measurement issues and monitoring and evaluating inclusive development programs. He has worked with many governments and international agencies on indicator development and the implementation of more inclusive social protection, anti-poverty, and education programs, and has published widely on issues pertaining to disability and the relation of disability to poverty. Currently he is an honorary senior research associate at the Leonard Cheshire Disability and Inclusive Development Centre at University College London. Prior to that, he was a senior economist at the World Bank for 10 years. While at the World Bank, he was also the chair of the Analytical Working Group of the U.N. Statistical Commission's Washington Group on Disability Statistics. He also was a principal analyst with the

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Andres Montes is population affairs officer at the United Nations Economic and Social Commission for Asia and the Pacific. Prior to this, he worked as a statistics specialist at the United Nations Development Programme's Human Development Report Office. He also worked at the Office of the Chief Economist of the Inter-American Development Bank, at the Office of the President of Mexico as Director of Statistics Center of the Presidency, and at Mexico's Ministry of Social Development as Director of Foreign Affairs. Mr. Montes holds a master's degree in public policy administration for the London School of Economics and is a PhD candidate in migration studies at the University College London. He is an expert on public policy planning, social development, disability, and international migration.

Wilma Nusselder, Ph.D. is an assistant professor at the Department of Public Health, Erasmus MC. She is a demographer with long research experience working at the intersection between public health and demography. Her main interest is in population health, including health expectancy (simulations), trajectories and predictors of disability, and (old age) mortality and health impact assessment. She has extensive experience in life table analysis, including the Sullivan and Multi-State method, in analysis of micro-level (longitudinal) data, and in health impact assessment using the DYNAMO-HIA tool. She has (co)authored about 60 papers on a wide range of topics, including studies on health expectancy trends and gaps, health expectancy method development and simulation studies. She has developed and disseminated tools that increase the public health relevance of health expectancy. She advises Statistics Netherlands (CBS), the National Institute of Public Health, and the Environment (RIVM) on health and life expectancy issues. She has been a member of REVES, the International Network on Health Expectancy and the Disability Process, since 1993, and has been co-investigator of several Euro-REVES projects including the European Health Expectancy Monitoring Unit (EHEMU). She is a core member of the Joint Action on EHLEIS (JA EHLEIS).

Elizabeth K. Rasch is a Staff Scientist and Chief of the Epidemiology and Biostatistics Section in the Rehabilitation Medicine Department at NIH. She received her BS in Physical Therapy (PT) from the University of Delaware, MS in PT from the University of Southern California, and PhD in Rehabilitation Science with a concentration in Epidemiology from the University of Maryland, Baltimore. As Section Chief, she currently supports major projects involving multiple collaborations with academic institutions as well as other Federal agencies, and oversees the work of 15 scientists and fellows. Her research is directed toward promoting the health, participation, and full inclusion of people with disabilities in family and community life by informing and impacting health services, programs, and policies. More specifically, she studies the development and consequences of secondary conditions among adults with disabilities, health care delivery related to these conditions, and the effects of these conditions on function. Dr. Rasch has coauthored over 50 articles. She is a member of the Editorial Board for the Disability and Health Journal and the Physical Therapy Journal. In 2009 and 2011, she was honored with Clinical Center's Director's Awards in science from NIH.

Jean-Marie Robine is a research director at INSERM, the French National Institute of Health and Medical Research (http://www.inserm.fr), within the CERMES Research group in Paris and the Unit 710 in Montpellier where he heads the research team biodemography of longevity and vitality. He is also a study director at the advanced school Ecole pratique des hautes études (http://www.ephe.sorbonne.fr) in Paris. He studies human longevity, with the aim of understanding the relations between health and longevity. In particular, he measures the impact that the increase in adult life durations may have on the health status of the elderly population. Since its creation in 1989, he has been the coordinator of the International Network on Health Expectancy (REVES), which brings together more some 100 researchers worldwide (www.reves-network.org). He was the project leader of the European Joint Action EHLEIS (2011–2014) which provided analysis of disability-free life expectancies in the European Union (www.eurohex.eu). He is co-responsible for the development of the International Database on Longevity (IDL) in association with the Max Planck Institute for Demographic Research (Rostock) and INED (Paris). He is the project leader of the healthy longevity project granted by AXA Research Fund: the Five-Country Oldest Old Project (5-COOP). He is one of the Directors of the new French Research Consortium on aging and longevity (GDR CNRS 3662, 2014–2017).

Marguerite Schneider, Ph.D. is a researcher in the field of disability studies and project manager at the Alan J Flisher Centre for Public Mental Health, University of Cape Town. Her early career was in Speech-Language Pathology and Audiology before moving into broader social science research focusing on disability studies. She obtained her PhD at the School of Public Health, University of the Witwatersrand, with a thesis entitled: "The social life of questionnaires: Exploring respondents' understanding and interpretation of disability measures." She has published on disability measurement and disability in relation to poverty and social protection.

Laura Smith-Khan is a doctoral candidate in linguistics at the Macquarie University, Sydney, Australia. She has bachelor degrees in law and arts from the University of Sydney where she is employed as a research assistant and sessional associate-lecturer. She has a master's degree in applied linguistics from Monash University in Melbourne. Laura is the lead researcher on Professor Crock's projects that have a disability focus. She is a coauthor of many of the articles written for the AusAID-funded "Protection of Refugees with Disabilities" Project (2012–2015).

Herman Van Oyen is director of the Operational Directorate Public Health and Surveillance of the WIV-ISP (Scientific Institute of Public Health, Belgium). He is professor epidemiology at the department of Public Health, University of Ghent. His research in the field of epidemiology and public health focus among others on epidemiological methods and survey research, methods of measuring population health, especially Summary Measures of Population Health (SMPH), and health inequality. He is member of the Belgian Superior Health Council and chair of the expert group on Public Health Genomics. He has been the promoter of the health expectancy indicators estimations in Belgium. Examples of his on-going research activities are the estimation of the impact of smoking on disability and disability-free life expectancy and the development of time series on socio-economic inequalities in Healthy Life Years (HLYs). He is a member of several national and European working groups on measuring health in populations.

Romulo A. Virola was secretary general of the National Statistical Coordination Board of the Philippines from 1991 until his retirement in July 2012. He completed his PhD in statistics at the University of Michigan in Ann Arbor, USA. He served on the faculty of statistics and mathematics at the University of the Philippines, has written/presented more than one hundred and fifty papers, and has served as resource person/speaker in local and international forums on various topics. He served as associate editor of the International Association for Official Statistics Journal and as editor of the *Philippine Statistician*. He was one of the ten achievement awardees of the National Research Council of the Philippines in 2007. He was a member of the Board/Executive Committee/Bureau/Steering Committee of the Partnership in Statistics for Development in the 21st Century, the UNESCAP Committee on Statistics, and the Washington Group on Disability Statistics, among others. He was a member of the jury of the 2012 Mahalanobis International Award of the International Statistical Institute, the Friends of the Chair of the U.N. Statistical Commission on the Fundamental Principles of Official Statistics, the International Advisory Group on Agricultural Statistics of the FAO, the Advisory Group of the Marrakech Action Plan for Statistics, and the Statistical Advisory Panel on the 2012/2013 Human Development Report. He has served as consultant for the U.N., the World Bank, the Asian Development Bank, the OECD, and various local institutions in the Philippines.

Julie D. Weeks a sociologist with a PhD from the University of Maryland, has been at the National Center for Health Statistics since 1989 and currently serves as the Chief of the Aging and Chronic Disease Statistics Branch in the Office of Analysis and Epidemiology. Since Dr. Weeks joined the center, she has concentrated her research efforts on trends in the health of older persons, including the measurement of health and functioning in this population. She was assistant project director for the 1984–1990 Longitudinal Study of Aging (LSOA), project director for the 1994–2000 Second Longitudinal Study of Aging (LSOA II), and a member of the design committee for the 1994–1995 National Health Interview Survey on Disability. More recently, her focus has broadened to include disability and functioning measurement and analysis and incorporating standard measures into both national and international data collections. Her current work also includes leading the Quality of Life and Well-Being work group for the DHHS Healthy People initiative, as well as serving on both the Disability and Health and Older Adults work groups; she has membership on both the Washington Group on Disability Statistics and the Budapest Initiative on Measuring Health State and is serving as a member of the American Statistical Association's Committee on Statistics and Disability.

Introduction

In 2015 as this book is written, the Washington City Group on Disability Statistics (WG) will have been in existence for 13 years having had their first meeting in February 2002. It was called into being at the end of a large international meeting on the status of disability statistics which was organized by the United Nations Statistical Division (UNSD). Over those 13 years, 130 countries have been involved with the group's work, at one point or another (see Chap. 3). Recently it became obvious to those involved in the work that we had been so busy working on improving disability measurement cross-nationally that a lot of the details of the work associated with the focus on developing internationally comparable measurement of disability were not getting disseminated as widely as they should. Although the work in progress and the presentations from each meeting are disseminated through the United Nations and the National Center for Health Statistics (NCHS) websites (http://www.cdc.gov/nchs/washington_group.htm) and a report is made to the United Nations Statistical Commission annually, the finished products such as testing protocols, new methodologies, country experiences, and results from use of questions in national censuses have not been distributed widely, particularly in research literature. Therefore, in order to provide more detailed information to the statistical and research communities and to find another source to inform the international public, particularly the international population with disabilities and organizations working with populations with disability, the focus of this volume is to provide details about the products and ongoing activities of the Washington Group. We have included finished products, national experiences, methodology advances, and first results from census uses of questions developed by the WG, and finally we provide information on future plans of the Washington Group.

In the context of the Convention on the Rights of Persons with Disabilities (CRPD) and the Millennium Development Goals (MDGs), the measurement of disability in national censuses and surveys is more important than ever. Understanding the age, gender, participation and locations of persons with disabilities, and the types of functional limitations they experience will help tremendously with the promotion and protection of the full and equal enjoyment of human rights, dignity, and freedoms for all persons with physical, mental, intellectual, or sensory impairments throughout the world. Measurement or counting through censuses and/or surveys can contribute immeasurably to policy development and monitoring improvement in regional, national, and international promotion of equalization of opportunities for persons with disabilities. Hopefully this volume will act as a stimulus for the inclusion of disability measurement in censuses and surveys by all Member States of the United Nations and encourage the production and dissemination of information about persons with disability by the Member States. In 2003 the United Nations Statistical Commission emphasized the need to insure the collection of internationally comparable statistics on disability and approved the collection of disability statistics on a regular basis through the United Nations Demographic Yearbook system using the Human Functioning and Disability Questionnaire developed by UNSD for this purpose. The Principles and Recommendations for Population and Housing Censuses, Revision 2, the current revision underway, not only recommend the inclusion of disability characteristics as a census topic, but the incorporation of the Washington Group Short Set as an example of an acceptable set of questions (United Nations, 2015). It is important that Member States who have not yet begun collecting data about disability in their nations begin to do so and that all Member States contribute this information to the Demographic Yearbook on a regular basis so that the CRPD and MDGs have this information available for their activities.

The Washington Group is trying to improve the measurement process so that Member States can address the needs of their populations with disability. As the authors of the Chap. 17 indicate, the Washington Group "tackles contentious issues related to complex matters of definitions, concepts, classifications, statistical methods, tabulation and analysis plans and policy relevance of data" which makes the transparency of the work and the decision-making processes even more important (Chap. 17). An earlier volume described the status of disability measurement cross-nationally prior to the founding meeting along with descriptions of the early work of the WG (Altman and Barnartt 2006); however, much has happened in the last 9–10 years and hopefully this volume will begin to document the continuing progress that has been made.

This volume is divided into four sections: (1) Origin of the Washington Group and Issues in Disability Data Collection; (2) Census/Survey Questions: Purpose, Process and Testing; (3) Moving Forward: Extended Question Sets and Methodological Advances; and (4) Conclusions: Outcomes and Place of the Washington Group Measures in International Data. Those sections give a little background on the origins of the Washington Group and how it organizes and implements the work it takes on, and the many problems associated with measurement of disability. It also includes the development of purpose and highlights the extensive testing processes and protocols that have developed providing an interesting example of the testing process that utilized the cooperation of three South American countries. It highlights the work that has taken place over the more recent period providing both a rational for developing questions that focus on children and detailing that process and also addressing the issue of measurement of the environmental context which will be a future activity. Finally, in the last section, there is documentation of statistics using the WG questions in censuses from the recent census cycle, an example of one national experience through their involvement with the Washington Group and two examinations of the Washington Group's contribution to disability statistics. There is also a significant chapter that indicates the use and importance of the WG questions for assessing the disability population among recent refugees so that their needs can be addressed.

Highlights of the Parts

Part I: Origin of the Washington Group and Issues in Disability Data Collection

Chapter 1 introduces the conceptualization of City Groups as defined by the United Nations and provides the background of the creation of the Washington City Group elaborating the early decisions that have guided the work of the group since its inception. Particularly informative for those who have not followed the work of the Washington Group or who may have been unfamiliar with its existence, this chapter provides concise descriptions of the early implementation of the Washington Group work and focus on providing culturally comparable measures of disability for cross-national use.

Chapter 2 explores the challenges that can make cross-national measurement of disability very difficult and provides the reader with a much greater understanding of the more common as well as some less common problems that can occur when trying to collect data on this subject. How loss of function is recognized, defined, and adapted to cross-culturally can be very different and seriously impact its measurement. Factors that create these differences can include the cultural conceptualization of disability and the complexity of the various types of disability. Its measurement can also be influenced by the context of surveys, potential sources of error in surveys, and how these are managed based on a growing body of evidence testing disability questions in different social, cultural, and geographic contexts. Dr. Schneider's chapter examines the broad range of issues that can affect measurement and provides the reader with an effective picture of the context in which the Washington Group seeks to do their work highlighting some of the very basic problems they need to address.

In the last chapter of Part I, Mr. Golden gives substantial background information on the involvement of nations, DPOs, and other organizations in the activities of the Washington Group, the development and implementation of the governance process for the group, and other details about the accomplishment of the Washington Group over its period of existence to this point. Of particular note is the documentation of the process of developing the short set of questions and the accompanying five documents on methodological guidance developed to facilitate implementation among all the population subgroups who will want to use the data. Chapter 3 also provides information on the development of the extended set, the testing partnership with the UN Economic and Social Commission for Asia and the Pacific, the development of other extended sets, and the recent development of the UNICEF/WG Module on child functioning and disability. Finally, the chapter documents the supporting technical assistance workshops in countries around the world which has turned out to be an ongoing activity of the WG that was not anticipated at its formation but one that has taken on major importance as the use of WG questions has expanded.

Part II: Census/Survey Questions: Purpose, Process and Testing

Chapter 4 provides an in-depth discussion of the process of developing the primary purpose for which disability measurement is to be constructed. In the context of the World Programme of Action Concerning Disabled Person, the equalization of opportunity approach had taken center stage, and it was important to incorporate that perspective on disability in order to create measures that would move away from the disease/impairment focus that had held sway for so long. Using the newly formatted language of the International Classification of Disability, Functioning and Health (ICF), along with other tools including a matrix to explore the variety of possible underlying purposes for measurement, the Washington Group was able to establish a very firm foundation for its work. By focusing on the equalization of opportunity factor, the WG oriented measurement to identifying persons who are at greater risk than the general population of experiencing restrictions in performing specific tasks or participating in specific role activities due to functioning limitations associated with health characteristics rather than just identifying those who experience a particular participation restriction. In that way they have provided measurement that can act as a social demographic and actually identify equalization of opportunity when data is analyzed appropriately.

A very important element in developing questions to identify persons with disability is the testing of those questions to assure their effectiveness and validity. Chapter 5 is a complete description of the testing that has taken place to this point on all the questions that have been developed by the Washington Group thus far. The chapter documents the difficulties and successes in that process as well as some of the analysis of the data that resulted from the testing. As part of this process, cognitive testing, a technique that is used extensively in the United States has been taught in many countries and a software program for tracking the cognitive testing process has been developed and used to monitor the international testing that has taken place. The testing of questions continues as this volume goes to press and will continue to produce innovations in the testing methodology along with the final product of improved and internationally comparable questions.

The last chapter in this second section provides insight into the cooperation among countries that has been stimulated by the testing of Washington Group questions. Dr. Bercovich's Chap. 6 describes the coordination of the testing of the short set of questions among Brazil, Argentina, Chile, Paraguay, and Uruguay. The experiences of joint tests in the border areas with observers from most South American countries and Mexico were fruitful and allowed the discovery of similarities and differences among the countries, facilitating question adjustment particularly related to question interpretation and cultural differences.

Part III: Moving Forward: Extended Question Sets and Methodological Advances

The third section of the volume includes many of the additional activities that the Washington Group has accomplished over and above developing and approving a short set of questions to be used in censuses. Chapter 7 describes the development, testing, and approval of the first extended set of questions for use in surveys to broaden the measurement of functioning initiated with the short set. Other basic activity and body function domains could not all be covered adequately by a single question and were thus not included in the short set. These include upper body functioning and the domains of pain, fatigue, and affect (anxiety and depression). All were deemed important for inclusion in the extended set of questions on functioning. Once tested and approved, analyses of the domain specific data and testing of various analytic algorithms have been carried out by the WG to determine the best possible analytic approach to create summary measures for each domain. A few of those domains are examined in detail in Chap. 7.

Chapter 8 describes the cognitive question evaluation and field testing of the extended set that was undertaken jointly by the Washington Group (WG) and the United Nations Economic and Social Commission of the Asia and the Pacific (ESCAP). The WG/ESCAP project aimed to a) raise awareness through regional and in-country workshops, b) develop standards for cognitive and field testing of questions and analyses, c) improve national capacity, and d) improve knowledge management. The participating countries were encouraged and funded to attend the 8th WG meeting held in Manila, Philippines, in 2008, the 9th WG meeting in Dar-es-Salaam, Tanzania, in 2009, and the 10th WG meeting in Luxembourg in 2010. The project afforded an opportunity to learn and improve methods for question evaluation and highlight the benefits of implementing a coordinated testing process and the project allowed for other issues to be raised and documented. Most importantly for the WG, the project generated extensive validation data for the WG's extended set questions.

The next two chapters, Chaps. 9 and 10, reflect the beginning of the work with UNICEF on the development of disability questions specifically for children. In Chap. 9, Dr. Meltzer makes the case for the relative dearth of information about disability among children and at the same time how important such information is for policy development and planning. He outlines the many challenges in conducting such surveys among children noting the interaction of conceptual, methodological, and operational difficulties that create barriers to the implementation of child disability surveys. While some national surveys have been carried out using different approaches, identifying the prevalence of disability among children has both health and economic advantages. Without such surveys, the burden that society puts on disabled children and the negative attitudes that they may face—primarily social exclusion and discrimination—will prevail.

In Chap. 10, the authors describe the process that has been taken by the Washington Group's Children's Workgroup to develop and test questions to address childhood disability cross-culturally. As of the publication of this chapter, the WG-UNICEF survey module on child functioning and disability is still under development, as is a companion manual that will fully annotate its technical properties and provide methodological guidance for its implementation. When finalized, the implementation of this module will aid in the production of comparable data cross-nationally that, in combination with other data collected on education, for example, can be used to determine the degree to which children and youth with disabilities are able to participate in society to the same degree as children and youth without disabilities. These data will support a country's ability to monitor and assess compliance with the U.N. Conventions and, over time, its progress toward the full implementation of the rights of children with disability. The WG meeting in October 2015 in Copenhagen, Denmark, should see the approval of the children's question set as officially endorsed by the Washington Group for use in national censuses or surveys. Full information on the children's questions should be available from the NCHS website by spring of 2016.

Continuing with the emphasis on children, Chap. 11 describes early testing of the Children's Question Set in India. Using a purposive sample of 72 respondents and recognized cognitive testing methodology, the testing took place in Mumbai. The team employed a consensus means of translation whereby groups discussed translation into Hindi and arrived at a consensus that was agreed had captured the true meaning of the question. After the initial translation, the questionnaire was reviewed by the participants prior to being tested, and it was decided to further adapt the translation into the local dialect of Hindi. A series of practice sessions also highlighted various issues such as an inability to accurately understand some questions due to the lack of concrete examples or examples that were alien to Indian culture. This resulted in second round adaptations. Other issues were identified as well, but for the most part, the cognitive interviewing study proved to be a successful endeavor in that it provided important insight into the performance of the child disability module, and a research team was trained on cognitive testing procedures and use of the Q-Notes package. The team conducted a large number of interviews and was able to determine whether the questions worked as intended.

Chapter 12 focuses on the foundational work for developing measures on environment which is another measurement area the Washington Group is pursuing. While surveys and censuses have identified individuals with some impairments for quite some time in order to track different aspects of their existence, age, gender, living arrangements, school attendance, ability to work, and in some instances their location in institutions, the impact of environment on that experience has been generally ignored because we have not had adequate measures of the environment.

Many of the theoretical approaches to the environmental impact associated with disability organize the environmental factors at two different levels, the individual and the societal levels, and thus this chapter examines both areas and also the various sources of environmental measurement that have been created to this point. The chapter also very carefully explores the cross-cultural problems associated with establishing environmental measures because of the many different ways environments are structured in different cultures. Based on extensive work done by rehabilitation professionals and others interested in the impact of environment on participation, the authors identify three approaches to measurement and develop a hierarchy of participation to serve as a basis for further work on developing cross-cultural measures of environment to enrich our understanding of disability.

Finally in Chap. 13, another important issue, the inclusion or exclusion of institutionalized persons in estimates of disability prevalence, is confronted. This is a methodological problem that the Washington Group has been concerned about and seeks to address. In fact, collecting information on both sections of the population, those in private households and those in nursing homes and other forms of housing for persons who need assistance, is difficult and rarely done in one survey. Private households are usually considered to be representative of the population as a whole and a sufficient representation of the population. However, a non-negligible share of the population with disabilities, particularly serious disabilities, lives outside private households. Not accounting for them leads to an underestimation of the level of disability in the population. In this chapter, the scale of this underestimation and the extent to which assumptions can be used to correct estimates are examined.

Part IV: Conclusions: Outcomes and Place of the Washington Group Measures in International Data

Part IV provides some insight into what the Washington Group has accomplished in its 14 years of existence with an example of the experience of an individual country, and with the very first analysis of actual counting of persons with disabilities in the first use of the WG questions in international censuses. The importance of what has also been accomplished in the collaboration among many countries and the many behind the scenes activities are also examined from two different perspectives.

Chapter 14 documents the involvement of the statistical branch of the Government of the Philippines from the beginning of the Washington Group in 2002. Virola Romulo, in his role as Secretary-General of the National Statistical Coordination Board of the Philippines from 1991 until his retirement in July 2012, and Jessamyn Encarnacion who is currently the interim assistant national statistician of the social sector statistics services of the Philippine Statistics Authority, are in a key position to document the impact of the Washington Group work on one of the countries that have actively participated in WG work from the beginning. This chapter presents the development and improvement of disability statistics in the Philippines, in the context of the efforts of the WG. Providing the background of the Philippine interest in development and use of disability statistics, this chapter provides appreciation for and examples of how the WG work contributed to the Philippine intentions in this area noting particularly the technical support and the regional meetings that the Philippine NSO were able to attend. The improved measurement of disability in the Philippines is definitely acknowledged with specific examples of the developmental and statistical capacity building activities provided.

The production of cross-nationally comparable data on disability has been one of the primary goals of the Washington Group since its inception in 2002. Chapter 15 is the first compilation of cross-national data using the Washington Group Census short set measure in either the 2010 census or a recent survey. About 30 countries indicated to the WG that they intended to use the short set of questions on this current (2010) round of censuses. The WG saw this as an opportunity to follow up on the implementation of the questions in practice and sought to collect information from all countries that were using the WG short set of questions (or not) to catalog the actual questions and response options used, the year of data collection and the venue (census or survey), and the prevalence of disability derived. Approximately 120 countries are annually requested to report back to the WG on national activities that relate to disability statistics. Responses are voluntary—and in this most recent request, responses were received from 65 countries. Although countries have reported disparate disability prevalence rates, with few exceptions, those that use the WG *as intended* have reported disability prevalence rates that are comparable. The information and data that are presented in this chapter indicate that WG efforts in fostering international cooperation in the area of health and disability statistics has begun to bear fruit through the development and implementation of a short set of general disability measures suitable for censuses. The data has the potential to provide the evidence that can be used to address whether countries have been successful, or the degree of their success, in meeting the general principles outlined in the Convention (Article 3) including the achievement of equalization of opportunity and accessibility.

The next chapter discusses the pragmatic use of the Washington Group short set of questions that was not originally anticipated by the Washington Group when the work was mapped out, but one that is obviously essential for the well-being of a population with disability. In Chapter 16 the authors reflect on the use of the Washington Group's approach to identifying disabilities in refugees from many areas that have been hit by war. The chapter reports on fieldwork funded by the Australian government and conducted by researchers from the University of Sydney exploring the adequacy of systems used by United Nations High Commission for Refugees (UNHCR) and other agencies to identify disabilities in populations of displaced persons. Humanitarian agencies have relied heavily on either self-reporting by persons with disabilities or on the visual identification of impairments. The inadequacies of this approach are apparent in agency records showing disability rates in refugee populations that fall way below the average suggested by the World Health Organization in its Global Disabilities Report. The authors found that the HCR was accurate in describing persons with disabilities as the invisible and forgotten refugees and provided dramatically different results achieved when versions of the Washington Group questions were used in a verification exercise in Pakistan. Using a similar approach adopted in refugee registration procedures across the world would generate data that aligns more closely with global standards and produce data on disabilities that is critical to developing accessible programs.

Chapter 17 discusses Washington Group products, implementation of WG data tools, and future activities. The primary aim of the work of the Washington Group was to institutionalize the collection of high-quality disability statistics as collected by national statistical offices. While the development of data tools is still ongoing, it has been an added benefit that the products already produced can be used across governmental agencies, NGOs, international organizations, and researchers. As the activities of the WG get more challenging such as development of environmental measures and the increased need for technical assistance to countries, the Australian Department of Foreign Affairs and Trade is working closely with the UN's Washington Group on Disability Statistics to establish a new 4-year partnership that will support the implementation of the questions developed by the Washington Group in national statistical systems and provide analysis of the data that are produced and dissemination of the information to inform policies and programs to improve the lives of persons with disabilities.

Finally, Chapter 18 asks the question "What if there were no Washington City Group"? In this chapter, the authors, who represent the area of disability statistics and disability policy, look at the accomplishments and the potential of the Washington Group from both the statistical and activists' perspectives. They note the changed approach to definitions and conceptualizations of disability as compared with the past, implemented by the World Health Organization Classification of Human Functioning and Disability (ICF), and the increasing use of disability as a population characteristic. They indicate these shifts in knowledge, attitude, and practices regarding definitions, concepts, and classifications of functioning and disability have far-reaching consequences, socially, economically, and politically. Since statistical methodology and statistics must keep up with these sweeping changes, the Washington City Group was formed by the Statistical Commission at an opportune time to tackle these challenging issues. Like measures of poverty or race, measurement of disability succeeds when it reflects the current state of affairs accurately, both in the present and to the extent possible, over time creating an enormous challenge for statisticians. Will the Washington City Group succeed in setting international standards for data collection and analysis of disability under these constantly shifting conditions and at times controversial situations? The authors have examined the activity of the Washington Group and address that question based on that activity—but I don't want to give away the ending.

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Part I

Origin of the Washington Group and Issues in Disability Data Collection

Chapter 1
Background and Origin of the Washington Group: Improving the State of Disability Data

Julie D. Weeks

Introduction

Increasing the quality of life for persons with disabilities, and ensuring full participation in all aspects of the human experience, are no longer new concepts to the large and diverse community of individuals and organizations whose work serves to inform and achieve these goals. More than any previous time, consensus exists about the values of inclusion in society and the provision of equal access and rights to these persons. Policies, programs and actions developed to address these goals must be appropriate, effective and enforced. They also must be informed using data of the highest quality, data that accurately capture and describe the intended population, data that are cross-culturally comparable, and data that are collected and applied consistently. Reliable, valid and comparable measurement of disability provides the essential basis on which these efforts depend.

For the past 14 years, the focus of the Washington Group on Disability Statistics (WG) has been to develop the measures needed for use in the global community to inform and improve such programs, policies and actions. To date, two sets of disability measures have been developed and adopted for use in population-based censuses and surveys. The Short Set on Functioning (SS-F) was developed for use in censuses where space and time constraints restrict the amount of information that can be collected. It collects information on difficulty experienced in a number of basic domains of functioning (vision, hearing, mobility, cognition, self-care, and communication). The SS-F items also serve as essential baseline elements of the Extended Set on Functioning (ES-F). The ES-F captures information on difficulty with a larger number of basic functioning domains (adding upper body, affect, pain and fatigue domains), as well as additional information about each domain. The

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ES-F is intended for use in population-based surveys, either general or disability-specific, which can accommodate a great number of questions. More information about these sets is provided in the chapters that follow.

The WG disability question sets are the result of careful and critical consideration of the prevailing definitions and models of disability; assessments of the current laws, policies, and general needs for disability data; identification of the specific conceptualization and operationalization of disability for the purposes of the WG mandates; methodical development of questions; multiple rounds of cognitive testing of item wording, response options, respondent and interviewer interpretations, and translation effects; field tests examining the performance of the questions in survey environments; analyses exploring the reliability, validity and comparability of the resulting data; and a dedicated and diverse group of WG members and others working with the WG. As the SS-F and ES-F become more widely incorporated into data collections throughout the world, the WG's support and outreach activities have grown. Regional and national trainings are provided to countries now testing and administering the questions in their censuses and surveys. Guidance on how to use and interpret the resulting data is also now being provided.

Much has been accomplished in the last 14 years. More work lies ahead. The WG remains committed to developing additional essential, high quality disability measures – in domains of functioning not previously addressed, in the types of information collected for a more complete understanding of the factors that contribute to the experience of disability, and in populations requiring specifically tailored disability measures. The WG continues to support an ever-increasing global network of countries now implementing the measures. The development of the measures was a necessary first step, however broad endorsement of the measures and their implementation are equally necessary, to improve the state of disability statistics.

The State of Disability Statistics

The collection of disability statistics is not new. The quality and comparability of the data collected, however, reflects the complex nature of disability. Disability is a concept that can be measured across multiple dimensions, none of which are straightforward themselves. There are multiple definitions and theoretical models of disability and the disabling process. Disability can be defined and measured at a variety of locations in these models, or it can be defined in terms of its relationship to any number of elements in the process. There is no single conceptualization of disability, nor is there a single purpose for its measurement. Multiple needs for disability statistics exist, including but not limited to, providing necessary data to the public health and research communities; guiding the development of disability-related policies, programs, and benefits; and informing and assessing human and civil rights efforts. Further adding to the complexity of disability measurement is the lack of consistency in the use of terms related to disability and the lack of comparability in the meaning of disability across cultures and nations.

Much has been written about the poor quality and comparability of disability data for use within and across countries (RSSD 2001, 2006). While most developed countries, and many less developed countries, have long-standing inclusion of disability measures in national data collections, differences ranging from question wording to cultural contexts and attitudes have seriously hampered the cross-comparability of the resulting data. Differences in what and how much data are collected, and how accurate the data are, have led to significant differences in prevalence estimates across countries. In one review of available data, estimates have ranged from 0.17% to 9.86% in less developed countries and 11.6% to 20% in a number of more developed countries (RSSD 2006). Even when there has been a high degree of consistency across collections with respect to the domains of functional activities captured, the disability definitions and individual tasks and activities measured have varied greatly, leading to such disparate prevalence data and impeding policy development and enforcement. Increasing recognition that efforts to align a) the adoption of fundamental concepts that provide operationalization parameters, b) identification of the purposes for measurement, and c) guidelines for the data systems measuring disability led to a number of significant developments designed to rectify the nature of disability measurement.

United Nations International Seminar on Measurement of Disability

In June of 2001, nearly 100 disability subject matter experts convened in New York to attend the United Nations International Seminar on the Measurement of Disability. Many were representatives from national statistical offices in divergent regions of the world. Others included disability measurement experts from academic settings. Representatives of the disability community, users of disability data, survey methodologists and international organizations – whose work is consistent with the objectives of the meeting – also participated. All were there to address the growing problems associated with the disparate conceptual frameworks, definitions and measures that characterized the state of disability statistics at the time.

The goals at the outset of the 3-day meeting were ambitious, but necessary to move the field forward. Foremost, the group was to review and assess the current status of methods used in population-based data collection activities to measure disability in national statistical systems. A comprehensive historical examination, as well as reviews of current disability measurement, provided a critical platform for the remaining content. In particular, attention was given to questionnaire design, especially as it relates to the development and use of appropriate and comparable measures. The group was also asked to develop recommendations and identify key priorities to advance work on measurement of disability. Finally, participants and their member organizations were charged with building – and contributing to – a network of institutions and experts, including producers and users of disability statistics, to implement the developments in this field.

A number of recommendations were made at the conclusion of the Seminar. The most fundamental priority identified was the need for comparable population-based measures of disability for individual country use and for international comparisons. This determination was based on the scarcity and general poor quality of data on disability, especially in developing countries, and the lack of internationally comparable measures, even among developed countries. Addressing this priority, and responding to all of the recommendations, would require ongoing, dedicated work. The U.N. Statistical Division (UNSD) called for the creation of a City Group to do just that.

City Groups

The importance of developing, implementing, and utilizing international standards for statistical data collections is central to the mission of the U.N. Statistical Commission. The process by which such standards are determined, and this work is accomplished, often is accomplished by city groups. City groups are comprised of subject matter experts, primarily from national statistical agencies, who collaboratively use their technical and practical expertise in a specific subject area to advance the measurement and collection of internationally comparable statistics. Participation is voluntary and the group is named after the location of its first meeting.

These relatively small, expert groups typically function informally, and for the most part are self-guided. City groups determine their own mechanisms of work, agendas and meeting sites. However, given that the purpose of their work is to facilitate and improve the international standards development process, standards which may be proposed for international use, strict terms of reference are set by the Commission. City groups report to the Commission on a regular basis. The Commission reviews the accomplishments of existing groups and examines the terms of reference for proposed new groups. Based on this, it encourages the existing groups to continue their work and identifies a number of critical problems around which new city groups might be formed.

The Washington Group on Disability Statistics

The recognition made in New York that statistical and methodological work was needed at an international level in order to facilitate the comparison of data on disability cross-nationally, and the UNSD's charge to utilize the city group format to address these needs, resulted in the formation of the Washington Group on Disability Statistics. The National Center for Health Statistics, the principle health statistics agency of the United States, was asked to host the first meeting of the WG. That meeting, held in Washington, DC February 18–22, 2002, determined the name of the city group and set the agenda for work that continues today.

Purpose of the WG

In broad terms, the WG was formed to address the complicated definitional and measurement issues surrounding the subject of disability. The recommendations made at the conclusion of the 2001 Seminar reflected important issues to be addressed: the need for standard principles and measures to be employed in censuses implemented in all countries; the improvement of cross-national comparability among the measures; the use of the World Health Organization International Classification on Functioning and Disability (ICF) as a guiding framework for disability measurement; the development of measures in domains of the disability framework that had yet to be developed or were at the early stages of development; and further methodological work, in particular work that would best inform the use of proxy respondents, measurement structure and practices, appropriate terminology, and special populations such as children or those living in institutions. All of these recommendations were embraced as part of the WG's work agenda. Over time, WG members further revised and clarified the recommendations made at the 2001 Seminar, and added additional objectives, where necessary, to structure the work ahead. These changes were presented to, and approved by, the U.N. Statistical Commission.

WG Guiding Principles and Objectives

The first meeting of the WG was organized to promote discussion and to develop agreement among the attending nations on the goals and products of the city group. In order to define objectives, the sessions were organized around short specific presentations that identified important measurement issues followed by periods of discussions. Points of agreement; suggestions for next steps; and unresolved issues which were to be discussed in later sessions or future meetings were established. The WG has followed this process in all of its subsequent meetings.

As the first order of business, the WG examined the objectives established by the planning committee. By the conclusion of the meeting the following objectives were accepted by the participants and used to guide the development of a work plan:

1. Recommend principles to guide the development of a small set of global measures of disability, for use in a census format, which are culturally compatible and that will provide basic necessary information on disability throughout the world.
2. Recommend one or more extended sets of survey items on disability, related to the shorter census set, that would obtain additional information on disability and related domains to be used as components of population surveys or as supplements to specialty surveys.
3. Ensure that the disability items developed have the requisite properties needed to ensure their successful use in cross-national and cross-cultural comparisons.

4. Utilize the ICF as a framework for the development and use of these items.
5. Address the methodological issues associated with the measurement of disability considered most important in facilitating their proper use.

In order to meet the WG objectives it was equally necessary to review and assess cross-cultural differences in disability definitions, and barriers to the collection of accurate disability data as a step in promoting comparability and usefulness of disability data collected either by census or survey. Other activities included reviewing sets of global measures used in censuses and survey measures currently, or proposed, in participating nations; developing the underlying principles that indicate successful measurement; evaluating methodological problems in developing measures – particularly in new areas of measurement of participation and environment, as well as in measurement of special populations, in order to promote development of culturally compatible measures in these areas. The WG members engaged in all of these activities, especially in the earliest meetings, where many fundamental decisions were made that would determine the very nature of the measures that would be developed.

Disability Measurement Considerations

At the outset, the WG members identified a number of key measurement and methodological issues or themes related to the development of successful disability measures. Decisions on these issues were discussed and made in the early WG meetings, and would guide the next 14 years of work. Of utmost importance was the need to choose a model to guide the development of the disability measures, and to examine the purposes for collecting disability information. A core element of the WG's initial discussions was the need to match the measurement *concept*, the aspect of disability to be operationalized, with the primary *purpose* the WG measures would serve.

Determining the Framework

Agreement on the model that would be used to operationalize the disability measures was achieved at the outset – the International Classification of Functioning, Disability, and Health (ICF) (WHO 2001) would be used as the basic framework for the development of all question sets. The ICF provides a common language and a common point of reference in realizing this conceptualization of disability. Embracing and operationalizing an ICF-based approach to disability, combined with a chosen purpose for measurement, would provide the WG with a clear and specific direction in the development of new measurement tools for use in censuses and surveys.

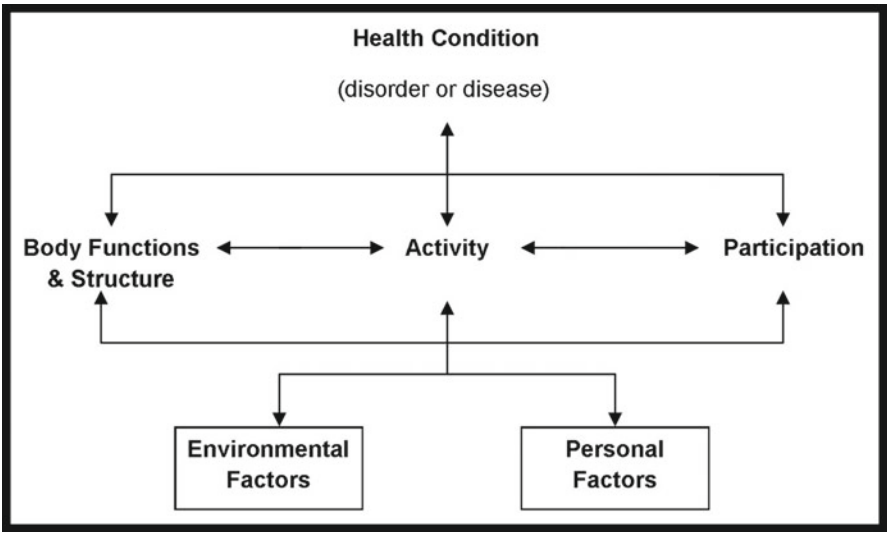

Fig. 1.1 Framework of the international classification of functioning, disability and health, World Health Organization 2001

The ICF is a framework for measuring both health and disability, at both the individual and population levels. The basic components to the model (Fig. 1.1) include an individual's body functions and structures, activities (from the most simple actions to more complicated tasks), and participation in social and environmental contexts. In this framework, disability involves the interaction of a person's functional status with their physical, cultural, and policy environments. If the environment in which one lives is designed for the full range of human functioning and incorporates appropriate accommodations and support mechanisms, then people with functional limitations would not be "disabled" in the sense that they would be able to fully participate in society. The classification's components are interactive and dynamic, and allow for measurement at any single dimension, or at the intersection of dimensions.

The neutral language of the ICF places emphasis on function rather than condition or disease. This shift from a medical orientation to a sociocultural one fit especially well with the goals of the WG. The earlier impairment-based, medical model approach that focused on medical conditions and asked some variation of the question: *Do you have a disability?* is no longer an acceptable method for identifying disability. This approach was particularly vulnerable to differences across cultures in interpretations of disability. Moreover, the measures employed in the data collections, as well as the data itself, reflected these variations. Instead, the focus of measurement has shifted to the individual's experience of *difficulties in basic actions* and *barriers to participation*. These concepts are less difficult to operationalize in a way that is relevant across cultures, as well as age groups and genders. For the WG, adoption of the ICF as the framework for development of disability measures to be used across heterogeneous populations, and for varying data collection methods, was a logical first step. Determining the particular measures would require identifying the purpose of measurement.

Purpose of Disability Measure

The identification of the purpose for which disability measures would be developed was a priority for the WG. This choice was critical given the broad scope of disability and recognition of the need to maintain a focused approach and guiding paradigm. Given the multidimensional nature of the concept of disability, a variety of measures exist to meet an array of needs. Not every measure is appropriate for every purpose, nor is a single measure always sufficient. Thus, clarifying the purpose of the collection of disability information and resulting data was essential in identifying the appropriate measures to develop.

In December 1982, the U.N. General Assembly adopted the World Programme of Action Concerning Disabled Persons (WPA) which made explicit recommendations for the purposes and uses of disability statistics. The WPA followed the 1981 International Year of Disabled Persons, during which activities underscored the importance of approaching disability from a human rights perspective. The WPA also endorsed this approach, stressing the principle that persons with disabilities be treated not in isolation, but within the normal context of all persons in the community. The WPA strategy emphasized three purposes for the promotion and collection of effective disability data: prevention, rehabilitation and the realization of the goals of "full participation and equality" of disabled persons in all aspects of life and development**.** Equalization of opportunities was defined in the WPA as, "the process through which the general system of society, such as the physical and cultural environment, housing and transportation, social and health services, educational and work opportunities, cultural and social life, including sports and recreational facilities, are made accessible to all." It further clarified, "the principle of equal rights for the disabled and non-disabled implies that the needs of each and every individual are of equal importance, that these needs must be made the basis for the planning of societies, and that all resources must be employed in such a way as to ensure, for every individual, equal opportunity for participation." The purposes for disability measurement outlined in the WPA guided the WG's early discussions related to choosing a purpose for the measures to be developed for censuses and surveys.

The WG agreed that there is more than one possible purpose for which a general disability measure can be used and, therefore, it may be necessary to develop multiple general measures to suit specific purposes. The WG reviewed three major classes of purposes for collecting disability data. The first is to provide services, including the development of programs and policies for service provision and the evaluation of these programs and services. Service provision seeks to identify those persons with specific needs, often those with the most serious needs. The second purpose is to monitor populations, specifically identifying the level activity or participation limitation in the general population. The third purpose for collecting disability data is equalization of opportunities, that is, assessing whether persons with disability are participating in social and economic life at the same level as persons without disability. In order to address this purpose, measures need to identify persons who are at greater risk than the general population of restrictions in performing specific tasks or activities.

The purpose chosen by the WG also had to meet two important criteria. The first was relevance: Is the purpose of relatively equal importance across countries with respect to measurement? The second criterion was feasibility: Is it possible to collect the proposed information using a comparable general disability measure that includes a small set of census-like questions? While all three purposes outlined above were determined to be relevant to the goals of the WG, the feasibility of developing a short, cross-culturally comparative, set of measures to meet each purpose varied. A much lengthier set of questions would be needed to inform service provision issues. Data to truly assess the needs for, and efficacy of, services need to be collected at the population, individual and environmental levels. In order to monitor levels of functioning in populations, data on specific kinds of activities (social and economic) and participation in such activities are needed, as well as whether limitation in participation is due to difficulties in functioning. Measures best suited for this purpose capture participation in common activities, the ability to accomplish tasks necessary for independence, and limitations in basic function activities. At a minimum, data to inform the third purpose for disability data, equalization of opportunities, need only to identify those *at risk* of disparately participating in society's activities. By conceiving of disability at the most basic elements of activities, a relatively limited number and types of measures can be identified to serve this purpose.

Given the need for brevity in developing census measures, and the need for measures which are meaningful across cultural contexts, the WG chose to develop measures that would provide the statistical data needed to assess equalization of opportunities. The WG recognized that the general disability measure developed to suit this purpose will not necessarily satisfy other purposes and will not provide a comprehensive assessment of disability or identify the "true" disabled population, if in fact such a subpopulation exists. However, the importance of identifying those persons at risk for restricted participation fit well with the data collections targeted for inclusion of these measures, and the resulting data would inform population monitoring purposes as well. Further, this purpose meets the criteria of relevance and feasibility of implementation internationally. In identifying a broad subpopulation, which can be further described using detailed information obtained via extended survey sets, much needed data to inform programs and policies related to the equal and civic rights of persons with disability would be obtained.

The relevance of assessing equalization of opportunity was reinforced just 4 years after the WG began its work. In December 2006, the U.N. General Assembly adopted the Convention on the Rights of Persons with Disabilities (CRPD), the first international human rights treaty affirming and protecting the rights of persons with disabilities. The CRPD's stated purpose is to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all people with disabilities and to promote respect for their human dignity." (CRPD, Article 1). By its adoption, inclusion of persons with disabilities in all aspects of society, including "full and effective participation", was not simply the guiding purpose for which the WG would develop disability measures. It became one of the most important purposes for the measures themselves – to provide the fundamental information necessary to monitor the policies and laws of the CRPD.

Coordination, Support and Promotion: The Ongoing Mission

The stated goals of the WG articulate the importance and need to promote and coordinate international cooperation, implementation, support, and use of disability statistics. The strong commitment to these goals has not waivered.

One of the key recommendations made at the conclusion of the 2001 U.N. Seminar was to include stakeholders and data users in the activities of the WG. Stakeholders referred to a wide range of organizations with international expertise in disability statistics. National statistical offices of U.N. member states appoint representatives to the WG. Adjunct members of the WG, those who participate but may not vote in decision-making processes, include international organizations with formal relationships to these statistical agencies such as disability organizations, U.N. affiliates, and non-governmental organizations representing statistical agencies. Representation of persons with disabilities is especially important to the WG, and international disability organizations have been invited to participate in WG meetings and activities from the start.

The WG is currently one of the U.N.'s longest operating city groups. One reason for this is the broad inclusion, and participation, of interested and knowledgeable persons and organizations. This involvement of such a diverse group of experts is fundamental to the success of the WG's developmental work, as well as the implementation of the disability sets, and future activities. In order to reach as many stakeholders as possible, the locations of the WG's annual meetings are rotated throughout regions of the world. When available, support for travel to meetings is provided to members who would otherwise not be able to attend. Regional workshops and meetings are held to involve additional organizations in the WG agenda and address region-specific issues. Trainings to support testing and implementation efforts have occurred with partners throughout the world. Few countries have not either participated in the work of the WG or become partners in activities to strengthen their national disability data collections.

The WG continues to build and support a network of institutions and experts, including producers and users of disability statistics, to implement the development in this field, and ensure the data collection instruments will be put to use to produce the high-quality information needed in this area. The WG remains involved in a number of collaborations and Expert Group Meetings to promote broad use of the WG measures. Collaborations, such as that with UNICEF to develop disability measures for children, are highly valued and have produced disability questions for international use in population-based surveys. The WG's SS-F measures are now included in the U.N.'s *Principles and Recommendations for Population and Housing Censuses: The 2020 Round* (2015), which includes disability as a core topic to be collected in censuses. The set is also included in the Conference of European Statistician's recommendations for regional census collections in the European Union programme for the 2021 round of population and housing censuses (UNECE 2015).

Perhaps the most important reason for the longevity of the WG is the continued and growing need for measures and data on disability. That need is a global one, and it is not diminishing. When the CRPD was adopted in 2006, more countries signed the treaty on its opening day than any other treaty introduced in U.N. history (Kanter 2015). Of the 159 countries which have signed, 151 have ratified the CRPD; 85 countries have ratified the Optional Protocol. These countries need the disability statistics that the WG work produces. The data are central to monitoring the laws and policies of the CRPD, as well as those country-specific laws, policies and programs targeted to improving the lives and inclusion of people with disabilities.

The WG's work to improve the availability and quality of disability measures for use in a number of data collection formats, and for international comparisons; to promote and support the use of these measures; and to develop and support strong working relationships and networks among countries and additional groups to further international cooperation on disability data topics is ongoing. The content included in this book describes the body of work and accomplishments thus far. The work is ongoing…

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Chapter 2
Cross-National Issues in Disability Data Collection

Marguerite Schneider

Introduction

The notion of disability is a universal one given that as humans we all experience directly or indirectly some loss of function. How this loss of function is interpreted and managed will, however, differ across different countries, cultures and level of resource availability. Some of these differences are explained by cultural norms and practices while others are better explained by technological development, educational levels and geographical contexts. Thus while the definition of disability and the measures based on this definition can be universal, the way the questions are interpreted and understood by respondents will not be universal. This lack of universal interpretation is potentially problematic in cross-national comparisons of disability statistics. This chapter sets out these cultural and context factors that affect how we collect disability survey data and interpret disability statistics at a global level.

There is a growing consensus, embodied in the U.N.'s Convention on the Rights of Persons with Disabilities (CRPD), that disability is an "evolving concept [resulting] from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others." (United Nations 2006: preamble). This evolving nature, arising from the interaction between shifting components within and external to the person, generates a construct of disability that is complex and fluid. The implications for measurement are important. Disability cannot be captured using one or two questions. Rather, Individual components must be identified and measured, and the outcomes of the interaction between these individual components need to be determined analytically. For example, difficulties in basic activities can

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be cross-tabulated with employment status to determine the effect of these activity limitations on employment status. The three individual components include person focused components (health condition, impairment and activity limitations), external factors that interact with these person focused components, and outcomes of this interaction. Thus, disability is a complex notion providing significant measurement challenges.

Measurement of disability is important to monitor prevalence of disability, service needs of people with disabilities, and level of participation by people with disabilities in society, as set out in Chap. 5 of this volume. Data are necessary for planning and for ensuring that the rights of people with disabilities are included in the rights of all people. But these data are useful only if the measures used are valid and reliable and users understand the potential sources of error generated in different cultural, geographic and socio-economic contexts.

The first hurdle of disability measurement is to ensure that the relevant components are measured in a way that reflects the complexity of disability without resorting to simplistic measures. The last few decades have seen a shift, as described by Shakespeare (1996), from a relatively essentialist view of the world, where phenomena were seen as simple and linear, to a more nuanced view that recognises the complexity of phenomena such as identity, poverty, development, wellbeing, and disability. This is also reflected in the growing use of intersectionality as an important framework for understanding complex phenomenon, especially in understanding people's identities (Cho et al. 2013; Nash 2008; Shaw et al. et al. 2011). Recognising this complexity has important implications for developing measures for these phenomena. As I have noted before,

> a very real tension in disability measurement (as in measurement of other complex phenomena such as poverty and wellbeing) is to keep measures simple and easy to administer in a standard manner, while recognizing and incorporating the complexity and preventing the statistics from being interpreted as reductionist versions of the phenomenon. The ideal of accurate and simple measures to represent a complex phenomenon is no simple task: the two could be construed as inherently contradictory. Reconciling this contradiction entails not only ensuring that the measures used are accurate, but also that those who use these measures and related statistics understand what is being measured and how to use and interpret the data. (Schneider 2012:8)

A good example of a reductionist view of disability is the use of categorical measures of impairments, such as asking if someone in the household is 'deaf, blind, crippled or mentally retarded',[1] or similar questions (Schneider 2012). This type of question remains in current use in a number of surveys and censuses primarily in developing countries, despite the validity and transparency of the measure (i.e. clarity on what is in fact being measured) being low (Schneider 2009, 2012) and the growing body of work showing that we need to move beyond such measures (UNESCAP 2010; Üstün et al. 2010; World Health Organization and World Bank 2011).

The strategy is not to deny the complexity, but also not to pretend to measure something complex while using a limited and simplistic measure. In the face of this complexity, we need simple, but not simplistic, measures.

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[1] I use single quotes to show that these are not acceptable category terms or a valid question.

The second dilemma of disability statistics is that of the survey context where the majority of disability measures are applied. One of the features of surveys is the 'systematic [measurement] … of the same set of properties or variables, for each of a number of cases' (Scott and Morrison 2007: 233). This requires a standard set of questions to be applied to a sample of respondents in the same manner, and the resulting data being analysed on the same way. The assumption is that the data are measuring the same thing across the different contexts and countries, and are equivalent in the information that they represent (Medina et al. 2009; Scott and Morrison 2007). Systematic measurement and equivalence across respondents is achieved, for the most part, if we can demonstrate that the understanding and interpretation of the questions is the same, and congruent with the question intent, for the majority of the respondents.

In this chapter I consider different potential sources of error in disability survey data and the reasons for these, including a discussion on how the issue of the complexity of disability measurement can best be managed. The primary focus is on observational errors (Willis 2005) and, specifically, on interviewer and respondent factors that may lead to errors in the survey data. These factors may be particular to a few contexts or be more generalised across any context. The focus is on the differences in interviewer and respondent sources of error across different contexts that make cross-national comparison of disability statistics difficult, but not impossible. The chapter ends with a discussion of some other hurdles to be addressed in disability survey data collection, such as design of the survey and different analytical strategies. Differences in the design and analysis will also challenge cross-national comparisons.

Observation Errors in Measures of Disability

Observation errors arise from either interviewer or respondent issues. Willis (2005: 14) describes response errors as arising from 'the characteristics of questions, and of respondent processing of those questions, [which] may lead to incorrect answers'. Interviewer errors arise from misunderstanding (by the interviewer) of the questions they ask, reading them incorrectly, or marking the incorrect response (Willis 2005). Different errors across different contexts will lead to problems in comparative analyses, even if using the same questions.

Interviewer Errors

Different countries have different levels of resources available for training data collectors. This is particularly relevant for censuses or more general surveys where a wide range of topics are covered within a single survey. Each individual section of the questionnaire requires detailed training and this need may well be overlooked. Poor training leads to incorrect administration of the questionnaire and incorrect responses.

While there is not much written on this issue, my experience in South Africa has led me to hypothesize this as a potentially important source of cross-national measurement of disability. The context is of the South African census of 2011 and some earlier General Household Surveys conducted by Statistics South Africa (StatsSA). As a lead up to the 2011 Census, StatsSA undertook research on the disability schedule with a view to revising the questions to be used in 2011 (Schneider and Couper 2007; Schneider et al. 2009; Schneider 2009; Statistics South Africa 2006). The work comprised two phases; the first being a qualitative study comprising a series of focus groups, to test the performance and interpretation of the Washington Group Short Set questions (WG Short Set) compared to the Census disability question of 2001 and the straightforward question 'Are you disabled?'. In addition, group participants' understanding of the concept of disability was also discussed.

This second phase comprised a national survey of 6000 households to further test the WG Short Set and compare responses to these questions with those for the 2001 census question and 'Are you disabled?'. The results showed that the WG Short Set provided a more transparent and valid measure of functional status than the other two questions (Schneider et al. 2009; Schneider 2009, 2012). The field survey identified up to 32 % of the South African population 15 years and older as having at least some difficulty on one domain of functioning. This figure is very different to the 12 % estimate from the same field survey (Statistics South Africa 2006) for the Census 2001 question (population 15 years and older). The explanations for this difference are twofold. The WG Short Set is a more inclusive measure focusing on functional status and identifying many people with 'some difficulty' who would not have reported being disabled or having a serious disability (as asked in the Census 2001 question). Secondly, reactions to questions including the words 'disabled' or 'disability' suggest that these are measures at best asking about identity as disabled and at worst some combination of identity and functional status.

The outcome of this question testing work was to adopt the WG Short Set questions for the 2011 Census and to change the heading of the content area from 'Disability' to 'Health and functioning' to avoid using the term disability anywhere in the questions. The survey in 2006 was a topic specific survey which allowed much of the training of fieldworkers to focus on disability and how to ask the questions. From the numerous anecdotal evidence I have collected on how the questions were asked in the census of 2011, it seems that little attention was given to this topic in the training, and that this, coupled with interviewers' perspectives on disability being limited to traditional notions of 'deaf, blind, crippled or mentally retarded', led to possible interviewer error in the data.

The anecdotes from a range of different sources (e.g. non-disabled and disabled people) showed a number of features. The first is that interviewers made assumptions that if they could not see a disability they did not need to ask the questions and marked all the responses for each member of the household as 'no difficulty'. Secondly, the questions were meant to be asked and not marked by observation, and this was clearly not followed by the interviewers. Finally, when a household member was obviously disabled (as was the case for a friend who is quadriplegic and uses a wheelchair), assumptions were made about their ability to walk. This friend in question was not asked the question, but an assumption was made by the interviewer that he had 'some difficulty' walking and climbing stairs. When challenged as to reason for marking this response the interviewer said that often people in wheelchair can walk a little bit!

This anecdotal evidence suggests that issues of training and interviewer perceptions lead to potentially poor data. The results of the Census 2011 (Statistics South Africa 2014) and other General Household Surveys also run by Stats SA (e.g. household surveys of 2009, 2010 and 2011 available at www.statssa.gove.za) show estimates below 9 % (7.5 % for Census 2011) for the population 5 years and older.

While some of the differences between the 2006 survey and Census 2011 results are explained by the different survey or census contexts (broad in census versus specific topics in 2006), a further explanation is the impact of interviewer factors. The attitudes and perceptions of interviewers coupled with limited training on the specifics of the disability measures results in poor data collection. The limited training provided could be due to either a lack of awareness of current understanding of disability by administrators of the survey, lack of time and money to train effectively, or a combination of both. This hypothesis on the effect of interviewers requires further investigation to confirm or reject the anecdotal evidence.

Respondent Error Due to Cultural Factors

Respondent factors that lead to potential data errors are related to cultural beliefs and understandings of disability, geographical and socio-economic contexts, and access to health care services. These factors may lead to differences in how questions are interpreted by respondents in different contexts.

Culture is very often evoked when trying to explain differences in phenomena, including differences in disability statistics. The danger is to overstate the role of cultural differences and potentially confuse cultural with other explanations, such as geographical or socio-economic factors. Disability as a phenomenon is well known in all and any human culture. As a species we all have the same basic capabilities of seeing, hearing, walking, thinking, feeling, taking care of oneself, and communicating. Thus, we all understand when these human capabilities are limited in some way, signalling a difference. Applying stigma to this difference is a common human characteristic found in many cultures. There is good historical and current descriptive evidence of stigmatization and marginalization that frames people with disabilities as outsiders and/or deviants. Miles (2000), a disability studies scholar, writes that these trends were evident in religious writings already 2500 years ago, while Baynton (2001), an historian, documents the way in which deviance, such as disability reflected in notions of physical or mental weakness, deformity and ill-health,[2] was used as a justification for inequalities at the turn of 19th to 20th century

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[2] Baynton (2001) also highlights how these terms were used to justify inequalities between men and women and between black slaves and their white owners. The feminist movement and black

and remains so currently. This discrimination, stigmatization and seeing disabled people as ‘abnormal’ human beings, is directly related to notions of personhood and citizenship as described by Ikäheimo (2009) in his essay on Personhood and the social inclusion of people with disabilities. His analysis sets out the conditions for personhood being fundamentally about being part of ‘us’ and not ‘them’, a feature so consistently noted throughout the world that it cannot be seen as a culture specific factor determining how people respond to questions asking about disability.

Nevertheless, there are some differences noted in the range of people who are included as being disabled. For example, in my analysis of how adults in a rural area of north-east South Africa understand disability (Schneider 2012), the basic category of functional limitations was regularly mentioned when respondents were asked to describe a disabled person. However, a good number of participants made reference, in addition, to having lost a relative or loved one and hence being disabled. This notion of disability as a loss was also noted in Kenya, where villagers, when asked to list who is disabled, included orphans as disabled if they had nobody to take care of them (Gona et al. 2010).

Cultural understandings of disability tend to be embodied in negative terminology (e.g. people with Albinism being referred to as monkeys in Southern Africa), and related negative actions (e.g. people with Albinism being mutilated and murdered in Tanzania). Use of negative terminology in measures of disability means that respondents will not endorse any of the questions if they do not identify as disabled. Thus, we obtain quite different endorsement rates for questions asking ‘Is anyone in this household deaf, blind, crippled or mentally retarded?’[3] or ‘Are you disabled?’ compared to questions asking respondents if they have difficulty doing various activities (Schneider et al. 2009; Schneider 2009). Disability is seen as being permanent, not curable, and being unable to do anything, as reported by participants in a series of focus groups with adults, disabled and non-disabled, in South Africa, while difficulty is temporary, solvable and about ‘normal’ life (Schneider and Couper 2007; Schneider 2009).

This finding confirms the importance of shifting the focus of disability measures from asking about a limited and marginalised group of people – ‘disabled people’ – to asking about everyone’s difficulties in doing various activities. In the remainder of the chapter I refer only to questions on difficulty people may have and consider different factors that affect cross-national measurement of disability using ‘difficulty’ questions.

The above argument holds true for measures of basic activities (as for the WG Short Set), but does not necessarily hold true for more complex activities that denote societal roles and responsibilities, such as taking care of the household, socialising or being financially independent. A female respondent in one context may say that

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rights movement have gone a long way to addressing these inequalities, and the disability rights movement is slowly gaining ground in addressing these.

[3] See U.N. Statistical Division’s DISTAT for examples of such questions still being used in censuses and surveys in a number of countries. http://unstats.un.org/unsd/demographic/sconcerns/disability/disab2.asp.

she is unable to be financially independent, not because of any health-related condition, but because of her societal context which does not allow women to be financially independent. Another female respondent in a societal context where women do work, may respond that she is unable to be financially independent because of barriers hindering her ability to get to work and be accommodated in her workplace as a wheelchair user. The same response (and data points) embodying two very different meanings.

The accurate measurement of complex domains of functioning is more difficult to achieve, but can be addressed to some extent. The first approach is to consider broad and generic categories of functioning, such as being included in relevant activities for a given context. The generic category is 'inclusion in daily life' (with further breakdown of this domain being possible), but the specific measure used in different cultural contexts being different. For example, in South Africa, in Bantu culture it is not appropriate for a younger person to have eye contact while talking to a person older than themselves. In Western culture it is inappropriate not to have eye contact with the person you are conversing with. The generic activity would be about 'conversing or communicating with others' and the specific measures would be different reflecting these cultural differences.

A second approach is one that is being used in contexts of disaster or conflict where a rapid assessment of functioning within a population is required (Bolton et al. 2003; Bolton and Tang 2002). Paul Bolton, Judith Bass and their colleagues develop functional assessment tools as required in individual contexts. Thus, when assessing depression related disability in rural Uganda, the assessment tool is developed and validated in that context. The process, as described by Bolton and Tang (2002) starts with free listing, by 30–40 target respondents, of the activities undertaken by that group of participants (with separate ones usually for men and women). These free listings are analysed and the most common nine activities are included in a brief functional assessment tool that targets the more complex activities of daily living, such as farming, manual labor, planning for the family, attending meetings, attending funerals, cooking and cleaning the house and surroundings (Bolton et al. 2003). The tenth item on the tool is left as 'other' and to be specified. The response options are a scale of 5 response options ranging from no difficulty completing the task through to 'often can't do the task'. The 10 item functional assessment tool is then validated on a larger sample (e.g. 60–80) of respondents from the target population. While this is a rough and ready tool, it does provide, as Bolton and Tang suggest, a culturally sensitive measure of functioning in complex domains. Because it targets the most important activities and tasks of the target population, the functional assessment tool provides comparable cross-national measures of difficulty in doing the 'most important tasks and activities', which will be different in each context of measurement. The category is generic (most important activities) but the measure is context specific. Currently, these measures have been used primarily in randomised controlled trials for psycho-social interventions and not for national statistics. However, the approach could be adapted for survey measures of disability.

Respondent Error Due to Non-cultural Factors

People's responses to questions about difficulties in basic activities are influenced by geographical contexts, translation issues, contexts of poverty and adversity, and access to health care services.

Geographical Differences

In the work undertaken by the Washington Group, there was clear evidence that people responded in a relative manner to the question 'Do you have difficulty walking or climbing stairs?'. In the context where it is common for people to walk long distances (e.g. living in a rural village far from services and without transport) the single question on the WG Short on walking and climbing elicited responses such as 'I have some difficulty'. However, the same person reported no difficulty at all in walking 500 m. When asked to explain his answer, the respondent said that now that he is older, he cannot walk as easily for 20 km or so, but he could when he was younger (Schneider 2012).

In a context where people go everywhere by car and do little walking, the context within which to judge one's level of difficulty would be different. This geographical influence on responses are of particular importance for surveys or censuses that ask only one question on walking and climbing stairs. However, if the survey allows for more questions, and additional questions use a specific distance reference, the geographical influence can be identified and the data adjusted accordingly.

A similar finding was noted for climbing stairs. In Almaty, Kazakhstan, most people live in high rise apartment blocks often with no elevator. People's experiences of climbing stairs is similar to the rural dweller walking long distances. A general question asking about difficulty climbing stairs may elicit responses of 'some' or 'a lot' of difficulty, but when asked about climbing one flight of stairs, these same respondents report 'no difficulty' (UNESCAP 2010).

Translation of Questions

Accurate translation of disability questions is difficult but important to do. The focus should be on translating concepts and not words or terms. The translation must be easily understood by all respondents and be easily readable by the interviewer in a face to face interviewing context. Using a combination of skilled translators, people knowledgeable in disability and people who talk the language at a local level will ensure that the translation is accurate and able to be understood by interviewers and respondents.

Evaluation of translated questions is a key component of ensuring cross-national comparable measures of disability. Of particular concern are terms such as depression and anxiety which arise from a Western medical context often with no simple equivalent in a non-western linguistic context. It may be important to provide examples of the type of feelings are considered to be symptoms of depression, such as 'thinking too much' (Lund et al. 2010; Patel and Kleinman 2003), or similar idioms of distress (Nichter 2010; Scobar et al. 2007).

Idioms of distress are ways that people express or mark their distress, usually through reporting difficulties with affect, pain, cognition and sleep (Gureje 2007; Miranda and Patel 2005; Moussavi et al. 2007; Patel and Kleinman 2003; Patel 2007; Scobar et al. 2007). The expression of distress is referred to an as idiom as it is expressed in culturally specific ways. An example is the response to the WG Short Set question asking about 'Difficulties with remembering or concentrating' when translated into Shangaan, one of the official languages of South Africa. Shangaan respondents often reported 'some' or 'a lot' of difficulty. When asked to explain their answers, the narratives provided referred to difficulty when thinking about a daughter dying, difficulty concentrating when it has to do with money but not if it does not involve money, and a range of similar responses (Schneider 2012). This is clearly an 'out of scope' or incongruent interpretation of 'difficulties with memories' rather than 'difficulty with memory or remembering'. The conclusion from this analysis is that translation should be revised with the addition of examples in order to convey the correct intent. Without correction the Shangaan interpretation would lead to much higher rates of 'remembering or concentrating' difficulties among Shangaan speakers than English ones but for the wrong reasons. The measure would be inaccurate and not comparable.

Context of Poverty and Adversity

The Washington Group testing of the extended set (UNESCAP 2010) and research in South Africa (Schneider 2012) show a consistent difference in endorsement rates for questions on the basic domains of functioning (seeing, hearing, mobility, cognition, self-care and communication) compared to what can be called the 'feeling' domains (pain, affect as in depression and anxiety, and fatigue or energy) – referred to as domains of body function and structure in the ICF classification (WHO 2001).

These domains are in the area of mental health, which is closely linked to overall well-being (Cummins 2009; Tomyn and Cummins 2010). Given that poverty and adversity are also closely linked to wellbeing and mental health (Cooper et al. 2012; Lund et al. 2010), it is important to try and understand the relationship between measures of mental health (especially those of anxiety and depression, or common mental disorders – CMD), wellbeing, poverty and adversity. These relationships can only be elucidated if measures of mental health are accurate and validated.

When asked to give reasons for reporting difficulties with anxiety and/or depression, a common narrative relates to not having enough money to buy food for the family, worrying about children not getting jobs, fear of crime, stressing about one's spouse, and so on (Schneider 2012; UNESCAP 2010). Furthermore, there is growing evidence of high prevalence of CMDs especially in low and middle income countries (Lund et al. 2010, 2011; Patel et al. 2001; Patel and Kleinman 2003).

Linked to the question at the end of the preceding paragraph, we need to determine the extent to which measure of CMDs reflect a clinical mental health disorder (e.g. major depression or anxiety disorder) or a realistic reaction to living in a context of adversity and/or poverty. A further possibility is that these measures identify people not only with clear depression or anxiety disorders but also those at risk of developing serious mental disorders. These latter respondents would be those with mild to moderate problems with depression and anxiety in response to their adverse life contexts. They are different from those respondents who do not have such problems but who live in similar life contexts. The difference between these two types of respondents would be that the former are more at risk of developing clinical depression and anxiety, while the latter may not be at risk.

These are all hypothetical arguments that need to be tested empirically. The point here is to raise these concerns in order to allow us to address them empirically. One such test would be to match the narratives to the actual responses provided by respondents. Narratives which describe a context that is likely to generate anxiety and possibly depression would match a response of mild, moderate or severe problems. This would be a response driven by external factors and in proportion with the context. Narratives that do not describe such contexts but show moderate to severe problems would reflect a response driven by internal factors, such as clinical depression or anxiety, and be out of proportion with the context.

A better understanding of what measures of CMD are in fact measuring will assist in determining the purpose of these measures. Two clear purposes are immediately apparent – firstly, the proportion of the population not coping with poverty and other adverse contexts, and, secondly, the proportion of the population requiring medical care for clinical depression and/or anxiety. The use of analytical strategies based on responses to multiple questions is one way to separate out these two purposes, as proposed in the Affect chapter of the ESCAP report of 2010 (UNESCAP 2010). The bivariate logistic regression models used in the ESCAP analyses showed that reports of frequent and intense episodes of depression or anxiety were related to explanations that included being diagnosed by a clinician with a CMD, these feelings causing chest pain or interfering with completing everyday tasks and activities. Those reporting less frequent and less intense episodes tended to explain these as related to their work context and economic problems.

Access to Health Care Service

Access to health care services vary significantly from high to low income countries. In high income countries, access is likely to be good and understanding of diagnoses and impairments will be high. Respondents will be able to report difficulties in hearing, for example, as they would have had access to audiometric assessments. In low and middle income contexts, this access is limited. Respondents will not necessarily identify difficulties in hearing and will rather report no difficulties (as they do not attribute these to a loss of hearing, as after all they are able to hear many things) or some other type of difficulty, possibly in communication. Similarly, lack of access to health care means lack of recognition and diagnosis of problems. This may translate into less problems being reported as, especially mild and moderate difficulties are not recognised as problems, or the cause of the problem not being understood. The South African national disability survey conducted in 1997/1998 asked a question on the cause of reported difficulties (Schneider et al. 1999). The results showed that the clarity of the cause (as reflected in a clear diagnostic category being provided) increased with increased education and access to services. Africans, as the most disadvantaged sector of the South African population in 1997 and now, (a racial categorisation that is relevant in South Africa due to the on-going disparities based on race as a legacy of apartheid) were most likely to report that they do not know the cause of their disability, and rural African dwellers were the most likely to report witchcraft as the cause.

Access to health care allows mild problems (e.g. middle ear infections in children) to be treated and long term consequences avoided. Poor access to health care results in late presentation of problems and limited resolution of milder problems. This results in more severe and long term problems developing (e.g. permanent hearing loss). This would result in more severe problems reported in areas with poor access to health care. The South African disability survey showed a higher number of rural dwellers with severe difficulties than urban dwellers, and this was particularly marked for the 0–10 year age group.

Survey Design in Cross Country Comparability

Comparison of survey findings requires that the survey designs are the same or similar enough to ensure that the results are comparable. The more common types of design in disability surveys are one or two phase designs.

One phase design has a single questionnaire (with possible variations for children and adults), and asks all questions of all respondents. There is no screening of disability status. The determination of who is disabled and who is not is made at the analysis stage and can include different cutoff points for this categorisation. The questions are asked directly of the respondents, unless they are unable to respond and a proxy respondent is used.

A two phase design requires a set of screening questions to be asked of one household respondent (usually the head of household or another adult knowledgeable about the whole household). These screening questions are asked personally of the household respondent and in proxy mode about other members of the household. The responses on these screening questions are used to determine who is included as disabled and non-disabled, providing a frame for selecting respondent for the second phase questionnaire – usually a detailed individual questionnaire. The individual questionnaire will usually be administered personally to the selected individual or their caregiver. Selected individual respondents should include both disabled and non-disabled individuals identified on the household questionnaire to check for false positives and negatives as reported by the household respondent.

The nature of the screening questions is important. If these questions are narrow in their focus, they will result in an under count compared to surveys that use a much broader set of screening questions. The aim should be to use a screening set of questions that are as inclusive as possible, with the second phase being used to provide more nuanced data.

Conclusion and Recommendations

In this chapter, I have set out potential hazards to address when interpreting disability statistics from different geographical and cultural contexts. Developing disability measures for global comparisons involves not only careful question design and translation, but also a sensitive review of what different concepts mean in different contexts once questions have been translated to ensure conceptual equivalence. The examples given earlier show how usual contexts determine responses, such as what a difficulty walking means for a person who walks everywhere compared to a person who does very little walking.

Asking about difficulties provides a more transparent measure of functional status and goes a long way to ensuring that measures are comparable for functional status. Measuring identity is important but separate measure and may require different measures in different contexts. The 'disabled' identity is generally linked to experiences of disadvantage, discrimination and stigma and is likely to be more culturally dependent and problematic as a cross-national measure.

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Chapter 3
Washington Group Meetings, Processes and Milestones

Cordell Golden

The Washington Group (WG) has sought to foster international collaboration on the development of disability measurement, and in particular, to insure that the efforts of the group are broad-based and inclusive of voices from all countries, from every region of the world and every state of development. Thus, representatives of national statistical authorities, Disabled People's Organizations (DPO), and other international organizations participate in the WG. All national statistical offices are eligible for membership in the WG and are invited to the meetings each year. Since its inception, representatives of the national statistical offices (NSO) from 130 different countries have participated in WG activities at one time or another. Fifteen different international non-governmental organizations, including organizations that represent persons with disabilities, the United Nations Statistics Division (UNSD), and other U.N. affiliates, have participated in the WG meetings and other activities on an ongoing basis. In addition, a large number of representatives from local national organizations usually participate as observers in meetings taking place within their region. The list of NSOs, DPOs and International organizations that have participated in the WG can be found in Table 3.1.

Annual meetings are rotated through major geographic regions to facilitate participation, especially of representatives from developing countries. The WG has held fourteen annual meetings since its inception in 2001. The locations and number of individual participants for each meeting are listed in Table 3.2.

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Table 3.1 National Statistical Offices, disabled people's organizations and international organizations who have participated in the Washington Group

National Statistical Offices (NSO) currently participating in the Washington Group		International and National Disabled People's organizations (DPO)	Other International Organizations
130		**26**	**15**
Afghanistan	Lebanon	**International DPOs (6):**	EUROSTAT
Albania	Lesotho	European Disability Forum	European Union Agency for Fundamental Rights (FRA)
Argentina	Lithuania	Rehabilitation International	Partnership Health, EU
Armenia	Luxembourg	Inter-American Institute on Disability	International Labor Organization
Aruba	Malawi	African Rehabilitation Institute	Organization for Economic Cooperation and Development
Australia	Malta	International Federation for Spina Bifida and Hydrocephalus	Inter-American Development Bank
Austria	Mauritius	International Disability Alliance (IDA)	International Development Project
Azerbaijan	Mexico	**National DPOs (20):**	World Bank
Bangladesh	Micronesia	National Disability Authority in Ireland	World Health Organization
Barbados	Moldova	Coordenadoria Nacional para Integracao da Pessoa Portadora de Deficiencia (CORDE) in Brazil	WHO Family of International Classifications Collaborating Center
Belgium	Mongolia	Secretaria Nacional para la Integracion de las personas con Discapacidad (SENADIS) in Panama	United Nations Children's Fund
Bermuda	Monserrat	Disabled Organization for Legal Affairs and Social Economic Development (DOLASED) in Tanzania	United Nations Economic and Social Commission for Asia and the Pacific
Bolivia	Morocco	Association Pro Personas Con Paralisis del Parque in Mexico	United Nations Economic Commission for Europe
Botswana	Mozambique	Puerto Rico Council on Developmental disabilities	United Nations Economic and Social Commission for Western Asia
Brazil	Netherlands	Office of the Ombudsman for People with Disabilities in Puerto Rico	United Nations Statistics Division

(continued)

Table 3.1 (continued)

National Statistical Offices (NSO) currently participating in the Washington Group		International and National Disabled People's organizations (DPO)	Other International Organizations
130		**26**	**15**
Bulgaria	New Zealand	National Institute on Disability and Rehabilitation Research in the U.S.A.	
Burundi	Norway	National Union of Persons with Disabilities of Uganda (NUDIPU)	
Cambodia	Oman	Age Concern Bermuda	
Canada	Pakistan	Bermuda Resources for the Advancement of Children with Special Needs	
Chad	Palestine	Bermuda Autism Support and Education	
Chile	Panama	Bermuda Government community Rehabilitation Occupational and Physiotherapy Services	
Croatia	Papua New Guinea	National Office for Seniors and the Physically Challenged, Bermuda	
China	Paraguay	Human Rights Commission, Bermuda	
Hong Kong, SAR	Peru	Department of National Drug Control, Bermuda	
Macao, SAR	Philippines	Bermuda Society for the Blind	
Colombia	Poland	Bermuda Hospital Board	
Costa Rica	Portugal	ADAPT (formerly The Spastics Society of India)	
Croatia	Qatar	Higher Council for Affairs of Persons with Disabilities (HCD)	
Cuba	Romania		
Curacao	Rwanda		
Cyprus	St. Lucia		
Czech Republic	St. Maarten		
Democratic Republic of the Congo	Samoa		
Denmark	Saudi Arabia		
Dominican Republic	Serbia and Montenegro		

(continued)

Table 3.1 (continued)

National Statistical Offices (NSO) currently participating in the Washington Group		International and National Disabled People's organizations (DPO)	Other International Organizations
130		**26**	**15**
Egypt	Sierra Leone		
Estonia	Singapore		
Fiji	Slovak Republic		
Finland	Slovenia		
France	Somalia		
Gambia	South Africa		
Georgia	Spain		
Germany	Sri Lanka		
Ghana	Sudan		
Greece	Sweden		
Guatemala	Syria		
Hungary	Tanzania		
India	Thailand		
Indonesia	Togo		
Iran	Tonga		
Iraq	Trinidad and Tobago		
Ireland	Tunisia		
Israel	Turkey		
Italy	Tuvalu		
Ivory Coast	Uganda		
Jamaica	United Arab Emirates		
Japan	United Kingdom		
Jordan	United States		
Kazakhstan	Uruguay		
Kenya	Vanuatu		
Korea	Venezuela		
Kuwait	Vietnam		
Kyrgyz Republic	Yemen		
Laos	Zambia		
Latvia	Zimbabwe		

Establishing Objectives and Organizing Washington Group Work

The mandate that created the Washington Group on Disability Measurement (WG) grew out of the initial work begun at the United Nations (UN) International Seminar on Measurement of Disability in New York on June 4–6, 2001. As a result of that

Table 3.2 Annual WG meeting locations and attendance

Year	Location	Number of participants
2002	Washington DC, USA	58
2003	Ottawa, Canada	38
2004	Brussels, Belgium	50
2004	Bangkok, Thailand	40
2005	Rio de Janeiro, Brazil	47
2006	Kampala, Uganda	73
2007	Dublin, Ireland	58
2008	Manila, Philippines	54
2009	Dar es Salaam, Tanzania	64
2010	Luxembourg	55
2011	Southampton, Bermuda	42
2012	Bangkok, Thailand	40
2013	Amman, Jordan	165
2014	Buenos Aires, Argentina	103

seminar, the United Nations Statistical Commission authorized the development of a City Group.[1] The National Center for Health Statistics (NCHS), the principal health statistics agency of the United States, was invited to host the first meeting to take place February 18–22, 2002 in Washington, DC. The meeting consisted of 3 days of sessions focused on developing agreement on the nature and objectives of global measures of disability to be recommended for use in censuses and surveys in the world community. The group also sought to develop an agenda of work priorities for future meetings associated with the most pressing issues in disability measurement and data collection.

The dissemination of the discussions and decisions resulting from each meeting was another important established priority. Several methods of dissemination were established. A short report on each meeting is presented to the United Nations Statistical Commission. That is followed by a full report of the annual meeting sent to all participating countries. In addition a WG website is hosted by NCHS (http://www.cdc.gov/nchs/washington_group.htm). The full report is also posted on the website annually, and provided to all the venues to which UN City Group materials are customarily distributed. Finally, all presentations given at the annual meeting are made available on the WG website. Other more academic forms of dissemination are also encouraged in professional journals and a volume about the earlier work of the group has been published (Altman and Barnartt 2006). A listing of articles authored by WG participants related to their WG work can be found in the Appendix.

The first meeting of the WG was organized to promote discussion and to develop agreement among the attending nations on the goals and products of the City Group.

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[1] City groups are informal groups of experts primarily from national statistical agencies. Participation by representatives is voluntary. The groups are named after the location of the first meeting.

In order to attain the objectives, the sessions were organized around short specific presentations that identified important measurement issues followed by periods of discussions. Each session ended with points of agreement, suggestions for next steps, and unresolved issues which were to be discussed in later sessions or future meetings. The WG has followed this process in all of its subsequent meetings.

As the first order of business, the WG examined the objectives established by the planning committee. By the conclusion of the meeting a set of objectives were accepted by the participants and used to guide the development of a work plan. The objectives are described in detail in Chap. 2. In order to meet these objectives it was necessary to first review and assess cross-cultural differences in disability definitions, purposes for collecting disability information and barriers to collection of accurate disability data. Other activities included reviewing sets of global measures currently used in censuses and surveys or under consideration in participating nations; developing the underlying principles of successful measurement; evaluating methodological challenges, particularly in the new areas of participation and environment as well as in special populations in order to promote culturally compatible measures in these areas; and continuing to build a network of institutions and experts, including producers and users of disability statistics, needed so that the data collection instruments will be put to use to produce information. All measures identified would be culturally comparable to the extent possible. The WHO International Classification of Functioning, Disability, and Health (ICF) would be used as the basic framework for the development of all question sets.

One of the first products of the WG was a matrix that cross-classified the purpose that a general disability measure could address (i.e., the use that the data will be put to) with a typology of question characteristics such as domain, severity, etiology and duration. The cells of the matrix described the information on each of the question characteristics that is needed to satisfy each of the specific purposes. In addition, an empirical version of the matrix was also developed that evaluated the characteristics of the general measures currently in use according to the dimensions of the matrix (Altman and Barnartt 2006). This matrix detailed what is needed to fulfill a variety of measurement purposes as well as what had been measured with existing general indicators so that the gaps existing in disability measurement were identified. The matrices were presented at the second meeting and helped to direct the future work plan for developing internationally comparable general measures of disability. Work on both versions of the matrix was led by a team with members from Italy, the United Nations, and the United States.

Based on the work done on the disability matrices, a position paper was presented at the third WG meeting on how to define the purpose of the initial census measures. Three related commentary papers were also developed. The discussion focused on selecting one purpose for the general disability measure. The rationale for the choice was based on relevance with respect to policy and feasibility of implementation, with special attention to comparability cross-nationally. Workgroups were organized to generate a draft set of questions related to this purpose, to propose methods for implementing the short set and to begin work on an approach for developing extended measurement sets related to the short set. The reliance on workgroups has also continued to be a WG organizational element that has furthered the development and improvement of measures.

Holding annual meetings in February made it difficult to report to the UN Statistical Commission at its annual meeting in March. To address this, WG meetings were moved to October or November. A second meeting was held in the fall of 2004 in Bangkok.

Washington Group Governance

A proposal for a formal governance process for the WG was presented at the Brussels meeting in 2004. Given the size of the WG and the need to accomplish the three main objectives of the WG (a short general disability measure, a set of extended measures, and related methodological issues), it had become increasingly apparent that an organizational plan for the governance (i.e. structure and operation) of the WG was needed. The draft plan was presented at the meeting and adopted by the representatives in attendance.

The governance plan outlined the terms for membership in the WG, the responsibility of each member, the organizational structure, and the WG's operating principles. It was agreed that the WG membership would be volunteers of the national statistical authorities of nation-states belonging to the United Nations. Primary representative would be selected by the head of each national statistical authority. The goal would be to obtain consensus among participants when making decisions on issues. However, in the event that consensus is not possible and balloting is necessary for decision-making, each member state would have one vote. Well-recognized international organizations having a formal relationship with national statistical authorities (WG member countries) and with expertise in disability statistics could become adjunct members of the WG. Adjunct members may include U.N. affiliates, international disability organizations, other international organizations with an interest in disability statistics, other organizations that represent combined national statistical agencies (such as Eurostat), or other groups with international expertise in disability statistics. Adjunct members would be invited to participate in all activities of the WG, such as participating in meeting discussions, and involvement in workgroup activities. However, they would not vote during decision-making processes. International organizations representing persons with disabilities will be invited and encouraged to participate in WG activities.

Each member was required to contribute substantively to the work of the WG through workgroup participation, individual or group contribution of position papers or activity reports, formal commentary, or participation in other specific, product-oriented work identified by the WG. Attendance at the annual meetings is strongly encouraged. Consistent with the UN guidelines, each representative is expected to fund his or her participation in the group. Each person designated as the primary country representative is responsible for submitting a 2-page "country report" on the activities in their country directly related to the work of the WG.

A summary of the reports is presented at each annual meeting. The primary representative is also responsible for maintaining communications with other parties in their country with expressed interest in the work of the WG. This provides a vehicle for a larger group of experts to have input into the work of the WG.

In the interest of stability of the WG and continuity of the work, a rotating body (steering committee) was established whereby no more than three participants of the group are replaced yearly. It was determined that the steering committee would be comprised of seven representatives of member nations. The committee includes current, past, and future meeting hosts, as well as representatives from each major geographical region of the world. Steering committee members are selected at the annual WG meeting by the full membership and serve 3-year terms with the option to complete a second term if the WG membership is in agreement. The roles of the steering committee members include:

- Serving as the planning committee for the annual meetings and selecting the annual meeting hosts, sites, and dates
- approving interim and annual reports to the UN
- developing the long-range work plan and timeline for implementation of the work plan to facilitate WG activities
- advising workgroups in the coordination of their work and providing recommendations about timeframe for completion of work and the form and content of work products
- with assistance from the secretariat, periodically preparing a written review of the overall progress of the WG to be presented at the annual meeting and posted on the website
- selecting the recipients of funding for meeting attendance when funds are available

The steering committee members select a chair to present the WG report at the annual United Nations Statistical Commission. If the chair is unable to attend the meeting, another representative from the steering committee will be designated to present the report.

Positions on the WG steering committee and the WG's executive secretariat are voluntary. At the 2004 meeting in Brussels, NCHS was selected as secretariat by the WG membership. The secretariat is a standing position that facilitates the continuity and consistency of communication within the WG and between the WG and external parties. The secretariat is institutionally based so that the work of the secretariat is an institutional commitment rather than an individual commitment. The secretariat serves as the central contact for timely communications with the full WG membership and addresses external inquiries. As such, the secretariat maintains and regularly updates the membership list. Other duties of the secretariat include:

- maintaining the WG website and providing annual updates to the City Group website maintained by the UN
- drafting annual and interim reports to the UN statistical commission

- soliciting volunteers to host the annual meetings
- serving as primary point-of-contact for the workgroups
- maintaining a list of members requesting funding for annual meetings and a list of funding opportunities to support member travel to the annual meeting
- informing primary representatives of nation-states of the annual deadline for submission of country reports
- accepting requests for technical support and informing the WG membership of these requests
- monitoring compliance of the WG with governance plan on an ongoing basis and informing the steering committee of any issues regarding compliance
- serving as an ex-officio member of the WG steering committee

The content of the annual meetings are organized around topical position papers and activity reports prepared by small working groups. Papers prepared by the working groups include a list of next steps, as well as, a plan and timeline for accomplishing those steps. WG members are allowed to suggest work topics that are clearly related to the objectives of the WG and have product-oriented and deliverable outcomes. Major work topics for the following year and future years are identified at each annual meeting. The annual WG meeting should take place sufficiently in advance of the deadline for the report to the annual UN Statistical Commission meeting in March (report deadline is the preceding November). Annual meetings are conducted over 2-3 days depending on the amount and depth of material to be addressed. Following each annual meeting, an Executive Summary of the proceedings of the meeting is prepared by the secretariat. The reports are submitted to the steering committee for revision and approval. Once approved the reports are distributed to the WG membership via the WG website.

The WG website serves as the primary means of communication with the full membership as well as other interested parties. The website contains meeting dates, locations, agendas, programs, and proceedings (including presented papers, workgroup and country reports, a list of participating countries/organizations, and the final meeting report). Reports to the UNSD are also posted on the website.

The Short Set of Census Questions

Development of Questions

A draft set of questions for the general disability measure were proposed and discussed at the second 2004 WG meeting in Bangkok. The questions addressed six domains of functioning: walking, seeing, hearing, cognition, self-care and communication. Response categories were structured as a severity scale rather than a simple yes/no categorization.

A new workgroup was formed, working with a consultant, to develop six implementation protocols for pre-testing the short set of disability measures. The protocols included: (1) establishing objectives and an evaluation plan for cognitive and pilot testing; (2) establishing plans for report writing including tabulation and analysis; (3) establishing plans for cognitive testing; (4) translation; (5) enumerator training; and (6) sample design (such as the number of households to be covered and identification of other census questions to be included with the disability questions on the pilot test). Existing protocols, such as the U.N. guidelines and the E.U. translation protocol were used for reference. The protocols were to be completed in a four month timeframe. Countries willing to participate in pre-testing were also identified.

A new workgroup on methodological issues was formed to address the topic of full population coverage as well as other methodological issues including the effects of proxy and non-response, the effects of questionnaire administration mode, and the potential for harmonization of health and disability data using modern calibration techniques. Additional questions would be included on the next country report to identify groups excluded from national surveys (e.g. institutionalized populations, homeless populations). The workgroup planned to examine whether it is feasible to include these subpopulations and whether the proposed questions on disability are relevant for these populations.

The work on the short set content and testing continued at the fifth meeting in Rio de Janeiro in 2005. Revisions were suggested and discussed for the short questions on communication, cognition, and hearing. Preliminary results from testing carried on in the United States and through WHO/ESCAP (see Chaps. 7 and 9) were presented and discussed. Several revisions to the implementation plans were suggested based on the pretesting that had already taken place including the use of a purposive sample in the instructions for the cognitive test and clarification in the cognitive protocol regarding in-country analyses versus cross-country analyses. The WG Secretariat was to carry out an analysis of the cross-country results and report on this at the following meeting. It was also suggested that revisions to the enumerator training manual be made so that it met the specific purposes of the WG. The workgroup was asked to add instructions in the field test guide for ordering additional questions and documenting key characteristics of country practices for purposes of analysis. Most importantly, the terminology across documents was to be made more consistent, specifically in the main implementation document. An extension of the Rio meeting provided technical assistance and training for the South American countries that had agreed to participate in the testing process.

Another new workgroup was formed to plan and implement analyses of the WG pre-tests of the short measure questions. All results pertaining to the six WG questions were to be considered by the new workgroup including the WG sponsored pre-tests, the WHO/ESCAP test, and other testing activities. In particular, this workgroup was instructed to study the field and cognitive testing results for the WHO Disability Assessment Schedule (WHODAS) and World Health Survey (WHS) to see if this could inform results of WG tests.

World Bank Development Grant

In 2004, a Development Grant Facility (DGF) was secured from the World Bank to support the activities of the WG relative to improvement of international efforts to collect data on disability. This type of work was greatly needed to improve the quality of data on disability in developing countries and also improve international comparability. The DGF supported: (1) inclusion of representatives from developing countries in WG activities; (2) execution of a series of pre-tests of the short set of WG questions on disability in order to arrive at a final set of questions; and (3) provision of technical assistance to developing countries to assist with pre-testing.

The goals of the DGF were to facilitate the translation and testing of the proposed questions in a variety of countries and assure that the efforts of the WG were broad-based and inclusive of voices from developing countries from every region of the world. Neither of these activities could have been accomplished without the World Bank funds to allow for testing and attendance at WG meetings.

Adoption of Short Set

A major accomplishment of the WG has been the development, testing and finally the endorsement of a short set of questions that can be used on censuses, sample-based national surveys, or other data collection formats, for the primary purpose of informing policy on the full inclusion of persons with disability into civil society. At the sixth meeting of the WG in Kampala, Uganda, test results from 15 countries (Argentina, Brazil, Congo, Egypt, Gambia, India, Kenya, Lesotho, Mauritius, Mexico, Paraguay, Philippines, Tanzania, Uganda and Vietnam) were reported and the short set of questions on disability was endorsed by the 23 countries and 5 international agencies in attendance. A very important outcome of the testing that had been done prior to the meeting was the development of a testing procedure designed for the evaluation of internationally comparable question sets. The testing procedures included both qualitative (cognitive testing) and quantitative methodologies. Training and other technical assistance were provided to countries conducting the WG tests and, more generally, on disability data collection methods. The question set included questions on six core functional domains: seeing, hearing, walking, cognition, self-care, and communication (see Appendix I). The WHO's International Classification of Functioning, Disability and Health, known more commonly as ICF, was used for guidance in developing the questions with a particular emphasis on international comparability.

The short question set is accompanied by a description of its technical properties, and methodological guidance is given on implementation and applicability to all population subgroups. To date, five documents have been written by members of the WG Secretariat and Steering Committee dealing with the use of the WG Short Set. The first two documents were developed to introduce the WG to Disabled Peoples'

Organizations and National Statistics Offices. A separate paper was written for each audience. The third document concerns the applicability of the WG questions in monitoring the U.N. Convention on the Rights of Persons with Disability. The fourth document is a paper on understanding and interpreting disability as measured using the WG Short Set of Questions. The fifth document provides recommendations for countries using the WG Short Set of Questions in their national Census. Copies of each of the documents can be found on the WG website: http://www.cdc.gov/nchs/washington_group/wg_documents.htm

- WG Report to Disabled People's Organizations http://www.cdc.gov/nchs/data/washington_group/meeting8/DPO_report.pdf
- WG Report to National Statistics Offices http://www.cdc.gov/nchs/data/washington_group/meeting8/NSO_report.pdf
- Monitoring the U.N. Convention on the Rights of Persons with Disability http://www.cdc.gov/nchs/data/washington_group/meeting8/UN_convention.pdf
- Understanding and Interpreting Disability as Measured using the WG Short Set of Questions http://www.cdc.gov/nchs/data/washington_group/meeting8/interpreting_disability.pdf
- Recommendations for the 2010 Round of Census http://www.cdc.gov/nchs/data/washington_group/recommendations_for_disability_measurement.pdf

There have also been several journal articles published based on the work of WG or using the WG Short Set questions. The list of known articles to date is provided in Appendix II.

Monitoring the Use of the WG Short Set

Based on information obtained from the country reports submitted by the primary country representatives between 2009 and 2014, 38 countries indicated that the short set of questions, or some variant, were included in the recent 2010 census round. The questions have been pre-tested or added to another survey in more than 50 countries. Table 3.3 identifies the different users of the WG Short Set.

Through the country reports submitted by the primary country representatives from National Statistical Offices, the WG has been monitoring the use the WG Short Set in national data collections (censuses and surveys). The information provided by the representatives include survey periodicity, sample size and frame, mode of data collection, language(s) used, exact question wording along with response options and finally prevalence estimates. Preliminary analyses of data provided by countries using the WG Short Set were initially presented at the eleventh meeting (2011). Of particular interest was the impact of modifications that had been made by certain countries to the question set. It was agreed to continue analyses of the data provided and to prepare reports for publication on the use of the WG Short Set (and other measures of disability) and the impact of wording changes to the standard set. Updates and results from further analysis of data have been provided

Table 3.3 List of countries using the WG Short Set Questions in Censuses, national surveys, disability modules and pre-tests

Countries using short set in 2010 census	Countries using short set on national surveys, disability modules or pre-tests
38	**50**
Argentina	Afghanistan
Aruba	Argentina
Bangladesh	Armenia
Brazil	Aruba
Cambodia	Bangladesh
Chad	Bermuda
Costa Rica	Brazil
Croatia	Burundi
Dominican Republic	Cambodia
Fiji	Canada
Israel	Chad
Italy	Croatia
Ivory Coast	China
Kazakhstan	Hong Kong, SAR
Kenya	Dominican Republic
Malawi	Egypt
Mexico	Estonia
Mongolia	Fiji
Mozambique	France
Netherlands Antilles	Iran
Oman	Israel
Palestine	Ivory Coast
Paraguay	Japan
Peru	Jordan
Philippines	Kazakhstan
Poland	Kenya
Qatar	Latvia
Rwanda	Malta
Samoa	Mexico
St. Maarten	Mongolia
South Africa	Mozambique
Sri Lanka	Oman
Tanzania	Palestine
Tunisia	Panama
Turkey	Paraguay
Uganda	Peru
Vietnam	Philippines
Zimbabwe	Poland
	Qatar

(continued)

Table 3.3 (continued)

Countries using short set in 2010 census	Countries using short set on national surveys, disability modules or pre-tests
38	**50**
	Rwanda
	St. Maarten
	South Africa
	Sri Lanka
	Thailand
	Turkey
	Uganda
	United Arab Emirates
	United States
	Yemen
	Zambia

at subsequent meetings. The final results and conclusions made from the analysis can be found in Chap. 16.

The WG Extended Sets of Measures on Disability

As the development of the short set was progressing, work on the extended set was begun. As early as the second meeting in 2004 the workgroup on extended measures was charged with the development of a plan (blueprint) for extended sets that would address the purpose, rationale, and justification for the set along with issues of international comparability.

The extended sets are intended as modules that will go into existing national surveys or can form the basis for a disability survey. The first extended set of questions would expand on the short general measure (more detail) by adding new domains and obtaining more information on each domain. Other extended sets would be developed encompassing (1) more complex activities/limitations, (2) participation/restrictions and (3) environmental factors.

A large part of the seventh meeting in Dublin (2007) was dedicated to a discussion of work being done on the extended set of disability questions for surveys and survey modules. It was agreed that the workgroup on extended measures would revisit the single short set questions and add multiple questions to certain domains that examine the use of assistive technology and functioning with and without assistance. Also, questions would be added on new domains including upper body functioning, learning, affect, pain and fatigue. The workgroup was also asked to consider the inclusion of supplementary questions within domains (cause, onset, and duration); how best to capture environmental factors (micro, meso, and macro levels); and to explore different ways to measure participation. It was suggested that the workgroup could coordinate its work with the work of the Budapest Initiative Task Force on Measuring Health Status (BI),[2] Eurostat, and the U.N. Economic and Social Commission for Asia and the Pacific (ESCAP); and compile lists of questions being used in other groups and by countries internationally.

Partnership with the U.N. Economic and Social Commission for Asia and the Pacific

The U.N. Economic and Social Commission for Asia and the Pacific (UNESCAP) has partnered with the WG on two projects aimed to improve disability statistics in the Asia and Pacific region. The first project supported by UNESCAP focused on the development and testing of disability questions designed for censuses. This work contributed to the development of the WG Short Set questions. This was followed by a second, UN Development Account, project entitled 'Improvement of Disability Measurement and Statistics in Support of Biwako Millennium Framework and Regional Census Programme'. This project focused on standardized methods for cognitive and field testing of an extended set of disability questions for surveys. The aim was to further promote better disability data collection by developing standard measurement tools, assessing and ensuring cross-national comparability, and improving national technical capacity. Much of the training and testing conducted to support the development of the WG Extended Set of Measures on Disability described in the chapter was funded by UNESCAP as part of this project.

Workplan for the Development of Extended Measures

In July 2008, a small working group consisting of members from the WG and BI met for 3 days at NCHS in Hyattsville, MD (USA). The goal of this meeting was to draft a proposed set of extended questions to be presented at the eighth WG meeting in Manila. The initial approach taken by the workgroup was to expand on the 6 domains (Vision, Hearing, Cognition, Mobility, Self-Care, and Communication) addressed in the WG Short Set. The focus was to look at questions that already existed and determine how the WG work was related to the work of other groups: BI, Eurostat, and UNESCAP. At this meeting, another "Matrix", designed as a

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[2] The Budapest Initiative Task Force on Measuring Health Status (BI), established 2005, is a collaboration of, among others, the World Health Organization (WHO), United Nations Economic Commission for Europe (UNECE), and Eurostat. This consortium was charged with the task of developing a short form questionnaire intended to provide the basis for the collection of comparable standardized information on population health focusing on *health state*. The BI defines health state in terms of functioning in a core set of health domains; and, like the WG, the BI has based the development of its questionnaire on a conceptual framework: the ICF.

framework for the development of the extended questions, was presented. The columns of the matrix include a full range of functional domains (the core set of six domains covered by the short set of questions plus additional domains) and the rows describe the type of information obtained for each domain, including the use of assistive devices/aids, functioning with and without the use of devices/aids where applicable, age at onset of functional difficulty and the impact of the difficulty on certain life activities. Additional rows address the impact of various aspects of the environment that may influence functioning and/or participation.

At the meeting in Manila, representatives from the workgroup provided the outcomes from the July meeting including an overview of the Matrix and the proposed set of extended questions. The presentation included outlining the rationale and framework used to develop the extended question sets. Discussions at the eighth meeting provided feedback on the issues/problems with each extended set question and/or answer categories that were identified. As part of the presentation and discussion each of the proposed questions was reviewed in detail. The strengths and limitations of asking each question and corresponding answer categories as proposed were debated. In many cases, the conclusion was that multiple versions of the questions should undergo cognitive and field testing. It was agreed that the WG would continue to collaborate with the BI, Eurostat and UNESCAP on the development of the extended sets.

Following the meeting in Manila, both the Matrix that guided the development of Extended set questions and the draft of the extended set questions were revised and edited. The updated Matrix was re-introduced at the ninth meeting in Dar es Salaam, Tanzania (2009). The primarily focus of the meeting was the presentation and discussion of results from the cognitive test and preliminary field tests on the extended question set.

Training for the cognitive and field testing of the proposed extended sets had taken place February 16–20, 2009 in Bangkok, Thailand. The combined testing exercises were carried out in collaboration with UNESCAP. Six UNESCAP countries participated in the cognitive/field testing workshop: Cambodia, Kazakhstan, Maldives, Mongolia, Sri Lanka and Philippines. Subsequent cognitive testing took place in these countries as well as Canada, the United States, and South Africa. A discussion of the cognitive and field testing conducted through UNESCAP can be found in Chap. 9. The goals of the cognitive test included determining:

- How do the respondents understand the survey question?
- Do respondents in different countries understand the survey question differently?
- Does the question mean the same in all the languages that it is asked?
- Does the question mean the same in all of the cultures that it is asked?
- In processing a question, do all respondents recall information and form an answer the same way?
- What groups should be considered for comparability?

Following the completion of the cognitive testing, a small group met at NCHS in Hyattsville, MD (USA) in May 2009 to discuss the preliminary analysis of the cognitive testing results. The group identified the ways in which each question performed among different respondents. The results from the cognitive test results were used to inform the field tests.

The results of this testing process were presented and discussed at the ninth meeting. A representative from each of the six UNESCAP countries provided their experiences with either the cognitive or the field test. The overall conclusion was that further analysis of the field test data was required before a final decision could be made regarding the extended set of questions.

During February-April 2010, cognitive testing of the extended set of question also took place in the United States and six European countries making up the Granada Group (France, Germany, Italy, Portugal, Spain, and Switzerland). The Granada Group (named after the location of the meeting) focused on seven domains from the WG extended set of questions: affect (anxiety and depression), pain, fatigue, cognition, communication, upper body, and learning. A total of 100 cognitive interviews were collected by the Granada Group. In April 2010, an analysis meeting was held in Rome. During the analysis meeting preliminary findings for each domain were presented and discussed. Through their discussions the group established an analytic direction for each domain.

The primary focus of the tenth meeting in Luxembourg (2010) was to review results obtained from the 2010 round of cognitive and field testing of the extended set of disability questions that took place in Europe and the United States (Granada Group) and South-East Asia (UNESCAP). Following the meeting in Luxembourg, the extended set of questions on functioning (ES-F) was adopted by the WG. In collaboration with the BI, a final version of a question set on health state (a subset of the extended set on functioning) was submitted to Eurostat for inclusion on the European Health Interview Survey (EHIS). The final version of the extended set on functioning and a document describing its development can be found on the WG website:

- Development of Disability Measures for Surveys: The Extended Set on Functioning (ES-F): http://www.cdc.gov/nchs/data/washington_group/Development_of_Disability_Measures_for_Surveys_The_Extended_Set_on_Functioning.pdf
- WG Extended Question Set on Functioning: http://www.cdc.gov/nchs/data/washington_group/WG_Extended_Question_Set_on_Functioning.pdf

Further Examination of the WG Extended Set on Functioning (ES-F)

The ES-F was added to the US National Health Interview Survey (NHIS) beginning in 2010. Preliminary findings from additional analyses of the WG extended set of disability questions using data obtained from the NHIS were initially presented at the eleventh meeting in Bermuda in 2011. The discussion focused on how the data could be used to better understand the question set and to provide analytic guidance. Individual domain analyses were conducted using 2010 and 2011 NHIS data and presented at the twelfth (Bangkok) and thirteenth (Amman) meetings. Final results were presented at the fourteenth meeting in Buenos Aires. Algorithms for combining multiple domain questions into single domain indicators of disability and developing standards for determination of cut-points were presented. Results for several of the domains are provided in Chapter 8. All analyses will be compiled and presented in a document describing the properties of individual domains of functioning and posted on the WG website.

Other Extended Sets

A workgroup on the development of environment questions had started its work at the tenth meeting in Luxembourg and subsequently presented its first evaluation of the available approaches and questions at the eleventh meeting in Bermuda. The discussion at that meeting reflected how much more complicated it is to address environmental aspects cross-culturally and identified the close relationship between environment and participation, particularly within the context of equalization of opportunity that had been adopted as the primary focus of measurement for the WG. While the membership was uncertain whether environmental aspects could be collected adequately cross-nationally, the WG agreed that the workgroup should continue their work to try to address this important aspect associated with participation. At the twelfth meeting (2012), it was agreed that the workgroup should continue to move forward with the development of a question set, reducing the scope to focus on one service area or basic area of activity. The workgroup continues work on the development of a draft module.

UNICEF/WG Module on Child Functioning and Disability

In 2009, the WG began work on the development of a set of questions on child disability for use in surveys. This coincided with the plans of UNICEF to revise the existing data collection module used in the Multiple Indicator Cluster Survey (MICS) programme (www.childinfo.org/mics). Following the eleventh meeting in Bermuda, a formal collaboration was arranged between the WG and UNICEF to work on the development of the extended set of questions on child functioning and disability. The questionnaire is designed to reflect the current thinking around child disability and produce internationally comparable data. The questionnaire focuses on children between 2 and 17 years of age, and assesses speech and language, hearing, vision, learning (cognition and intellectual development), mobility and motor skills, emotions and behaviors. A draft of the proposed UNICEF/WG module was discussed and revised during a three-day expert consultation at UNICEF in June

2012. The consultation meeting brought together 35 experts from around the world on a variety of topics ranging from pediatric development to survey design. Since then, the questionnaire has undergone cognitive testing in Oman, Belize, India, Montenegro and the USA. Results from the cognitive tests and a revised version of the module based on the cognitive testing results were presented at the WG meeting in Buenos Aires (2014).

Field testing has also taken place using preliminary versions of the module in Cameroon, Italy, and Haiti. Additional field testing using the revised version of the module is planned for 2015. UNICEF and the WG are also working on the development of a manual to support the implementation of the module. The manual will include all the necessary background documentation that will accompany the module, including tabulation plans, templates for reporting, instructions for interviewers and training material. The new module and the manual for its implementation are expected to be ready for actual data collection and use by countries in 2015.

The WG and UNICEF have also begun working on the development of a survey module on child environment and school participation. The aim is to measure the barriers/facilitators to education by children with/without disabilities. This module will complement the module on child functioning and disability. Together, they will provide a comprehensive measurement of disability assessing functional limitations as well as their interaction with the environment. The module will cover four areas: attitudes, accessibility, getting to school and affordability. A draft of the module is expected to be finalized for cognitive and field testing in 2015. Results are anticipated for the fifteenth WG meeting in Copenhagen, Denmark (October 2015).

Regional Workshops and Technical Assistance

An ongoing activity of the WG that was not anticipated at its formation has been supporting technical assistance workshops in countries around the world. Initially, the WG organized and held two regional workshops in 2005. One in Africa (Nairobi, Kenya) and one in Latin America (Rio de Janeiro, Brazil) in order to provide technical assistance for the testing of the short set which was taking place at that time. These workshops were primarily directed toward countries in the region that were interested in including disability questions in their national censuses. The workshops allowed countries in the region to become familiar with the WG short set questions on disability, the accompanying rationale, and the procedures for testing the questions. These workshops helped to build capacity for data collection on disability in many developing countries in Africa and Latin America. In addition to receiving training for conducting the tests of the WG questions, the participating countries began to work internally to improve their overall approaches to data collection on disability.

Another similar workshop sponsored by UNECE was held in U.N. Special Programme for the Economies of Central Asia (SPECA) member countries – (Bishkek, Kyrgyz Republic, 13-15 December 2006). The aim of the Training

Workshop was to introduce participants to the best practices on Disability Statistics and to develop the know-how in methodologies of measurement of the health status of the population. It was organized for health statistics directors and staff engaged in the measurement of disabilities in the national statistical offices and ministries of health in Central Asia and Azerbaijan.

As preparations for the 2010 round of censuses began, the WG was called upon to participate in a number of regional workshops:

Joint UNECE-UNFPA Training Workshop on Census Management in South East Europe (Sarajevo, 18–22 February 2008).

Workshop on Strengthening Capacity for Disability Measurement across South Asia sponsored by the World Bank and a Regional Workshop on Promoting Disability Data Collection through the 2010 Population and Housing Censuses sponsored by the UN in Bangkok, Thailand (April, 2008).

Joint UNECE-UNFPA Regional Training Workshop on Population and Housing Censuses for South Eastern European countries held in Ohrid, the former Yugoslav Republic of Macedonia (November 2008). The workshop was organized for senior professionals/experts from the State Statistical Offices of Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Kosovo, the former Yugoslav Republic of Macedonia, Montenegro, Romania, and Serbia.

A training workshop in August/September 2009, at the request of the World Bank, to assist the Bangladesh Bureau of Statistics in the collection of disability and functioning data using the ICF-based WG approach, and implementation of the WG short set of questions in their national Household Income and Expenditure Survey and the 2010 census.

As the testing preparations were underway for the extended set of questions, another series of workshops provided technical assistance for national organizations to help with the testing process:

A regional workshop was held in collaboration with UNESCAP in December 2009 in Bangkok. The workshop aimed to increase participants' knowledge on the implementation of cognitive and pilot tests for questionnaire design, by disseminating the results of the cognitive and field tests of the WG/UNESCAP extended question set to measure disability through surveys and further advocate WHO's ICF-based approach for disability data collection through training on census and survey data collection.

In July 2010, the WG held a workshop in collaboration with UNESCAP focused on training country participants in cognitive survey methods and presenting the results from the disability study's pilot and cognitive tests. The workshop was attended by representatives from national statistical offices in Cambodia, Kazakhstan, Maldives, Mongolia, Philippines, and Sri Lanka.

A training workshop for question evaluation and cognitive interview methodologies was held in Muscat, Oman in October 2010. The objectives were to inform researchers of, and train them in, current cognitive interview methodology and question evaluation techniques with respect to the WG extended set of disability questions. The workshop was hosted by the Ministry of National Economy and was attended by representatives from national statistical offices in Syria, Jordan, Tunisia, Sudan, Oman, Palestine, Egypt, Yemen and Morocco.

A series of workshops have been scheduled to train and prepare countries for testing the children's questions developed in collaboration with UNICEF. Two of these workshops have already taken place and others are planned.

ADAPT (formerly The Spastics Society of India) sponsored a training workshop in Mumbai, India in September 2012. Workshop participants were presented a preliminary version of the WG/UNICEF module on child functioning and disability and trained in question design and cognitive interview methodology developed by the Question Design Research Laboratory (QDRL) at NCHS.

In 2013, the UNICEF regional offices in Belize, Oman, and Montenegro each sponsored a training workshop in their respective regions. The aim of the workshops was to present the WG/UNICEF module on child functioning and disability and train workshop participants in the QDRL question design and cognitive interview methodology.

Finally, the WG has participated in the following workshops aimed to help build capacity for data collection on disability:

In December 2010, the Arab Institute for Training and Research in Statistics (AITRS) sponsored a disability seminar in Damascus, Syria. The specific goals were to transfer knowledge with representatives from national statistical offices from Arab countries on disability definition and measurement. The seminar was attended by representatives from national statistical offices in Syria, Jordan, Bahrain, Tunisia, Sudan, Iraq, Oman, Palestine, Libya, Egypt, Morocco and Yemen.

In May 2011, AITRS sponsored a training workshop in Sharjah, United Arab Emirates (UAE). The aim was to train representatives from national statistical offices from Arab countries in understanding and operationalizing disability measures developed by the WG. The training workshop was attended by representatives from the U.N. Relief and Works Agency (UNRWA) and national statistical offices in Jordan, UAE, Bahrain, Tunisia, Djibouti, Saudi Arabia, Sudan, Syria, Somalia, Iraq, Oman, Kuwait, Lebanon, Egypt, and Morocco.

In July 2012, a training workshop sponsored by the United Nations Population Fund (UNFPA) and the National Administrative Department of Statistics (DANE) was held in Bogotá, Colombia. The goal was to inform participants about the WG short set of questions and provide training to workshop participants in question design and cognitive interview methodology developed by the QDRL at NCHS.

In May 2013, Higher Council for Affairs of Persons with Disabilities (HCD) and Jordan Department of Statistics sponsored a training workshop in Amman, Jordan. The goal was to inform workshop participants about the WG short set questions and provide training in the QDRL's question design and cognitive interview methodology.

In August 2013, UNFPA and DANE sponsored a second training workshop in Bogotá, Colombia. This was a follow-up to the workshop that took place in July 2012.

In June 2014, the WG facilitated a training workshop in Apia, Samoa sponsored by UNICEF. The goal was to assist the Samoa Bureau of Statistics in preparation for the upcoming Demographic Health Survey.

New Initiatives

The thirteenth WG meeting in Jordan had the largest attendance of any WG meeting to date. The meeting was attended by over 150 representatives from the disability community within the Middle East region. The development of measures specific to mental health and the use of data registers for the compilation of disability statistics were initially presented for discussion at this meeting. Proposals were made for the creation of workgroups to address these tasks. Since the thirteenth meeting, two workgroups have been formed to determine the feasibility of addressing these tasks. The workgroups continue to pursue these initiatives and will provide updates on the status of their work at future WG meetings.

At the meeting in Buenos Aires, the chair of the WG steering committee led a discussion on developing strategies for analysis, implementation, and dissemination of data collected using the WG questions. It was agreed that providing countries with guidance on implementation of the WG questions and dissemination of the data collected should become areas of focus for the WG. As a result, a new workgroup was formed to address these tasks and report on any developments at the future WG meetings.

Appendices

Appendix I – The Washington Group Short Set of Questions on Disability

Introductory Phrase

The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

1. Do you have difficulty seeing, even if wearing glasses?
   (a) No – no difficulty
   (b) Yes – some difficulty
   (c) Yes – a lot of difficulty
   (d) Cannot do at all

2. Do you have difficulty hearing, even if using a hearing aid?
    (a) No – no difficulty
    (b) Yes – some difficulty
    (c) Yes – a lot of difficulty
    (d) Cannot do at all
3. Do you have difficulty walking or climbing steps?
    (a) No – no difficulty
    (b) Yes – some difficulty
    (c) Yes – a lot of difficulty
    (d) Cannot do at all
4. Do you have difficulty remembering or concentrating?
    (a) No – no difficulty
    (b) Yes – some difficulty
    (c) Yes – a lot of difficulty
    (d) Cannot do at all
5. Do you have difficulty (with self-care such as) washing all over or dressing?
    (a) No – no difficulty
    (b) Yes – some difficulty
    (c) Yes – a lot of difficulty
    (d) Cannot do at all
6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?
    (a) No – no difficulty
    (b) Yes – some difficulty
    (c) Yes – a lot of difficulty
    (d) Cannot do at all

Appendix II – List of Articles and Books Based on WG Activities or Utilizing the WG Short Set Questions

Articles based on WG activities:

1. Maitland A, K. Miller, M. Loeb, and J. Madans. The Development and Evaluation of Disability Measures Using a Mixed-Method Approach; Proceedings of the 10th Conference on Health Survey Research Methods; Survey Research Laboratory, University of Illinois, Chicago, April 8–11, 2011. Available online at: http://www.srl.uic.edu/hsrm/HSRM10_intro&session1.pdf

2. Miller K., D. Mont, A. Maitland, B. Altman, and J. Madans. Results of a cross-national structured cognitive interviewing protocol to test measures of disability. *Quality & Quantity*, 2011; 45(4): 801–815.
3. Loeb M. Disability Statistics: and integral but missing (and misunderstood) component of development work. *NJHR*, 2013; 31(3):306–24.
4. Madans J.H. and M.E. Loeb. Methods to Improve International Comparability of Census and Survey Measures of Disability. *Disability & Rehabilitation*, 2013; 35(13):1070–3.
5. Loeb M. A White Paper on Disability Measurement. *Journal for Disability and International Development*, 2012; 1:4-11. Available online at: http://www.zbdw.de/projekt01/media/pdf/2012_1_BiE.pdf
6. Madans J.H., M.E. Loeb, and B.M. Altman. Measuring Disability and Monitoring the UN Convention on the Rights of Persons with Disabilities: the work of the Washington Group on Disability Statistics. *BMC Public Health*, 2011; 11(Suppl 4):S4

Articles that operationalize the WG Short Set in research:

1. Trani J-F and M. Loeb. Poverty and disability: A vicious circle? Evidence from Afghanistan and Zambia. *Journal of International Development*, January 2012; 24(Suppl S1):S19-S52.
2. Loeb M.E., A.H. Eide, and D. Mont. Approaching the measurement of disability prevalence: the case of Zambia. *ALTER: European Journal of Disability Research*, 2008; 2(1):32-43.

Book based on early work of Washington Group:

1. Altman, B.M. and Barnartt, S. (co-editors) International Views on Disability Measures: Moving Toward Comparative Measurement, Research in Social Science and Disability Series, Vol. 4, London, England: Elsevier Publishers, January 2006.

Reference

Altman, B. M., & Barnartt, S. (Eds.). (2006) *International views on disability measures: moving toward comparative measurement*. Research in social science and disability series (Vol. 4). London: Elsevier.

Part II
Census/Survey Questions: Purpose, Process and Testing

Chapter 4
Purpose of an International Comparable Census Disability Measure

Barbara M. Altman and Elizabeth K. Rasch

Introduction

In February of 2004 the original version of this paper was presented in conjunction with the 3rd Annual Meeting of the Washington Group (WG) which took place in Brussels, Belgium (Madans et al. 2004). The major topic for the meeting was the initiation of development of a short set of questions to be used in national censuses. Establishing a set of questions for national censuses is the most general and broad based use of disability measurement and necessitates serious consideration of objectives. The disability matrix, which was developed for an earlier meeting to delineate the association between measurement purposes, measurement concepts and characteristics of questions, was used to organize the process to systematically represent conceptual components of disability (Altman et al. 2006). Much has changed from the original period during which the organizing purpose for census questions was initiated, so it is useful to revisit the formative purpose and to examine its relevance today, especially with the introduction of new international policy (U.N. Convention on Rights of Persons with Disability) and the ongoing products of the Washington Group (first extended question set, child disability question set and investigation of environmental components).

The discussions at the first WG meeting identified the International Classification of Functioning, Disability and Health (ICF) as a framework for measurement development (WHO 2001). The ICF belongs to a family of international classifications developed by the World Health Organization (WHO). The ICF was seen by the WG participants as a more detailed classification of the conceptual elements of disability

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than those developed by the Nagi or IOM models although in general elements overlap substantially (Nagi 1965; Brandt and Pope 1997). While the ICF model ***does not*** provide specific operationalization of the more general concepts associated with disability for developing questions, it does provide standardized language with which to frame disability. It also provides a comprehensive conceptual description of health related states, the environmental context for those health states along with a detailed classification of the elements of various conceptual components associated with disability.

The conceptual elements contained in the ICF describe body functions and their associated physical structural elements; action or task activities and a variety of areas of participation systematically grouped into different domains. The resulting classification scheme uses generic qualifiers to allow the identification of the extent or magnitude of impairment or limitation demonstrated in the various components of function, structure, activity or participation. The model also includes a classification of environmental contexts within which the person functions and notes the relevance of personal factors, although that element of the model is not classified. In addition to working with a systematic model of the disability process, the Washington Group had to consider how measurement of disability would be used within various nations and also cross-nationally.

At that point in time the World Programme of Action Concerning Disabled Persons adopted by the UN in 1982 was the global strategy for disability prevention, rehabilitation and equalization of opportunities. It served as the basis for understanding programmatic and policy issues for which disability measurement could possibly be used.

As stated in the objectives. "The purpose of the World Programme of Action concerning Disabled Persons is to promote effective measures for prevention of disability, rehabilitation and the realization of the goals of 'full participation' of disabled persons in social life and development, and of 'equality'. This means opportunities equal to those of the whole population and an equal share in the improvement in living conditions resulting from social and economic development"(Preamble, World Programme of Action concerning Disabled Persons, United Nations, New York, 1983).

The purpose of the U.N. Convention on the Rights of Persons with Disabilities, which was enacted after the Washington Group had started its work, was even more direct in indicating that the Convention "is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (CRPD 2006, p. 3). Of particular importance with CRPD was the recognition that the right to reasonable accommodation as a separate and enforceable human right identified in several articles. Article 5, for example, recognizes that: "in order to promote equality and eliminate discrimination, State Parties shall take all appropriate steps to ensure that reasonable accommodation is provided." (Kanter 2015)

While the prevention component of the World Programme did not provide guidance for the measurement development process, the emphasis on rehabilitation and equalization of opportunity provided a wide range of possible purposes for the measures the WG would be developing (World Programme, http://www.un.org/disabilities/default.asp?id=23). The definitions of impairment, disability and handicap (terminology in use at that time) separated some of the conceptual components of the disabling process which could be represented by the body/structure, activity and participation/environment aspects of the ICF. In addition, the definitions of rehabilitation and equalization of opportunities helped outline the general areas where measurement would be useful. Rehabilitation, which is intended to facilitate social adjustment or readjustment through a wide range of programmatic activities from benefit programs to programs providing physical or mental health therapies, was one possible use of the data provided by a measure.

The equalization of opportunity process addressed an even broader range of areas through which society may process data about disability. Housing and transportation, health services, education and work, cultural and social life including religious, sports and recreational facilities were all expected to be accessible. This meant that both the physical and social environments also needed to be examined and if possible data provided.

Developing a Process to Establish the Purpose of a Census Measure

In order to facilitate the WG use of the ICF and the World Programme of Action, two separate tools were developed prior to the meeting. First, in order to improve cross-national understanding of the ICF terminology and to avoid confusion a few more detailed terms were added to the general ICF terms in order to facilitate discussions relative to developing both measurement purposes and actual measures. In some instances the ICF terminology is very general, so it was necessary to narrow the meaning of the terminology in order to be more specific in discussions. We have provided a glossary of additional terminology used in the Washington Group meeting discussions in the Appendix. The Glossary indicates the terms added to help with details in discussions about the undifferentiated Activity/Participation section of the ICF. The glossary was not developed as a stand alone construct. It was intended to be a tool to simplify discussion and interpretation of the multiple purposes for measurement that are presented here and were discussed in 2004 at the Washington Group meeting. However, the application of the terminology adjustments and additions has extended over the continuing work of the Washington Group and may be useful for other purposes. ICF standardized concepts and terminology are used, to the extent possible, to contribute to greater international comparability of measurement methods and outcomes.

As the WG moved forward with its first objective, the development of an internationally comparable short question set to use primarily for censuses, it was necessary to develop one or two principle purposes for the data collection rather than to address every need. The general disability measure developed to accomplish the initial purpose will not necessarily satisfy other more specific purposes and will not provide a comprehensive assessment of disability or identify the "true" disabled population, if in fact such a subpopulation exists. Disability measurement attempts to dichotomize a continuum, and that problem in itself limits the capacity or interpretation of the measures (Zola 1993). In some instances limitations in current data collection processes will also affect our ability to capture some persons with characteristics of relevance.

Disability Measurement Matrix

Using the ICF model which describes the conceptual domains of disability along with the programmatic and policy areas of concern described by the World Programme of Action the WG developed a matrix to use as a tool to examine the relationships between the many possible areas of the disability process and the purposes of measurement that had been defined. The ICF conceptual framework describing the disability process encompasses multiple domains (classes) resulting in a variety of different ways of identifying disability. The purposes of data collection, identified for the meeting discussion included service provision, monitoring trends and equalization of opportunity which require indicators of a variety of different domains associated with the disability process in order to meet the various data needs and uses. Alternatively, different domains of the disability process can address different aspects of the purpose of data collection.

The development of a variety of theoretical models of disability (Nagi 1965; Brandt and Pope 1997; WHO 2001) has created an increasingly complex set of concepts and relationships that interact in the disabling process. While disability can appear to be a relatively simple concept related to health problems, in reality disability reflects a combination of circumstances that are influenced not only by the immediate disease/trauma, but the availability of medical care, the characteristics of the person who experiences the disease/trauma (age, gender, race, nationality, income, etc), the social and structural context in which the event takes place, the cultural norms or mores of the community where the event takes place, and the national or local policies of the governing bodies within the geographic location of the person.

Recognizing the interrelatedness of the factors inherent in the disability construct, Altman, Rasch and Madans created a matrix to help identify the individual components that contribute to the measurement of this process and to give some insight into the complications associated with measurement (Altman et al. 2006). The matrix was an attempt to examine the multiple physical and social settings within the various conceptual domains which could provide measurement points. For example in the medical evaluation of the disease/trauma, the wound may be identified by medical personnel in terms of the body structure as a crush injury requiring surgical amputation of the leg either above or below the knee. From the individual's perspective the leg wound can be identified in numerous ways associated either with functioning associated with the pain of the wound, the loss of mobility that will be associated with the amputation or from the psychological impact of the loss of wholeness of the person. Introducing contextual factors, both physical and social, (those created by the culture, social institutions, physical environment and attitudes of significant others) give rise to additional ways to define the situation and all these aspects contribute to a variety of ways to measure the outcome, defined in general as a “disability”. The matrix, which results from a combination of the various purposes of data collection and the variety of conceptual domains associated with disability creates a map to guide the selection of types of measures that are relevant to the data collection purpose. The combinations of purpose and conceptual domain within each cell of the matrix provides the possible characteristics of the questions (and answers) that will tap into the representations of disability that are necessary to fulfill the purpose within each specific domain.

The original measurement of disability, at least in censuses in the United States, originally counted persons with blindness or deafness, ostensibly to identify the need for services or assistance. So, one of the original purposes of data collection on disability was to identify information about persons with service needs. More recently the civil rights legislation as passed in the United States, the Americans with Disabilities Act (ADA), and legislation in other developed countries as well as the World Programme of Action and more recently the International Convention on the Rights of Persons with Disability has focused on another purpose for data collection, to examine equal access and participation for the population with disabilities. A third purpose of disability data collection focuses on population estimates and trends that also relate to policy development.

Decision Process for Identifying the Purpose of the WG Measures

It was proposed that the purpose/s selected should meet two criteria:

1. **Relevance:** Is the purpose of relatively equal importance across countries with respect to policy (i.e. a central theme)?
2. **Feasibility:** Is it possible to collect the proposed information using a comparable general disability measure that includes a small set of census-like questions?

Three major classes of purposes were articulated for identifying persons with disabilities: (1) to provide services to address needs, including the development of programs and policies for service provision and the evaluation of these programs and services, (2) to monitor the prevalence and trends of disability in the population, and (3) to assess equalization of participation and opportunities. The provision of services at the population level includes, but is not limited to, addressing needs for housing, transportation, assistive technology, vocational or educational rehabilitation and other health services, long-term care including personal services. Monitoring prevalence of disabilities includes estimating rates and analyzing trends of the various indicators of disability (from an epidemiological perspective this can relate to various types of impairments or from a social perspective it can relate to types of participation). The prevalence of disability in the population is considered a primary health and social indicator, which characterizes the health or vitality of a society. Finally the assessment of equalization of participation and opportunity involves monitoring and evaluating outcomes of anti-discrimination laws and policies, environmental management, and service and rehabilitation programs designed to improve all aspects of basic functioning and thus through the combination of programs/policies equalize the inclusion of persons with impairments in all aspects of life. The intent of these three purposes for measurement is consistent with that of the World Programme of Action concerning Disabled Persons and the UN Convention on the Rights of Persons with Disability (CRPD), which both outline major goals for policy formulation and program planning internationally. The common goal of both documents is to promote the inclusion of persons with disabilities in all aspects of life by preventing the onset and consequences of impairments, promoting optimal levels of functioning, providing physical and social access and equalizing opportunities for participation.

In this paper, each of the three major purposes for measurement at the population level is evaluated for international relevance and feasibility of implementation. The purpose selected must also be one that facilitates valid cross-national comparisons. Using measures that are minimally influenced by culture and context optimizes international comparisons by capturing a comparable population across countries.

Evaluation of Purposes: Relevance and Feasibility

Provision of Services

The need to identify the population of persons who may require specialized services or assistance is clearly important at the international level, as expressed in the WPA as well as at the first meeting of the WG. Rehabilitation, which is one of the three basic components of the WPA, for example, addressed the need to provide persons with tools to improve functioning. Therefore it is important to collect data to identify the population which requires rehabilitation or other specialized medical and nonmedical services. However, this requires detailed information about the specific needs a person may have and requires detailed information about their financial situation, their environment as well as medical and rehabilitation needs. It is not always feasible to obtain the necessary level of personal detail and environmental context to address the purpose of service provision with a small set of questions as required in a census format. Because of the greater need for personal details, such as age, specific type of impairment, how long the impairment or condition has been active, ability to transport to a facility, financial situation etc., this purpose is better suited to a specific module or extended question set supplements in surveys that can capture more extensive information on individual and environmental characteristics. While such data for the general population would be most useful for policy purposes, it also can be addressed with surveys that specifically focus on the rehabilitation or specific service provision activity, although such surveys can lack representation of the total general population if done in small settings.

Level of service provision and types of services provided are also highly variant across cultures making development of a general representation of the rehabilitation process or other forms of special assistance very difficult and therefore unlikely to be comparable. Cultural expectations and attitudes toward providing services for younger people versus older people may vary considerably along with attitudes about the needs of women versus men to name just two culturally determined approaches. While the purpose of service provision meets the criteria for relevance, at this time it does not meet the criteria for feasibility of implementation using a small set of questions cross-nationally.

Monitoring the Prevalence of Disability in the Population

Monitoring the prevalence of disability in the population was acknowledged as an important purpose for disability measurement at the first WG meeting since it is used to track progress in the health care system and evaluate interventions at the population or aggregate level. Measures of disability in the community are often used as a general indicator of health in the population. Since disability in the ICF encompasses the conceptual domains of body functions and structures as well as activities and participation, it can be represented by numerous varieties of measures if all of the domains outlined in the ICF model are used.

Many general indicators of population disability target activities like bathing, dressing, eating, or participation in primary roles to summarize the consequences of limited functioning in other domains. Participation requires the most complex measurement strategies as it involves at least three elements of measurement: *willful actions*, *specific tasks and organized activities*, which are all influenced by the environmental context in which they take place (see Glossary in Appendix for definitions of these elements). The most basic level of measurement of functioning is associated with willful or purposeful bodily or sensory actions such as walking, bending, reading, or speaking. A more complex level of action relates to performing *specific tasks*, such as dressing, shopping, and doing laundry. More commonly, the level of participation within the social structure is targeted to the third most complex element, *organized activity*, including participation in roles such as employment. The level of participation in the community reflects the outcome of the combined effects of *willful actions* and *specific tasks* as they are combined to accomplish an *organized activity* within the environmental context and with the available accommodations (see Fig. 4.2 in the Appendix for a brief description about how each level of measurement is operationalized). Even if experiencing physical, mental or emotional functional limitations, persons who have adequate accommodations and favorable environments may have no participation limitations, similar to persons with minimal or no impairments. Therefore, it may also be useful to characterize environment as a mediator between limited basic actions and tasks, or activities. Monitoring the three aspects of actions, activity and participation as it is defined by the ICF is a very complicated process involving components of measurement that have not yet been fully developed.

An example of a contemporary participation measure currently used to monitor population role performance comes from the U.S. 2013 National Health Interview Survey. Information on participation in the work role is obtained from the following question: "*Are you limited in the kind or amount of work you can do because of a physical, mental, or emotional problem?*" An affirmative response to this question identifies persons with limitations in participation in the work role because of an un-accommodated health problem. Persons with physical, mental or emotional functioning limitations caused by impairments who have succeeded in adapting to their limitations may not experience work role participation limitations, and would not be identified as having a disability by this question. Therefore, they cannot be distinguished from other persons without any impairments. Since the goal of monitoring participation is to track the proportion of persons in the population who actually experience participation limitations, in this case employment, this approach is probably the most appropriate. If, however, we want to know about persons with functional limitations who successfully accommodate, this measure is inadequate. If we want to know about persons who may be at risk of limitations in participation if the physical or social environment changes, we would also come up short in our estimates.

Monitoring participation presents an additional problem of response comparability. Since the standard against which persons rate their activity and participation in a community is culturally as well as environmentally determined, attaining comparability in responses presents a problem, particularly at the international level. Disability models (such as the ICF or IOM models) represent disability as a multidimensional phenomenon that occurs along a continuum. For dimensions such as body functions and structures as well as the more basic actions or physical, mental or emotional functioning which is represented by measures of willful actions, the standard against which respondents rate themselves is more explicit and universal and therefore more comparable. For dimensions composed of more complicated activities, represented by measures such as performance of specific tasks and organized activities, also reflecting participation, the standard is less explicit and therefore leaves more room for respondent interpretation and cultural differences. Expectation can also effect the determination of whether participation limitations exist. Lowered expectations resulting from limited opportunities could result in reporting no limitation when from a policy perspective limitation is occurring.

Since respondents' subjective interpretations are, to some degree, socially determined, it is more difficult to achieve comparability between respondents in measures of complicated activity (such as organized activities or role participation) than in measures of certain impairments, such as blindness, deafness or loss of limbs or in basic physical functional limitations such as walking, bending, or lifting one's arms over their heads. This is particularly true at the international level where cultures, environments, and resources vary widely. Thus, the purpose of monitoring the level of physical, mental and emotional functioning in the population meets the criteria for relevance, but participation performance does not meet the criteria for feasibility of implementation primarily due to the problem of international comparability.

Assessing Equalization of Opportunity

Both the WG meeting discussions and the U.N. statements on disability (WPA and CRPD) are consistent in their emphasis on the importance of assessing equalization of opportunities. Equalization of opportunity may imply that measurement of activities and participation is required. If we assume this is the only approach to measurement of equalization of opportunity we can have methodological difficulties associated with the variety of cross-cultural differences involved in certain areas of participation. However, if we approach equalization of opportunity by focusing on the person in whatever context they experience we may reduce the cross-cultural complications.

In the equalization of opportunity approach the physical, mental or emotional functional limitation caused by the impairment are assessed separately from the organized activity that represent elements of participation. This allows the identification of all persons with disability rather than just those with participation restrictions or limitations. Disentangling the conceptual dimensions of functional limitation/impairment from task activities and participation provides the opportunity to determine the various intervening mechanisms that facilitate or interfere with performance of tasks and organized activity, such as the availability of assistive devices or assistance and the multiple environmental factors that can create barriers or provide facilitation. When assessing opportunity equalization, *the connection between the primary disability elements (the basic actions influenced by physical, mental or emotional limitations associated with the impairment) and the actual form of participation is made during analysis* (see Fig. 4.1). Whereas for the monitoring of participation limitation due to physical and mental and emotional functioning limitation *the connection is made in the question itself*. The measure of disability is thus being used as a demographic characteristic of the person like their age and gender. We can also control for factors associated with the environment to better understand how the environment and the functional limitation interact. However at this stage of measure development we are just beginning to develop environmental measures that are useable cross-culturally.

In order to address the equalization purpose, we need to start by identifying persons who are at greater risk than the general population of experiencing restrictions in performing specific tasks or participating in specific role activities due to health characteristics This group would include persons with functional limitations who also experience limitations in task activities and/or restrictions in participation

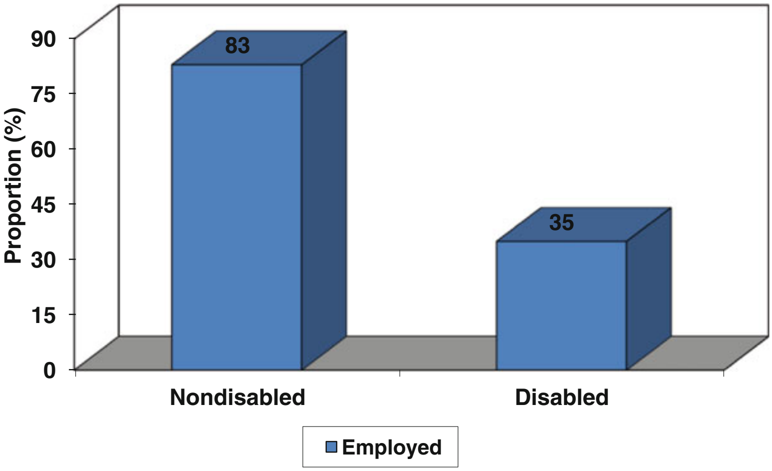

Fig. 4.1 Disability as a demographic-an analysis of employment

whether or not they use assistive devices, have a supportive environment or have plentiful resources. It would also include persons with functional limitations *who do not* experience limitations in the specific tasks or activities or participation because the necessary accommodations or adaptations have been made at the person or environmental levels. The latter group would still be considered to be at greater risk for restrictions in activities and/or participation than the general population because of the presence of impairments resulting in functional limitations and because the current level of accommodation might not always be available or might not continue to produce the same level of functioning.

Information about actual participation can be captured from other census or survey indicators, such as questions about employment, education, use of the transportation system, etc. For example, disability status, defined as the increased risk of experiencing restrictions in physical, mental or emotional function due to an impairment (the general measures being proposed), can be cross-classified with a measure of employment to identify the proportion of persons with and without disability who are employed. This is an assessment of the equality of employment opportunities (see Fig. 4.1). If policy interventions are initiated to enhance workplace accommodations, the effect on employment of persons with disability (i.e. equalization of opportunity) can be determined. In order to enhance the meaningfulness of the general disability measure that we are recommending, it will be important to collect data on a variety of forms of participation, such as education, employment, housing, transportation, social and health services, in addition to other aspects of cultural and social life in other sections of the survey or census. From a theoretical perspective, if opportunities have been optimized then participation should be equivalent between persons with and without functional limitations associated with impairments, and trend analysis should show improvements in participation among those with functional limitations/impairments over a period of time even if at the same time there is no change or even an increase in the population with the physical, mental or emotional limitations in functioning. Constraints in the number of participation questions or questions about accommodation in a census may limit the information on participation and restrict documentation of the types of adaptation or accommodation, but these are separate issues from the measurement of disability.

The purpose of assessing equalization of opportunities requires measurement of the presence of willful action limitations, measures with reasonable international comparability that are feasible to implement for the majority of the population via a small set of questions. Additional modules and extended survey sets could be used in conjunction with the general measure to further subdivide the population into groups of particular interest. Thus, the purpose of assessing equalization of opportunities meets the criteria for relevance **and** feasibility of implementation using a small set of questions that possess the most promise for internationally comparable results. As with the other purposes discussed above, there will be challenges in implementing this approach. What is sorely missing from this approach is information about the possible environmental mechanisms that facilitate or impede participation. Some elements of those mechanisms could be included in extended survey sets, such as use of assistive devices, access to personal assistance, and environmental facilitators. Other mechanisms that are related to the physical and social environment are still in conceptualization stages and are not ready for use, although conceptual models such as the ICF indicate their appropriateness. Some mechanisms, such as programs that provide financial benefits, may be culturally specific but could be built in where appropriate.

Summary

The assessment of equalization of opportunity was accepted as the purpose for the first general disability measure to be developed by the WG at the Brussels' meeting. This purpose meets the criteria of relevance and feasibility of implementation internationally. Benefits of choosing this purpose include identification of a broad subpopulation, which can be further described using detailed information obtained via extended survey sets. The extended survey sets can be administered as part of the same data collection activity or as part of a follow-up study. The minimal questions used in a census cannot identify all persons with disabilities, but can give the data collection a start in the right direction. As stated earlier, it is imperative to recognize that the general disability measure developed to suit our proposed purpose may not suit other purposes. Nor will it provide a comprehensive assessment of disability or identify the "true" disabled population. Methodological challenges will affect our ability to capture all persons with characteristics of relevance. Users must be aware of the limitations that accompany the proposed purpose and its operationalization in order for outcomes to be meaningful and comparable.

The U.N. Convention on the Rights of Persons with Disabilities takes the issues of full participation by disabled persons one step further recognizing "the importance of the principles and policy guidelines contained in the World Programme" and asserting that a comprehensive international convention to promote and protect the rights and dignity of persons with disabilities "will make a significant contributions to redressing the profound social disadvantage of persons with disabilities and promote their participation in the civil, political, economic, social and cultural spheres with equal opportunities in both developing and developed countries." (Preamble, UN, Convention on the rights of Persons with Disabilities, 2006)

Of particular importance in the CRPD is the discussion of statistics and data collection and international cooperation. Article 31 of CRPD directs State parties to undertake the task of collecting appropriate information to enable formulation and implementation of policies to give effect to the Convention. In addition to expectations that such data collection adhere to international norms to protect human rights and protect confidentiality, such data collected in accordance with this article should be used to assess implementation of obligations under the Convention and to address barriers faced by persons with disabilities in exercising their rights (Article 31, UN Convention, 2006). Article 32 of CRPD calls for the support of national efforts for the realization of the purpose of the Convention and toward that end calls for undertaking "appropriate and effective measures in this regard, between and among States and as appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities." (Article 32, UN Convention, 2006) Such international cooperation was already in place with the beginning of the Washington Group in 2001 and has benefited the development of statistical capacity, particularly of developing countries, in order to monitor the realization of the objectives of the Convention.

Appendix

Glossary Additions: For Washington Group Discussions

Functioning *In the ICF, functioning is an umbrella term encompassing all body functions and structures, activities and participation.* The term denotes positive aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors) (ICF p. 3, 212). Functioning in the ICF is associated with the person's ability to perform body functions, activity or participation. **Disability** *serves as the umbrella term for denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).*

While the WG uses the term 'functioning' as it is used in the ICF, their term is also used in the more usual sense to describe the level at which persons accomplish actions, tasks and activities in core domains. Functioning relates to a specific area / domain associated with basic actions or specific physical, mental and emotional functions of the whole person and can be measured both with and without accommodation.

Willful Action Based on either performance or capacity, action reflects the individual's will to carry out basic volitional bodily operations at the level of the organism (whole person). Examples include walking, climbing steps, seeing, reading, communicating, etc. It is distinct from body functions (ICF) which are "physiological functions of body systems" rather than intended functions of the whole person. When combined, multiple actions can result in performance of tasks (Nordenfelt 2003). In the ICF, basic actions are included in the domain of activity defined as "the execution of a task or action by an individual, representing the individual perspective of functioning" (ICF short version, p. 190). The ICF does not differentiate actions and tasks, the Washington Group did differentiate basic willful actions from tasks.

Specific Task The execution of a group of willful actions by an individual. It is an indicator of a series of related or more complicated actions necessary to accomplish an objective, which is a central component of role behavior. Examples include bathing, dressing, and feeding which are central elements of self-care, or reading a book or doing homework, which can be central elements of going to school. In the ICF, tasks are included in the domain of activity defined as "the execution of a task or action by an individual, representing the individual perspective of functioning" (ICF short version, p. 190). The ICF does not differentiate actions and tasks.

Organized Activity Represents the accomplishment of a variety of willful actions in order to accomplish more than one specific task in order to complete an activity that is socially recognized or defined in a culture. An example would be going out to dinner which entails making reservations, getting dressed appropriately, finding transportation, engaging with friends, reading a menu, ordering, paying the bill, leaving a tip and other details.

Figure 4.2 shows the variety of levels of measurement that are available to provide information about activities and participation. Unlike body structure and function categories which can be represented as present or not present and expanded by an indication of the level of severity when the problem is present, human activity is much more difficult to capture and exists at several levels of complexity as represented by the four levels noted here. The indication of the types of questions possible (A and B) demonstrate part of that complexity in terms of topic area. However greater complexity is also introduced by both the variety of actual question foci (i.e. capacity for various distances to be walked in a mobility question) or variety in answer categories (i.e. a yes/no answer alternative versus one with a range of answer possibilities).

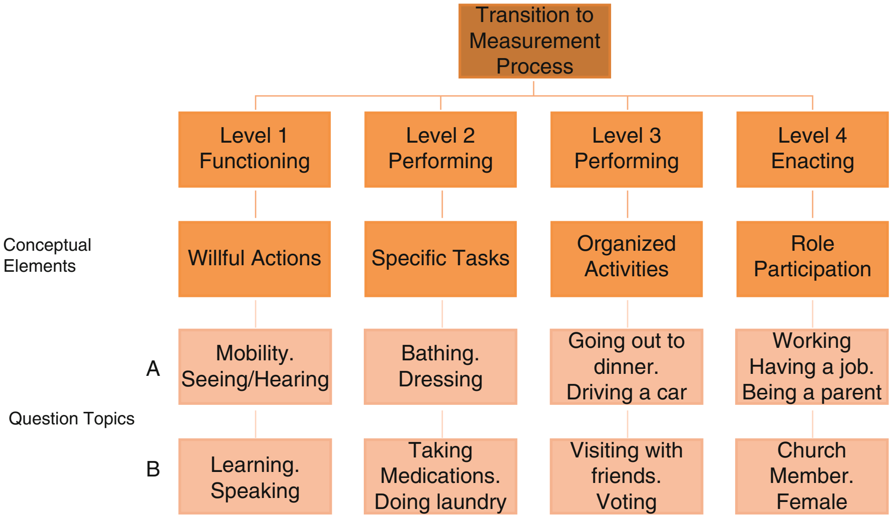

Fig. 4.2 Transition from conception to empirical measures using ICF model

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Chapter 5
Summary of Washington Group Question Evaluation Studies

Kristen Miller

Introduction

A primary effort of the Washington Group (WG) is to develop survey questions that would collect globally comparable disability statistics. While much effort has focused on the operationalization of disability and construct development, question evaluation also occupies a significant role, ensuring that questions indeed capture the intended conceptual constructs. The WG has conducted numerous evaluation studies, including individual country and collaborative multi-national cognitive interviewing studies as well as two large-scale multi-national field tests. The various evaluation studies were not always similar in design or scope, partly because of particular constraints and limitations but also because of methodological advancements. This chapter presents an overview of those studies, including the research goals, methodologies utilized, limitations and methodological advancements.

Question Evaluation Methodology

The underlying goal of a question evaluation project is to determine whether survey questions capture the pre-determined construct. Specifically, the intended phenomena must be similarly considered by all respondents in the formulation of their answer. Comparability is a necessary component of question evaluation studies so that resulting survey data are consistent across socio-cultural and lingual groups. While any survey involving a heterogeneous sample should be concerned with comparability, questionnaires intended for global use must be especially concerned

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about issues of comparability. Since the WG questions are intended to be used throughout the world, an important component of the question evaluation studies included an examination of question performance within differing national, socio-cultural, and lingual contexts. With construct comparability as the main focus for the evaluation studies, the primary method used by the WG was cognitive interviewing. Additionally, in the two large-scale multi-national, field tests were used in conjunction with cognitive interviewing methodology.

Cognitive Interviewing

Cognitive interviewing[1] is a qualitative method that examines the question response process, specifically the processes and considerations used by respondents as they form answers to survey questions. Traditionally the method has been used as a pretest method to identify question response problems prior to fielding the full survey. The method is practiced in various ways (Forsyth and Lessler 1991), but is commonly characterized by conducting in-depth interviews with a small, purposive sample of respondents to reveal their cognitive processes. The interview structure consists of respondents first answering a survey question and then providing narrative information which reveals how they went about answering the question. More specifically, cognitive interview respondents are asked to describe how and why they answered the question as they did. Through the interviewing process, various types of question-response difficulties, such as interpretive errors and recall accuracy, are identified. DeMaio and Rothgeb (1996) describe these types of problems as ‘silent misunderstandings’ because they are not normally identified in the highly structured survey interview. When respondents have difficulty interpreting the questions or forming an answer, the question is typically identified as ‘having problems’ and can be modified to address these difficulties.[2]

In addition to examining respondent difficulties, cognitive interviewing studies determine the ways in which respondents interpret questions and apply those questions to their own lives, experiences and perceptions. Since cognitive interviewing studies identify the content or experiences contained in respondents’ answers, the method examines construct validity. That is, the method identifies the phenomena or sets of phenomena that a variable would measure. By comparing how respondents across groups (e.g. lingual or socio-cultural groups) interpret and process questions, cognitive interviewing studies can also examine comparability. For example, if a particular cultural group interprets a question differently from the other groups, it is likely measuring different constructs. These differences could indicate that translations are not accurate or that there is lack of cultural equivalence (i.e., the concept in question may not exist or may differ in salience across the surveyed cultures)

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[1] See Miller et al. (2011) for a comprehensive discussion of cognitive interviewing methodology.

[2] See Miller and DeMaio (2006) as an example of a cognitive interviewing study to evaluate problems in disability questions.

(Fitzgerald et al. 2009; Willis and Miller 2011; Goerman and Caspar 2010). To this end, cognitive interviewing studies can encompass much more than identifying question problems. Cognitive interviewing studies can determine the way in which questions perform, specifically the concept captured and the phenomena represented in the resulting statistic across socio-cultural and lingual groups.

Evaluation of the Washington Group Short Set

Initial testing of the short set questions was conducted by staff at the Question Design Research Laboratory (QDRL) at the National Center for Health Statistics. For this study, 21 English-speaking and 20 Spanish-speaking respondents with a range of disabilities were interviewed. Interviews followed the traditional format of a cognitive interviewing study, and the study was conducted in an iterative fashion. That is, when problems were discovered in the interviews, questions were revised and then re-tested. The resulting battery of short set questions consisted of six questions that were ready to be tested in an international context.

Fifteen countries[3] participated in the international evaluation of the short set questions.[4] It was determined from the outset that cognitive interviewing would be an important component. However, certain limitations made it impossible to conduct a traditional cognitive interviewing study. Most countries had little or no experience conducting this type of evaluation and had no skilled or experienced cognitive interviewers to perform the work. Given the limited financial resources, it was not feasible for a single research team to oversee the work in the different countries. Additionally, the number of languages within and across the countries also made it impossible for such a team to analyze resulting qualitative data.

Given these circumstances, it was determined that, rather than a traditional cognitive testing protocol, the protocol for the WG short set study would consist of a structured cognitive interview. Specifically, the interview would consist primarily of close-ended questions and be administered more like a standard survey interview than a semi-structured, open-ended interview. This structured format would offset the need for skilled cognitive interviewers. Finally, the instrument would capture mostly quantitative data so that a combined data set with each participating country's data could be analyzed by a joint committee. Open-ended questions would be kept to a minimum, but would be incorporated so that qualitative data could verify hypotheses posed by the quantitative analysis.

The final protocol, though unconventional because it primarily collected quantitative data, was structured around the theoretical principles of traditional cognitive interviewing and designed to collect information regarding the question response

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[3] Countries include: Argentina, Brazil, Congo, Egypt, Gambia, India, Kenya, Lesotho, Mauritius, Mexico, Paraguay, Philippines, Tanzania, Uganda, Vietnam.

[4] For a more thorough presentation of the study, see Miller et al. (2010).

process, including patterns of interpretation, evaluation and decision-making patterns, as well as potential response error.

Study Protocol

The questionnaire consisted of the six core short set questions followed by probe questions designed to illustrate: (1) whether short set questions were administered with relative ease; (2) how the questions were interpreted by respondents; (3) the factors considered by respondents when forming answers to the questions; and (4) the degree of consistency between short set question responses and responses to a set of more detailed questions addressing respondent functioning in each of the domains covered by the six short set questions. To ensure that this testing instrument performed as intended, it also underwent cognitive testing in the United States (English), Mexico (Spanish), and Kenya (Swahili). In both Mexico and Kenya, interviewers were intensively trained by QDRL staff ensuring successful testing of the structured questionnaire.

The final questionnaire consisted of interviewer coded questions to determine whether a question had to be repeated, open-ended probe questions (*Why did you answer that way?*), and close-ended cognitive follow-up and functioning follow-up probe questions. The functioning probe-questions came from existing and previously fielded disability questions and were used to provide more specific assessments of respondents' basic functioning—information that would be used (in conjunction with data from the other questions) to assess the validity of the WG question. Demographic and general health questionnaire sections provided background information used to understand whether the proposed questions worked consistently across all respondents, or if nationality, education, gender or socioeconomic status impacted the ways in which respondents interpreted the question or other aspects of the question response process. A total of 1290 interviews were conducted. Table 5.1 presents the number of interviews conducted by each country.

Analysis and Findings

To perform the evaluation, the consistency between individual respondents' answers to the WG questions and their responses to the various functioning follow-up questions was examined. With the additional information provided by the cognitive follow-up variables and qualitative data, the end goal of the analysis was to explain discrepancies between the core question and the follow-up questions. A discrepancy could be the result of a problem with the WG question (e.g. a misunderstood word, cultural difference or a translation problem) or because of a similar type of problem with one of the follow-up questions. For example, if a respondent answered *no*

Table 5.1 Total number of interviews conducted by country

Country	Respondents
Argentina	102
Brazil	179
Congo	20
Egypt	70
Gambia	86
India	120
Kenya	54
Lesotho	25
Mauritius	24
Mexico	223
Paraguay	111
Philippines	32
Tanzania	25
Uganda	85
Vietnam	134
Total	1290

Table 5.2 Vision response patterns

Pattern	WG disability	Wears glasses	Follow-up disability
A	No	No	No
B	No	Yes	No (corrected)
C	Yes	No	Yes
D	Yes	Yes	Yes (not corrected)
E	Yes	Yes	No (corrected)
F	Yes	No	No
G	No	Yes	Yes (not corrected)
H	No	No	Yes

difficulty to the WG vision question, but answered *a lot of difficulty* to the far-sighted follow-up question and *no difficulty* to the near-sighted follow-up question, this was characterized as a discrepancy. For a particular reason (yet to be determined), the respondent had incorrectly answered either the WG question or the far-sighted functioning follow-up question. Another possible discrepancy is that the WG question may have captured more dimensions of the disability (such as night blindness) with its simple, yet broad design than would be captured in the far and near-sighted follow-up questions, and respondents would have answered positively to the WG question but negatively to the follow-up questions. If this were the case, this discrepancy would not be viewed as a problem with the WG question, but rather as an advantage.

To systematically examine inconsistencies, all cases were classified according to a series of response patterns relating to respondents' answers to the WG question and the functioning follow-up probes. This was done for each domain. Analysis of the vision domain provides a simple example; Table 5.2 displays the possible response patterns within the vision domain. Pattern A represents those respondents who reported having no difficulty seeing when asked the WG vision question. Consistently, they reported no difficulty to both the near-sighted and far-sighted questions. Pattern A respondents, additionally, reported that they do not wear glasses. These were respondents who clearly had no vision problems. Pattern B respondents, on the other hand, reported wearing glasses because of a near-sighted or far-sighted problem, but because their glasses corrected the problem, they reported no difficulty when asked the WG question and no difficulty to the follow-up questions. Pattern C respondents reported either a near-sighted or far-sighted problem in the follow-up questions, that they do not wear glasses and, consistently, reported a vision problem with the WG question. Finally, Pattern D respondents reported having glasses that do not resolve their vision problem, and therefore, reported vision difficulty when asked the WG question and at least one of the follow-up vision questions. Each of these response patterns (i.e. A through D) is consistent and understandable. It was, therefore, surmised that these respondents responded to the question as intended—the WG question as well as each of the functioning follow-up questions.

Patterns E through H, however, showed inconsistent responses, that is, respondents' answers to the various questions were contradictory, and the discrepancies for these cases would need to be more closely examined. For example, Pattern E respondents reported having glasses that corrected their vision problem on the follow-up questions, yet they still answered having a vision problem when asked the WG question. Pattern F respondents wore no glasses and reported no near or far-sighted difficulties in the follow-up questions, yet answered having a vision problem in the WG question. For the WG question, these two patterns (E and F), at face value, appeared to consist of respondents who made false positive reports. Conversely, Pattern G and H respondents appeared to be those cases of false negative reports. Pattern G respondents reported not having a vision problem, yet reported having glasses that do not correct either a far-sighted or near-sighted problem. And, Pattern H respondents reported no vision problem, yet reported either a near or far-sighted problem and had no glasses to correct the problem.

Pattern Analysis of the Vision Domain

Table 5.3 illustrates the number of cases that were found in each response pattern for the vision domain, and that the majority, 969 cases or 83.2 %, were not problematic (Patterns A through D). Of all of the cases, a total of 194 cases (16.6 %) fell into one of the problematic response patterns. A full 12.8 % fell into two of the potential false positive patterns, that is, patterns E and F, with a majority of those cases (10.2 %) in Pattern E.

To identify the cause of discrepancies in the vision domain's potential false positive reports, the cognitive follow-up variables were examined. These questions were

Table 5.3 Frequency distribution of vision response patterns

Pattern	N	Percent	Potential error
A	468	40.2	None
B	149	12.8	None
C	183	15.7	None
D	169	14.5	None
E	119	10.2	False positive
F	30	2.6	False positive
G	21	1.8	False negative
H	24	2.0	False negative
Total	1163	100	

asked of all respondents who reported any difficulty to the WG question. They include:

1. [With your glasses,] how much effort do you have to put into seeing?
2. [With your glasses,] how often do you have difficulty seeing well?

Interestingly, of the 149 cases of potential false positive reports, 53.7 % (80 cases) responded that they put forth no effort to seeing and never had difficulty seeing. Additionally, of these 80 responses, 71 (all but 9) fell into pattern E—those whose near or far-sighted problem is corrected with their eyeglasses. Similarly, 23 respondents reported no amount of effort needed to see or no frequency in vision difficulty, and all but one of those respondents were from Pattern E. With corroboration from the qualitative data, it was concluded that the glasses clause, *even when wearing glasses*, caused confusion for some respondents who used glasses. Furthermore, it was concluded that over two thirds of the 149 potential false positives (102 cases) were most likely to be truly false positive reports, and the response error was likely triggered by glasses clause.

In contrast, the potential false positive reports of Pattern F reflected an entirely different set of circumstances. These were respondents who wore no glasses and reported no near or far-sighted difficulty, yet still answered having a vision problem to the WG question. Compared to those in Pattern E, Pattern F respondents more often reported requiring effort to see and having frequent difficulty seeing. In fact, two-thirds (20 out of 30 cases) of Pattern F respondents answered positively to both the effort and frequency questions. Indeed, an examination of the available qualitative data confirmed that, for many of these cases, respondents experienced a vision problem that was unrelated to near or far-sightedness, such as night blindness or injury to one eye. Consequently, it was determined, while Pattern E reflected a false positive response with the WG question, the discrepancy within Pattern F reflected an advantage of the WG question.

Demographic Analysis of Error Patterns to Test for Comparability

Given that Pattern E consisted of isolated cases of error, specifically, false positive reports caused by misinterpretation of the glasses clause, it was possible to determine whether this misinterpretation was randomly distributed across respondents or if, in fact, the error was characteristic of particular type of respondent. To determine whether this question design feature might bias results, Pattern E was examined in relationship to age, gender, disability and nationality. Because Pattern E was specifically a problem identified as one for glasses-users, it was necessary to control for glasses. Table 5.4 reveals a clear correlation between gender and Pattern E, but that the same is not true for age or for the presence of disability in other domains. While there was no statistical difference between men's and women's rate of wearing glasses, men were significantly more likely to exhibit a misunderstanding of the glasses clause. While older respondents and those with difficulties in other domains were more likely to wear glasses, they were not more likely to have difficulty with the glasses clause.

By far the most important factor in determining whether a respondent fell into Pattern E was their nationality. Figure 5.1 displays the percentage of glasses wearers falling into Pattern E by country. That percentage ranges from zero in Mauritius to 40.5 % in Paraguay.

The most likely reason to account for these differences is translation. In most of these countries the questions were actually translated into more than one other language. Several country teams expressed difficulty when translating the "even if wearing glasses clause" in a simple and concise manner. Findings of this study highlight the importance of translation and the necessity of adequate country

Table 5.4 Glasses clause problems (Pattern E) among those wearing glasses by gender, age, and whether or not the respondent had a disability in at least one other Washington Group domain

	Female	Male		
Gender	Percent			Significance
Pattern E	21.4	29.6		p < .05
Other patterns	78.6	70.4		
	100 (n = 192)	100 (n = 264)		
Age	10–44	45–64	65+	
Pattern E	25.0	28.7	21.5	n.s.
Other patterns	75.0	71.3	78.5	
	100 (n = 172)	100 (n = 185)	100 (n = 93)	
Disability in other domains	Yes	No		
Pattern E	27.2	25.7		n.s.
Other patterns	72.8	74.3		
	100 (n = 114)	100 (n = 343)		

Note. Significance tests are based on Chi-Square statistics

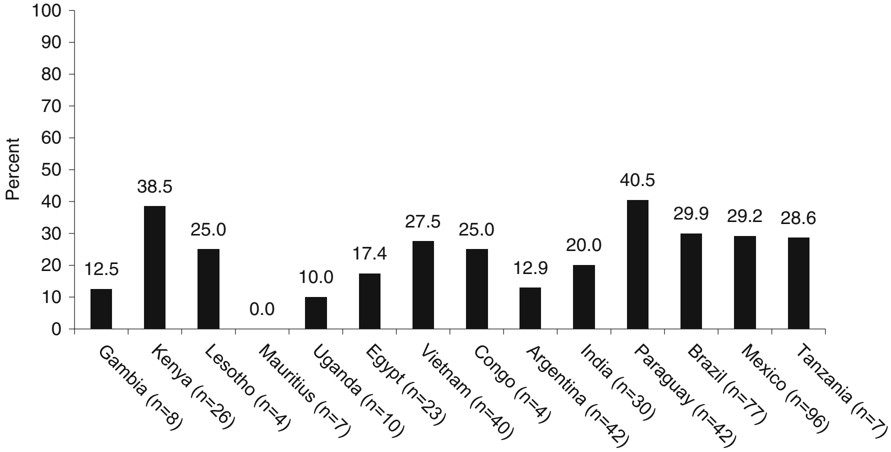

Fig. 5.1 Percentage of glass wearers with glasses clause problems by country

instruction. Translation protocols should focus not so much on literal translations but capturing the intended concept.

By integrating cognitive interview and quantitative approaches, this study design allowed for an examination of comparability across various groups of respondents. Given the limitations of the study, however, qualitative data and interpretive insight were limited. Consequently, the study was unable to determine how respondents fully interpreted the question and the experiences or perceptions that they considered when forming their answers. Future Washington Group question evaluation studies were able to overcome these limitations and more fully incorporated qualitative data.

Evaluation of the Budapest Initiative Questions to Measure Health States

The Budapest Initiative (BI) was a collaborative effort to develop internationally comparable measures of health states.[5] The BI Task Force included the WG, national statistical office, the WHO and the UNECE. By late 2006, the Task Force had developed a set of questions that were tested individually by four country statistical offices: The Australia Bureau of Statistics, Statistics Canada, The National Institute of Statistics (Italy), and The National Center for Health Statistics (United States). In total, 114 cognitive interviews were conducted.[6] In January 2007, each of the four

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[5] For more information see: http://www.unece.org/stats/health_stat.html.

[6] The Australia Bureau of Statistics conducted 25 interview, Statistics Canada conducted 24 interviews, The National Institute of Statistics conducted 25 interviews, and The National Center for Health Statistics conducted 40 interviews.

testing sites presented results of their studies. Not all findings, however, were consistent across the four studies. And, because the group was not able to analyze each other's interview data, it was not possible to explain the different findings. Differences could be due to problems with translations, regional or cultural differences, or lack of comparability across studies including disparate levels of cognitive interview data quality. Without such explanations it was difficult to assess question performance and to determine whether or not questions should be revised. In order to make these determinations, it would be necessary to coordinate across countries so that interviews and data quality were comparable and so that analysis could be conducted systematically across all interviews.

The Comparative Cognitive Testing Workgroup, a collaborative group representing the WG and the European Social Survey (ESS), was established to develop a methodology which could overcome these limitations. Specifically, the group set forth to develop and implement an evidence-based methodology for testing survey questions in cross-cultural or multinational contexts. At the outset, the group identified aspects of cognitive interviewing methodology that can undermine cross-national cognitive interviewing. For example, the non-standardized interviewing protocol, which is critical for fully exploring how each respondent interprets and formulates a response to a question, makes comparative analyses between multiple sites difficult. Unless analyses across the test sites are coordinated and conducted in concert, cognitive interviews themselves may not be comparable. Additionally, in conducting a comparative analysis, it is important to consider how data were collected (e.g. with trained or inexperienced interviewers, from thinking aloud narratives or pre-scripted follow-up probes), how the interviews were recorded (e.g. interviewer notes or transcriptions), as well as how the cognitive interview data may be limited or even flawed. That is, in conducting a comparative analysis, it is critical to consider the validity of the cognitive interview data itself and how the data quality might vary across the different interviewing sites. Without taking this necessary step, it is difficult to distinguish an "actual" comparative finding from artifacts of the cognitive interviewing process, particularly if that process involves numerous locations with different interviewers conducting interviews in multiple languages.

For this project, the coalition consisted of representatives from seven different nations and incorporated six different languages: the US (in English and Spanish), the UK, Bulgaria, Portugal, Switzerland (in French), Germany, and Spain. For its testing project, the workgroup examined the performance of the BI revised health states questions as well as some ESS attitude questions.

In Fall 2007, workgroup members met in London to discuss project goals and to determine the process and protocol for conducting the study. Unlike the initial BI testing, the testing was conducted jointly with each country using the same protocol, and interviews were analyzed by the group as one entire data set. In the next 5 months, 135 cognitive interviews were conducted by participating countries. In February, 2008, the group held a joint analysis meeting whereby a process was developed to conduct a systematic, comparative analysis of those interviews. Through this process, the group was able to identify various interpretive patterns resulting from socio-cultural and language-related differences among countries as well as other patterns of error that could potentially undermine the comparability of survey data. Findings from this collaborative effort were used to refine the BI questions (Miller 2008).

By and large, this project was deemed successful in that the protocol developed by the workgroup provided the interpretive data required to assess comparability across countries and languages. Not only was the analysis capable of identifying differences, it was able to explain those differences, providing the necessary information required to make decisions about question revision. The largest problem with the protocol, however, was the difficulty in analyzing the large qualitative dataset. Each interview was summarized for each question, and when the entire set of summaries was compiled, the result was a large binder that required analysts to constantly flip through while making notes in the margins.

Development of Q-Notes

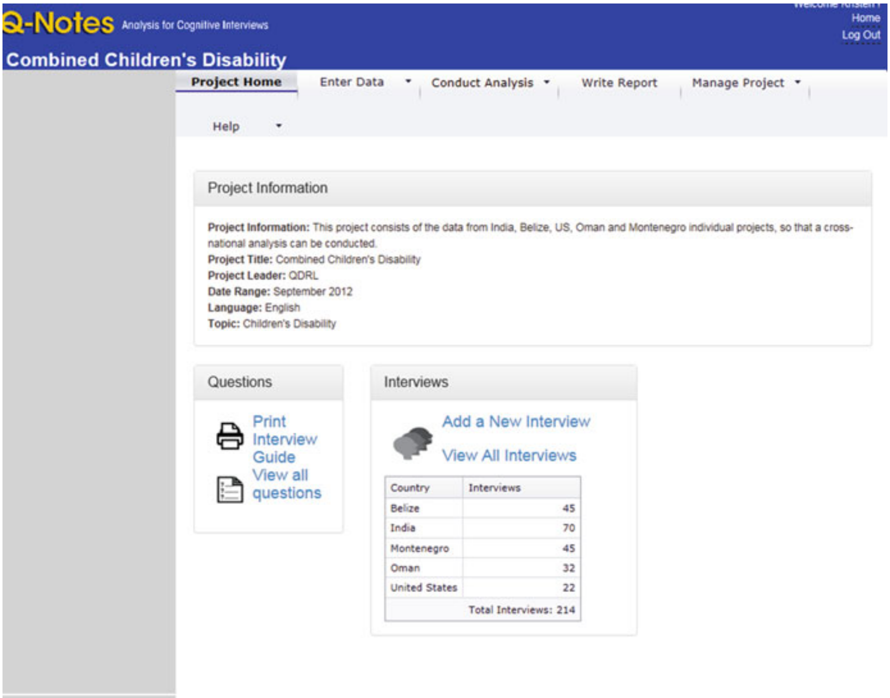
Needing a more efficient manner to analyze large amounts of cognitive interview data, the QDRL/NCHS developed Q-Notes—a data entry and analysis application for cognitive interviewing studies (Mezetin and Massey 2014). The application is online and accessible to anyone who has registered for a Q-Notes account. Since it is online, interviewers are able to enter summary notes from any location, allowing for collaboration across sites and the analysis of a single data set.

Figure 5.2 shows a project home page for an international children's disability project that was jointly conducted in 2014 by the WG and UNICEF. For this project, 214 interviews were conducted in five countries.

Along with the number of interviews conducted in each country, the home screen displays project level information including the topic of questions, the purpose, date and the project lead. From this screen, a user is able to navigate to any task in the research process: entering data, conducting analysis, writing a report or managing the project.

The data entry component of Q-Notes is organized so that interview summaries are entered by individual question. Figure 5.3 shows a data entry screen for the question "Do you have any difficulty using your hands and fingers, such as picking up small objects, for example, a button or pencil, or opening or closing containers and bottles?"

Each screen indicates the respondent ID as well as the interviewer and date of the interview. The respondent's answer is chosen by a drop down menu, and notes are written in the box below. The notes describe why the respondent answered the question as they did, indicating how the question was interpreted and what was considered. As shown in Fig. 5.3, to move from question to question, the arrow buttons next to the questionnaire icon can be clicked. The user can also move from interview to interview by clicking the arrow buttons next to the respondent icon located above the questionnaire icon.



Project Information: This project consists of the data from India, Belize, US, Oman and Montenegro individual projects, so that a cross-national analysis can be conducted.
Project Title: Combined Children's Disability
Project Leader: QDRL
Date Range: September 2012
Language: English
Topic: Children's Disability

Country	Interviews
Belize	45
India	70
Montenegro	45
Oman	32
United States	22
	Total Interviews: 214

Fig. 5.2 Q-notes project home screen

For the next question, click the right arrow button. For the previous question, click the arrow to the left.

Respondent ID: United States 12
Interviewer: Kristen 3/25/2010

8 - UPPERBODY2: Do you have difficulty using your hands and fingers, such as picking up small objects, for example, a button or pencil, or opening or closing containers or bottles?

Answer:
No difficulty

Interview Notes in English:
He quickly said no difficulty and picked up the pen on the desk and said "no problem". When I asked what he was thinking about he also mentioned tickets and coins.

Fig. 5.3 Q-notes data entry screen

Thus, Q-Notes allows for efficient data entry and centralizes the process by locating all interview data in a single project location rather than separate files and folders. This centralization allows for consistency across interviews because all data are recorded in a uniform format. This feature is particularly useful for project managers who need to monitor the status of a project as well as the quality of interview data, even if they are not on location. This is a particularly useful feature for cross-national studies in which interviewers are newly trained and inexperienced in conducting such interviews.[7]

Once all of the interviews are conducted and summary notes entered into Q-Notes, analysis can be conducted using the entire data set. The analytic features of Q-Notes are based on a 5-step approach outlined in Miller et al. (2014). Specifically, Q-Notes is uniquely designed to help researchers analyze data when (1) conducting interviews, (2) summarizing interview notes, (3) developing thematic schema, (4) making cross-group comparisons and (5) drawing conclusions about question performance. Figure 5.4 shows the various types of analyses that are possible in the Q-notes applications.

Particularly important for international testing projects, Level 4 provides several analytic features that can facilitate examination of comparability. That is, the application allows the analyst to examine whether or not a question performs similarly across countries, languages or any other type of sub-group, such as gender or disability status.

Significantly, Q-Notes enhances transparency in the research process, providing users with an audit trail of interview notes, coded themes, respondent demographics and frequency counts of the sub-group and cross-group comparisons that inform the thematic schema. This transparency enhances the validity of the cognitive interview findings, as researchers coming in at any phase of analysis can use this audit trail to reconstruct the analysis in order to draw similar conclusions or, alternatively, build upon existing ones.

Evalution of the Washington Group Extended Set

To evaluate the WG extended set, two multi-national, multi-lingual studies were conducted: one in collaboration with UNESCAP and six Asian countries; the other in collaboration with six European academics and methodologists from country statistical offices. In both studies, interviews were combined from all locations and analyzed as one set. Additionally, both studies utilized the newly developed Q-Notes application to facilitate the comparative analysis of the large qualitative data sets.

For the European testing, 100 total interviews were conducted in France, Germany, Italy, Portugal, Spain, Switzerland, and the United States. Similar to the BI study conducted by the Comparative Cognitive Testing Workgroup, a single study protocol was developed so that interviews and data quality were comparable.

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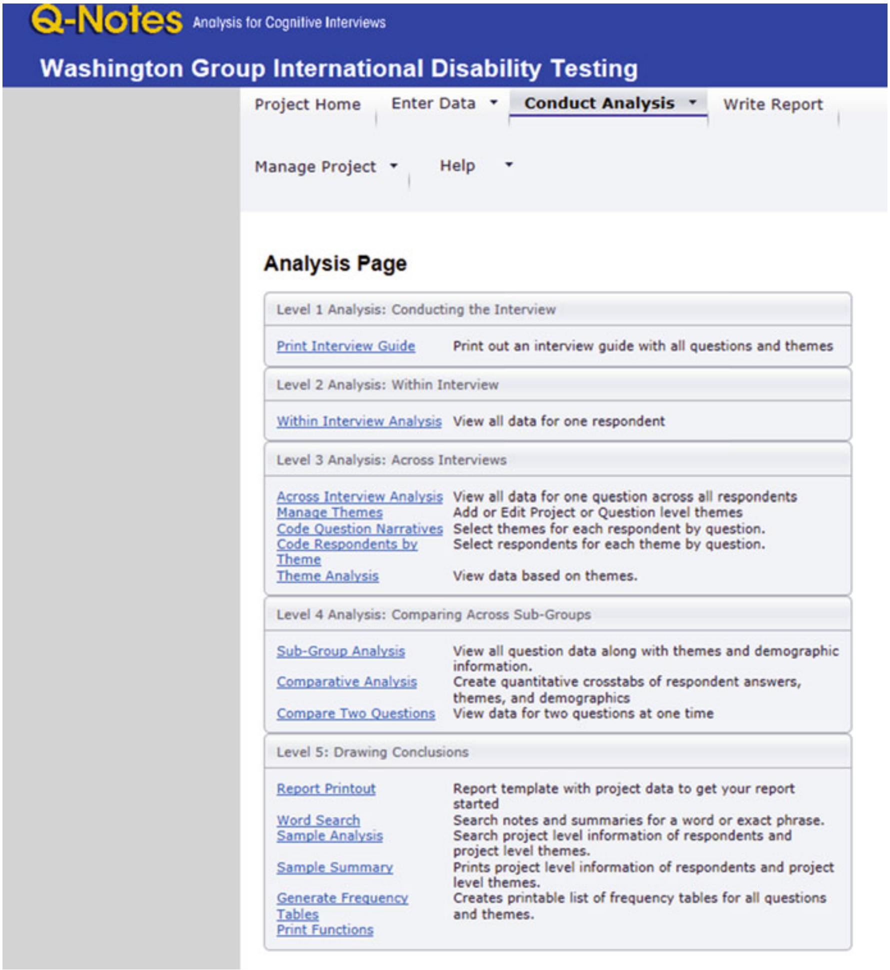
[7] For more information and access to Q-Notes: http://wwwn.cdc.gov/qnotes.



Analysis Page

Level 1 Analysis: Conducting the Interview	
Print Interview Guide	Print out an interview guide with all questions and themes

Level 2 Analysis: Within Interview	
Within Interview Analysis	View all data for one respondent

Level 3 Analysis: Across Interviews	
Across Interview Analysis	View all data for one question across all respondents
Manage Themes	Add or Edit Project or Question level themes
Code Question Narratives	Select themes for each respondent by question.
Code Respondents by Theme	Select respondents for each theme by question.
Theme Analysis	View data based on themes.

Level 4 Analysis: Comparing Across Sub-Groups	
Sub-Group Analysis	View all question data along with themes and demographic information.
Comparative Analysis	Create quantitative crosstabs of respondent answers, themes, and demographics
Compare Two Questions	View data for two questions at one time

Level 5: Drawing Conclusions	
Report Printout	Report template with project data to get your report started
Word Search	Search notes and summaries for a word or exact phrase.
Sample Analysis	Search project level information of respondents and project level themes.
Sample Summary	Prints project level information of respondents and project level themes.
Generate Frequency Tables	Creates printable list of frequency tables for all questions and themes.
Print Functions	

Fig. 5.4 Q-notes analysis page

As a result, findings were able to identify differences across countries as well as to explain those differences, providing the necessary information required to make decisions about question revision. Findings from the study were presented in 2010 at the 10th annual meeting of the WG.

For the Asian testing, the evaluation consisted of a two-step mixed method design, involving a cognitive interview study and a randomly drawn field test in each participating country.[8] First, 143 total semi-structured, qualitative cognitive interviews were conducted in the six participating countries in order to understand the ways in which each question performed and the specific constructs captured.

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[8] Countries included: Cambodia, Kazakhstan, Maldives, Mongolia, the Philippines and Sri Lanka.

Based on the analysis of the cognitive interviews, follow-up probe questions were developed and placed on the field test questionnaire. Each country then conducted approximately 1000 standardized survey interviews drawn from a random sample. Resulting survey data from the follow-up probe questions were used to examine the extent of valid and non-valid interpretive themes in a cross-national environment.

A significant methodological contribution of the Asian evaluation study was the advancement of field testing as a question evaluation method, particularly as it is performed in conjunction with a cognitive interviewing component. Cognitive interviewing methodology, with its ability to reveal the substantive meaning behind a survey statistic, is a primary method for question evaluation. Nonetheless, while cognitive interviewing can show that a particular interpretive pattern does indeed exist, it cannot determine the extent or magnitude to which that pattern would occur in a survey sample or differs across socio-cultural groups. In short, as a qualitative methodology, cognitive interviewing studies lack ability to provide quantitative assessment—a component particularly essential to the field of survey methodology. Likewise, strictly quantitative methods of question and questionnaire evaluation using metrics such as item non-response and missing rates can indicate, but not explain, source of response error. This study illustrated how it is possible to address this issue by integrating qualitative and quantitative question evaluation methods.

Conclusion

A primary effort of the Washington Group is to develop survey questions to collect globally comparable disability statistics. To this end, numerous evaluation studies were conducted ensuring that questions capture the intended conceptual constructs consistently in multi-national, multi-lingual contexts. This chapter has presented an overview of those studies while describing the progression of methodological limitations and advancements. Since cognitive interviewing methodology can determine the phenomena that respondents consider when formulating responses, it is the best method for examining construct validity and comparability. However, a number of practical as well as methodological considerations were required in order to conduct successful evaluations, including the analysis of large datasets, consistency across interviews, and interviewer experience. The development of Q-Notes was a noteworthy advancement in conducting large multi-country cognitive interviewing studies and is an important tool used in ongoing WG studies. Integration of field tests into a mixed-method design, as was illustrated in the WG/UNESCAP study, is also a noteworthy advancement and will likely be included in future studies.

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Chapter 6
The Harmonized Joint Pilot Tests for 2010 Population Census Round in Latin American Countries: An Integration Experience

Alicia Bercovich

Introduction

Since the 2000 Census Round planning, six Latin American countries have made a joint effort to harmonize a set of common variables, their concepts, definitions and classifications. The Census methodology was also partially harmonized, from the initial phases of Census work to dissemination results.

The Project goals were, among others, widening the cooperation between the countries in the production, use and dissemination of Census data and compiling socioeconomic statistics that would enable comparisons among the countries.

For the 2010 Census round, countries agreed on adding three new topics to be harmonized. The themes were selected based on users demand and relevance for all the participating countries: ***disabled population***, ***international migration*** **and** ***indigenous people***. Argentina, Brazil, Paraguay and Uruguay carried out several harmonized pilot tests on those topics as part of the 2010 Round Harmonized Population Censuses Project planning. The disability and migration tests were carried out at the triple border between Argentina, Brazil and Paraguay on 2006 and 2007 respectively. Uruguay also carried out the test on 2008.

The test on indigenous population was carried out at indigenous communities belonging to the same ethnic group, both sides of Paraguay-Brazil border. The field work was accompanied by non-participative observers representing National Statistical Offices (NSO's) of almost all South American countries and Mexico.

This paper addresses the development of the harmonization project since the 2000 census round, with the Joint Pilot Test on Disability for the 2010 round as an example of the work done to harmonize concepts. There are also shown some results and an example of the comparative analysis done by the countries.

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Background

The project for the economic integration of the Mercosur countries had shown the need to compile socioeconomic statistics that enable comparisons to be made among the countries. Considering the different contents and methodologies of the respective Censuses, the comparison of data had been difficult, mostly an aggregation of tables (IBGE 1993; INDEC 1995).

During the 1990s the NSO's representatives met to evaluate the experiences of the last censuses, and the topics most frequently addressed related to the need for integration and comparability between the data produced by each country. Representatives of the NSOs considered the possibility of harmonizing the Population Censuses from the planning stage, beginning the project of the Joint Population Census for the Mercosur countries, plus Bolivia and Chile.[1]

The integration project began in May of 1997, during the initial phase of work on the censuses for the year 2000 round. From then on, a great effort was made to harmonize the variables, concepts, definitions and classifications, starting from the planning phase of the Censuses for the six countries, Argentina, Brazil, Paraguay, Uruguay, Bolivia and Chile. The project included the generation of a common micro data base with harmonized information on the six countries.

Since it would not be possible to harmonize all the variables of all the censuses, it was decided to select a set of common variables, and for those variables, to make definitions and concepts comparable. The strategic objective, besides obtaining comparable statistical data, was to optimize the methodological, human and technological resources of the countries for all the Censuses to be carried out in an harmonized way. This also would allow institutional support to be able to carry out the six Censuses as close to the year 2000 as possible, to make the horizontal cooperation easier and to potentialize the technical international support.

It was considered important to try to achieve methodological homogenization, and to ensure comparability of the classification and coding systems. The goal was to prepare common tabulations and create a unique database. To test the feasibility of the harmonization effort for the selected variables, Joint Pilot Tests were carried out at the borders between the countries, as described later.

Variables, Concepts and Classifications

Considering the heterogeneous nature of the census forms of each country, a subset of variables were selected to be harmonized for the Common Census:

- Some characteristics of dwellings, common to all forms, particularly those relating to sanitation conditions;

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[1] The members of Mercosur are Argentina, Brazil, Paraguay and Uruguay, but since the beginning Bolivia and Chile have been working with the group.

- The basic demographic characteristics of the individuals;
- Some educational characteristics, such as completed years of schooling and school attendance;
- The economically active and employed population, considering only the status in employment and Industry Classification; but after the enthusiastic work of the nomenclatures group, a preliminary common classification of occupations was also convened;
- Migration characteristics, especially migration between countries in the region.

Joint Pilot Tests

The first joint fieldwork experience was the first Joint Mercosur Pilot Test. This was initiated in November 1998 with the participation of Argentina, Bolivia and Brazil in border areas. The second took place between Argentina and Paraguay in 1999. The objectives of these experiments were to test the common content of the questionnaires of each country, test training methodologies, processing and construction of the common database.

The evaluation was done by the field teams of the participating countries and observers from the other countries. The results of the tests surpassed expectations: the population of the regions included in the tests collaborated enthusiastically and the census activities were widely disseminated by the media.

Achievements

All the countries of the Project carried out their 2000 Round Censuses and considered the observer's comments for the design. The common classifications of Industry (CAES Mercosur) and Occupation were ratified by the countries. One outstanding characteristic of the Project was the Horizontal Cooperation between the Institutes through which experiences and technological progress were shared with a spirit of collaboration and great openness.

The attempt to achieve processing homogenization was partly successful: Uruguay, Argentina, Brazil, Bolivia and Chile used scanners for data capture and intelligent character recognition (ICR).

The countries established a technical cooperation network that included not only common methodologies but also the loan of scanners, support in capacity building, printing one country's test forms by another, mutual collaboration in automated/assisted coding, and support between countries in scanning/ICR experience. Representatives from all the countries participated as observers of the Censuses field operations of the other members of the Project. The Censuses of Brazil, Bolivia, Argentina, Chile and Paraguay including Paraguay Indigenous Census, were conducted between 2000 and 2002. It was also agreed to create a multidimensional database, which would be generated using the micro data from the censuses.

The Joint Pilot Test on Disability

The pilot test on disability was carried out at the border between Argentina, Paraguay and Brazil in 2006. The three countries tested the short set of questions proposed by the Washington Group for Disability Statistics. All the countries had previously carried out cognitive testing of the original set of questions. Non-participative observers representing NSO's of almost all South American countries and Mexico accompanied the fieldwork. Also experts on disability statistics from International Agencies were integrated with the observer's team. After the field work, the observers participated in an evaluation workshop to discuss their observations.

The three countries produced reports with analogous data analyses; this allowed comparison of the results. Some of the analyses were discussed at a Washington Group meeting, and proposed by its members as part of the harmonization task.

Results and Analysis

The analysis target was to test the consistency of the census questions proposed on disability, to evaluate how their interpretation may differ across diverse core domains, countries, and subpopulations. This analysis complemented the cognitive testing already carried out by the three countries in early 2006 to gain deeper insight into how these core questions were understood by respondents. As the core questions proposed are very general, an extended set of questions could depict a more detailed picture of a person's level of functioning. So, in order to get a better sense of what responses to the core questions indicated, the pilot test included some extended questions in the core domains in order to benchmark the responses to the more general questions.

The analysis consisted in comparing the answers to the short set of questions with the ones to the extended set, in a way that would provide evidence that the core questions were good enough to identify people with disabilities in the investigated domains. All the countries did the same analysis, which allowed for comparison of general prevalence levels of disability and also identified prevalence for each separate domain by severity level. Some of the results are shown below.

The Figs. 6.1, 6.2 and 6.3 show the comparison between P (prevalence as measured by the core questions) and PE (prevalence measured by the positive answers to the extended set of questions), for the three countries. The numbers P1, P2 or P3 identify level of severity: P1: if response was *some difficulty, a lot of difficulty, or can't do at all* in at least one domain; P2: if response was *a lot of difficulty or can't do at all* in at least one domain and P3: if response was *can't do at all* in at least one domain.

As can be seen, the core questions (darker) were good to identify people with at least one disability (Fig. 6.1), if compared with the people who answered positively

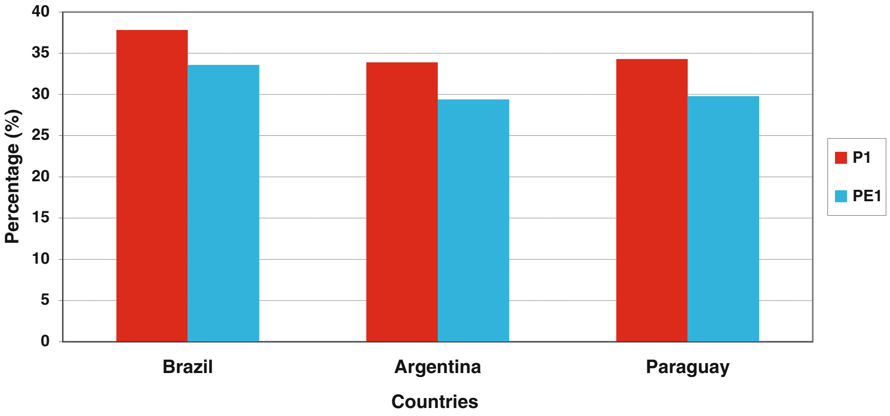

Fig. 6.1 Disability prevalence by country, set of questions and level of severity P1 vs PE1 (Source: Data from 1st Joint Pilot Test on Disability: Brazil, Argentina and Paraguay, Nov. 2006)

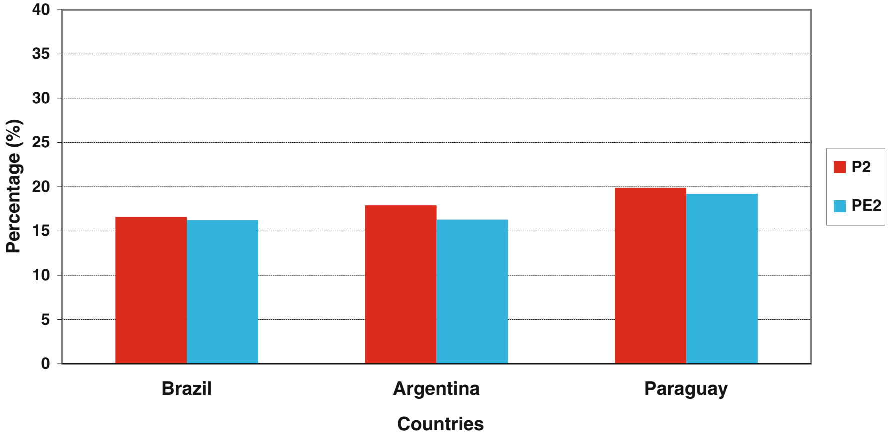

Fig. 6.2 Disability prevalence by country, set of questions and level of severity P2 vs PE2 (Source: Data from 1st Joint Pilot Test on Disability: Brazil, Argentina and Paraguay, Nov. 2006)

to the extended set (lighter). The proportion of people with at least one disability was bigger for Brazilians than for people of Paraguay or Argentina. For the highest level of severity, Paraguay had higher proportion of persons in these categories.

The same analysis was performed by domain, and the core domains (vision, hearing, mobility) had a good identification of disabled people through the core

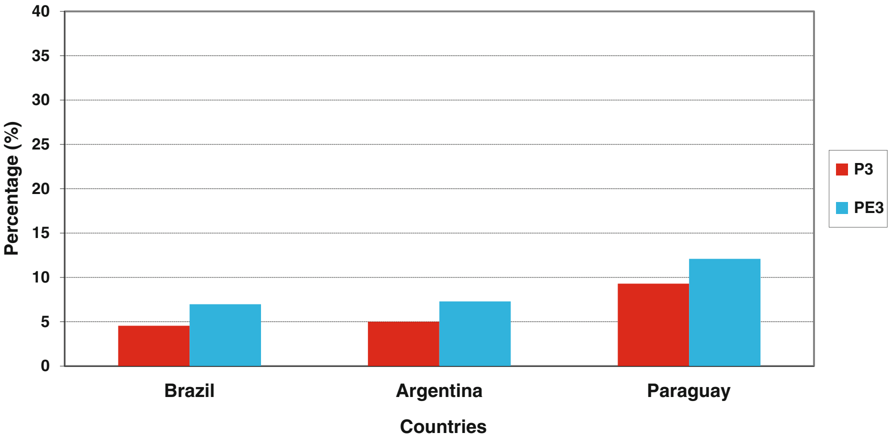

Fig. 6.3 Disability prevalence by country, set of questions and level of severity P3 vc PE3 (Source: Data from 1st Joint Pilot Test on Disability: Brazil, Argentina and Paraguay, Nov. 2006)

questions. For the other domains, the best performance was for the questions on self care.

Correlation Analysis

To make easier statistical comparisons, the responses to the core questions were transformed from categorical variables to binary variables (Mont 2005).

D1, D2, D3 were defined for each domain such that:

D1 = 1 if response is *some difficulty*, *a lot of difficulty*, or *can't do at all*, else =0
D2 = 1 if response is *a lot of difficulty* or *can't do at all*, else =0
D3 = 1 if response is *can't do at all*, else = 0

As can be seen, D1 is the broadest definition of a disability and D3 is the most limited. The same was done for the extended set of questions.

The relationship between D1, D2, and D3 for the core questions and ED1, ED2, and ED3 for the extended questions was analyzed constructing the correlation matrix for each domain. Each cell is the correlation coefficient of the variables in the corresponding row and column. D0 and ED0 have been added, which represent people without reported difficulties in the core questions and in the extended set respectively.

Table 6.1 shows the correlation between the answers to the core questions and extended set for ***Self Care***, for the three countries and the three levels of severity.

The correlation coefficients in the matrix are used to test if there are statistically significant differences between the Di and EDi measures. If those differences were statistically significant then the measures are not equivalent. The comparisons between measures are done looking to the diagonal of the matrix for each one of the domains tested.

For Brazil, all the correlations Di vs. EDi are higher than 0.80 for *Self Care Domain*, and also Argentina and Paraguay had acceptable values, as it is shown in Table 6.1.

Generally, the Domains of: Vision, Hearing, Mobility and Self Care had acceptable levels of correlation for the three countries. Communication and Cognition had lower correlations, corresponding to problems that had already been pointed out by the observers of the field work.

Especially in Vision Domain, it can be observed, for Brazil, a very low correlation only between D3 and ED3, as shown in Table 6.2. It was detected that the translation to Portuguese of "Cannot do at all" yielded to confusion with "No difficulty". The wording was modified for the next pilot test.

Other domains, like hearing, presented the same problem of misinterpretation. New wording was also introduced for those domains. The two pilot tests carried out afterwards with modified wording, showed that apparently, that problem was solved.

Table 6.1 Correlation matrix by country and domain self-care

Short set of questions	Extended set of questions											
	Brazil				Argentina				Paraguay			
	ED0	ED1	ED2	ED3	ED0	ED1	ED2	ED3	ED0	ED1	ED2	ED3
D0	**0.82**	–0.82	–0.75	–0.66	**0.61**	–0.61	–0.54	–0.49	**0.57**	–0.57	–0.56	–0.53
D1	–0.82	**0.82**	0.75	0.66	–0.61	**0.61**	0.54	0.49	–0.57	**0.57**	0.56	0.53
D2	–0.73	0.73	**0.83**	0.77	–0.64	0.64	**0.70**	0.64	–0.58	0.58	**0.63**	0.62
D3	–0.60	0.60	0.73	**0.85**	–0.60	0.60	0.74	**0.77**	–0.55	0.55	0.62	**0.66**

Source: Data from 1st Joint Pilot Test on Disability: Brazil, Argentina and Paraguay, Nov. 2006

Table 6.2 Correlation matrix by country and domain

Short set of questions	Extended set of questions											
	Brazil				Argentina				Paraguay			
	ED0	ED1	ED2	ED3	ED0	ED1	ED2	ED3	ED0	ED1	ED2	ED3
D0	**0.65**	–0.65	–0.46	–0.17	**0.59**	–0.59	–0.45	–0.19	**0.29**	–0.29	–0.15	–0.03
D1	–0.65	**0.65**	0.46	0.17	–0.59	**0.59**	0.45	0.19	–0.29	**0.29**	0.15	0.03
D2	–0.45	0.45	**0.54**	0.23	–0.46	0.46	**0.60**	0.30	–0.14	0.14	**0.15**	0.05
D3	–0.01	0.01	0.03	**0.05**	–0.19	0.19	0.31	**0.74**	–0.03	0.03	0.05	**0.07**

Source: Data from 1st Joint Pilot Test on Disability: Brazil, Argentina and Paraguay, Nov. 2006

Table 6.3 Correlation matrix by country and domain mobility

Short set of questions	Extended set of questions											
	Brazil				Argentina				Paraguay			
	ED0	ED1	ED2	ED3	ED0	ED1	ED2	ED3	ED0	ED1	ED2	ED3
D0	**0.66**	–0.66	–0.57	–0.37	**0.78**	–0.78	–0.69	–0.45	**0.74**	–0.74	–0.74	–0.58
D1	–0.66	**0.66**	0.57	0.37	–0.78	**0.78**	0.69	0.45	–0.74	**0.74**	0.74	0.58
D2	–0.56	0.56	**0.67**	0.50	–0.66	0.66	**0.79**	0.59	–0.64	0.64	**0.77**	0.64
D3	–0.34	0.34	0.46	**0.65**	–0.37	0.37	0.48	**0.69**	–0.42	0.42	0.52	**0.64**

Source: Data from 1st Joint Pilot Test on Disability: Brazil, Argentina and Paraguay, Nov. 2006

Table 6.4 Correlation matrix by country and domain cognition

Short set of questions	Extended set of questions											
	Brazil				Argentina				Paraguay			
	ED0	ED1	ED2	ED3	ED0	ED1	ED2	ED3	ED0	ED1	ED2	ED3
D0	**0.46**	–0.46	–0.34	–0.22	**0.55**	–0.55	–0.42	–0.30	**0.52**	–0.52	–0.50	–0.40
D1	–0.46	**0.46**	0.34	0.22	–0.55	**0.55**	0.42	0.30	–0.52	**0.52**	0.50	0.40
D2	–0.47	0.47	**0.54**	0.39	–0.56	0.56	**0.63**	0.47	–0.49	0.49	**0.58**	0.50
D3	–0.29	0.29	0.46	**0.68**	–0.43	0.43	0.52	**0.70**	–0.36	0.36	0.48	**0.60**

Source: Data from 1st Joint Pilot Test on Disability: Brazil, Argentina and Paraguay, Nov. 2006

In the case of Paraguay, one of the questions on Vision was missing in the final version of the form, so the low correlations for Vision Domain could not be considered for evaluation.

Tables 6.3 and 6.4 show the Correlation Matrix for the Mobility and Cognition Domains respectively.

Final Remarks

It was shown how some Latin American Countries worked together to carry out harmonized censuses for the 2010 Round. The analysis of the Pilot and Cognitive tests on disability helped to identify the questions to propose to be included in the Census. The experience of joint tests in the border was again fruitful and allowed the discovery of similarities and differences among the countries, even when the same questions were applied in the field.

This harmonization strategy stimulated horizontal cooperation, solidarity among participants and an interchange of knowledge and experiences that had not been foreseen in the design of the original project. This experience, which arose from the political will of the Institutes and the manifest interest of the technical staff in combining weaknesses to construct strengths, can be considered a paradigm of an efficient and participative working style. Part of the success is probably due to the spontaneity of the project, with the countries demonstrating openness to harmonize their efforts, no one taking the leadership.

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Part III
Moving Forward: Extended Question Sets and Methodological Advances

Chapter 7
Development of Disability Measures for Surveys: The Washington Group Extended Set on Functioning

Mitchell Loeb

Development of Disability Measures for Surveys: The Washington Group Extended Set on Functioning

Background & Rational for the Development of the WG Extended Set Questions

The Washington Group on Disability Statistics (WG) chose to focus its initial efforts on the development of a short set of questions suitable for national censuses understanding that in low income counties in particular, the decennial census may be the sole means of collecting population data. Censuses cover the entire population, and therefore, for reasons related to both cost and logistics, must limit the number of questions that can be included. The challenge with identifying disability through a census is that it cannot be measured with a single question (Madans et al. 2004).

The development of a short set of disability questions suitable for censuses has been completed and is documented in greater detail elsewhere (see: http://www.cdc.gov/nchs/data/washington_group/meeting8/NSO_report.pdf).

Just as the complexity of disability defies the use of a single question, it also cannot be completely captured by six questions on basic functioning. It was acknowledged early in the question design and development process that the WG short set of questions would capture the majority of, but not all, persons with limitations; encompass the most commonly occurring limitations in basic actions, and be able to capture persons with similar problems across countries. It was clear that certain

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of the short set domains could be expanded by asking additional questions that would elucidate further the functional difficulties a person experiences. For example difficulty walking and climbing stairs are simple basic actions but other elements of interest include the use of technical aids or assistance – and the difficulty experienced walking a short or a longer distance. Similarly with the hearing domain (that includes the use of hearing aids) it would be of interest to determine the extent of the hearing difficulty by asking additional questions that would elicit difficulty hearing in a noisy or a quiet room.

Other basic activity and body function domains could not be covered adequately by a single question and were thus not included in the short set. These include upper body functioning, and the domains of pain, fatigue and affect (anxiety and depression). All were deemed important for inclusion in the extended set of questions on functioning.

Work on extended sets of disability questions was facilitated with the creation of a second matrix (see Appendix 1) designed to be a framework to guide the development of these questions. The columns of the matrix include a full range of domains related to functioning and disability: basic activity domains (including the core set of domains covered by the WG short set of questions plus upper body functioning and affect), body function domains (including pain, and fatigue), and complex activity or participation domains (including ADLs/IADLs, getting along with people, major life activities and participation in society) (WHO –World Health Organization 2001). The rows of the matrix describe the type of information obtained about each domain, such as the use of assistive devices/aids, functioning with and without the use of devices/aids where applicable, age at onset of functional difficulty and the impact of the difficulty on certain life activities. Additional rows address the impact of various aspects of the meso- and macro-environment that may influence functioning and/or participation. To complete the matrix in its entirety, developing questions for each cell, would be to devise a comprehensive disability survey that would cover limitations in core domains, activity limitations, participation restrictions, environmental facilitators and barriers and ultimately provide a complete picture of the disability experience.

Following adoption of the WG short set of questions, at its annual meeting in 2007 the WG turned to the development of extended sets of questions on functioning. Guided by the matrix, work on the first extended set of questions on functioning (ES-F) – confined to the first four rows of the matrix (Appendix 1) – progressed as follows:

1. A review of existing question sets already in use in other national or research surveys. These included, but were not restricted to, the WHO Disability Assessment Schedule (WHO DAS); the WHO World Health Survey; the Australian ANS: Survey of Disability, Aging and Carers; Ireland: National Disability Survey; Canada: PALS (Participation and Activity Limitations Survey); Eurostat: European Health Interview Survey; Tanzania: Detailed Adult Questionnaire for People with Disabilities; and SINTEF (Norway): Surveys of Living Conditions among People with Disabilities in Southern

Africa. The purpose of this review was to inventory other questions and approaches to collecting expanded information on disability and to use, where appropriate, already tested and valid measures.

2. Selection of domains: The goal was to expand upon the six WG short set domains (vision, hearing, cognition, mobility, self-care, and communication) to include additional basic activity and body function domains that would capture those missed by the use of the short set alone. There was some concern expressed post-WG SS acceptance that limitations in certain domains of functioning, in particular intellectual and psychological disabilities, were not being captured as completely as other domains of functioning. Domains discussed for inclusion in the extended set were: upper body functioning, learning, affect (anxiety and depression), pain, and fatigue. Also considered for specific domains of functioning was the collection of additional information per domain, for example, functioning with and without assistance. This would allow for a determination of both capacity (functioning without assistance) and performance (functioning with the use of aids or assistance).
3. At a joint WG/Budapest Initiative[1] (BI) meeting held in Washington, D.C., in July 2008, the results of the above review were presented and discussions focused on question design and development. A draft survey instrument was prepared at this meeting.
4. This was followed by the development of a cognitive test protocol.
5. In 2008, the work being conducted by the WG, the BI and the United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP) on the development of an extended set of questions on functioning was brought together under a common umbrella, and an agreement was reached to conduct regional testing of the extended set of questions on functioning through UNESCAP.
6. UNESCAP/WG training was held from 16 to 20 February 2009 in Bangkok, to train six UNESCAP countries (Cambodia, Kazakhstan, Maldives, Mongolia, the Philippines and Sri Lanka) in cognitive and field test procedures for the extended set.
7. Subsequently, cognitive testing took place in these countries as well as in Canada, the United States and South Africa (see Chap. 9);
8. A WG Extended Set Analysis Workshop was held in Washington, D.C., in May 2009 to discuss the results of the cognitive testing – and lay preparations for field testing.
9. This was followed by the development of a field test protocol and field testing in the same six UNESCAP countries.

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[1] The Budapest Initiative (BI), established 2005, is a collaboration of, among others, the World Health Organization (WHO), United Nations Economic Commission for Europe (UNECE), and Eurostat. This consortium was charged with the task of developing a short form questionnaire intended to provide the basis for the collection of comparable standardized information on population health focusing on health state for inclusion in the European Health Interview Survey (EHIS). The BI defines health state in terms of functioning in a core set of health domains.

10. Results from cognitive testing and preliminary field testing were presented to the ninth meeting of the WG in Dar es Salaam October, 2009.
11. The finalized extended set of disability questions were presented and adopted at the 10th Meeting of the WG held in Luxembourg in November, 2010.

Cognitive Testing and Question Evaluation

Over the years, the Washington Group has, as one of its goals, honed and refined a comparable testing methodology for question design, evaluation and development. An early study was an evaluation of the WG short set of six disability questions intended for censuses. Fifteen countries took part in this study: Argentina, Brazil, Congo, Egypt, Gambia, India, Kenya, Lesotho, Mauritius, Mexico, Paraguay, Philippines, Tanzania, Uganda and Vietnam. The results of this first evaluation have been published (Miller et al. 2011). A second large scale evaluation study that advanced this methodology was the combined WG/BI/UNESCAP project.

As the use of cognitive interview methodology to improve survey questions is increasing, survey researchers are faced with the challenge of how best to combine qualitative evidence from cognitive interviews with quantitative field test results. Multiple benefits can be obtained by combining evidence from both methods in a question evaluation project. In cross-cultural/national surveys, a mixed-method approach can provide evidence of the prevalence of the interpretation patterns found by cognitive interviewing, and the extent to which differences in understanding the question's meaning can be linked to different type of response biases or to real differences in understanding of the intended construct of the question.

The aim of the WG/BI/UNESCAP project was to recommend a set of questions for surveys that would expand upon the WG SS and support regional census programs and the Biwako Millennium Framework (UNESCAP – United Nations Economic and Social Commission for Asia and the Pacific 2002). A two-phase mixed method approach for question evaluation was utilized to produce a set of questions that would yield comparable data cross-culturally and cross-nationally. In the first phase, 143 qualitative cognitive interviews were conducted in the nine participating countries (six in Asia and the Pacific, plus the USA, Canada and South Africa) in order to better understand the ways in which each question performed. The second field test phase consisted of approximately 1000 face-to-face interviews using the revised questionnaire in each of the six Asia-Pacific countries. (For more details on the WG/BI/UNESCAP project, please see Chap. 9.)

Cognitive testing provides rich, contextual insight into the question/response process. In particular, cognitive testing will provide information on how respondents comprehend and interpret a question, how they consider and weigh relevant aspects of their own lives in relation to the question being asked and, finally, how they use that information to formulate a response that fits the response options. These patterns of interpretation, or themes, may recur among respondents – some of these emergent themes may indicate that respondents were not interpreting the questions as the developers intended. These themes can then be included in surveys as follow-up probe questions in order to quantify, in a random sample of the population, how often the themes occur to determine the potential extent of false positive or false negative responses. Themes that emerged from the WG/BI/UNESCAP cognitive testing in Asia and the Pacific were added to the field testing phase as follow-up probe questions and used to quantify response patterns and assess the reliability of the responses. It should be stressed that these additional questions are not designed as gold standards for the purpose of validating responses. They are also prone to error or interpretation. The intent of the follow-up survey questions is to provide additional information on the response process in a representative sample.

A third question evaluation initiative included the Granada Group Study. The Granada Group, consisting of France, Germany, Italy, Portugal, Spain, Switzerland and the US, took a somewhat different approach to that taken by the WG/BI/UNESCAP project, in looking at the same set of extended questions. While the Group collected cognitive data from qualitative interviews, and analyzed these along the same lines as the UNESCAP project, their approach focused on the further development of question evaluation methodology and best practices in cognitive research methodology. A by-product was however, an additional evaluation of the extended question set.

Based on the results of the cognitive and filed testing from both the UNESCAP region and the Granada Group, the BI recommended that the BI-M2 (Budapest Initiative Question Set - Mark 2 version) be included in the 2014 European Health Interview Survey (EHIS) as a complete set or section. This would facilitate both international comparability on the individual domains and the computation of summary measures of health state. The extended set of question on functioning have also been included on the National Health Interview Survey (NHIS) in the US for the past few years (2010–2013) and analyses are currently underway to better understand the attributes of individual domains and make recommendations for analytic approaches to define disability based on these extended questions. These issues will be addressed below.

Developing Summary Measures for Individual Domains of the WG Extended Set

The WG/BI/UNESCAP initiative expanded on the short set of single domain questions to include more complex domains that require multiple questions to determine the extent of functional limitations (e.g. affect, pain and fatigue). To further advance this work, analyses of the domain specific data and testing of various analytic algorithms has been carried out by the WG to determine the best possible analytic approach to create summary measures for each domain. A few of these domain specific analyses will be presented here – and a complete review of the methodological approach to analyzing all domains will be available in a separate publication.

The multiple questions within each domain were analyzed in order to arrive at a better understanding of domain specific functional difficulties. Individuals were classified according to the cross-classification of the extended questions for the domain in question. Upon examination of that cross-classification, a categorization was proposed that described a severity continuum for the domain. That categorization was subsequently verified using other information relevant to that domain that was available in the NHIS. Once a summary measure for a domain is defined, the next step was to verify the gradient against other information available in the NHIS. For example, the fatigue domain includes aspects of frequency, intensity and duration of experienced fatigue. The analysis focused on determining how these dimensions of fatigue were related and how best to combine these aspects of fatigue to create a summary measure that described fatigue along a gradient of severity. This might be the WG short set question (if available) or other data collected on the NHIS that could explain or confirm the gradient constructed. These analyses were conducted in 2013 and will be summarized here for selected domains of functioning.

Data Source and Study Population

The quantitative analyses of the extended set disability questions were performed using the 2010 and 2011 National Health Interview Survey (NHIS).[2] (NCHS – National Center for Health Statistics 2011; 2012) Data from the 2011 NHIS were used for analysis of the hearing domain; and, because follow-up probe questions were only included on to the 2010 NHIS, this file was used for the analyses of the pain, fatigue and affect domains – which made use of these probe questions. NHIS data are collected continuously throughout the year by the National Center for Health Statistics (NCHS). The survey uses a multi-stage clustered sample design, with oversampling of black, Hispanic, and Asian persons, and produces nationally representative data on health insurance coverage, health care access and utilization, health status, health behaviors, and other health-related topics.

Interviewers with the U.S. Census Bureau conduct the computer-assisted personal interviews (CAPI) in respondents' homes, although follow-ups to complete interviews may be conducted over the telephone. The core survey instrument has four main modules: Household, Family, Sample Child, and Sample Adult. The first two modules collect health and socio-demographic information on each member of each family residing within a sampled household. Within each family, additional information is collected from one randomly selected adult (the "sample adult") aged 18 years or older and (if applicable) one randomly selected child (the "sample

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[2] The National Health Interview Survey (NHIS) has monitored the health of the nation since 1957. NHIS data on a broad range of health topics are collected through personal household interviews. Survey results have been instrumental in providing data to track health status, health care access, and progress toward achieving national health objectives.

child") aged 17 years or younger. The information presented in this paper was reported by the sample adult and is found in the Sample Adult component of the survey. For further information about NHIS and the questionnaire, visit the NHIS website.

For the 2010 NHIS, interviews were conducted in 34,329 households, accounting for 89,976 persons in 35,177 families. Disability survey questions addressed in this paper (for pain, fatigue and affect) are found in the 'Quality of Life' section of the 2010 NHIS sample adult component. The final response rate for the Sample Adult component was 60.8 % of persons identified as sample adults (Division of Health Interview Statistics 2011). The 2010 sample adult file contains 27,157 respondents; and approximately one quarter of the sample adults were randomly selected to receive the 'Quality of Life' section. Data for the 6775 persons 18 years of age or older from this random quarter of sample adults formed the basis of the analyses of the pain, fatigue and affect domains.

For the 2011 NHIS, interviews were conducted in 39,509 households, accounting for 101,875 persons in 40,496 families. Disability survey questions addressed in this paper (for the hearing domain) are found in the Sample Adult section of the 2011 NHIS. The final response rate for the Sample Adult component was 66.3 % of persons identified as sample adults (Division of Health Interview Statistics 2012). The 2011 sample adult file contains 33,014 respondents; and approximately one half of the sample adults were randomly selected to receive the disability questions. Data for the 16,540 persons 18 years of age or older from this random half of sample adults formed the basis of the analyses of the hearing domain.

All analyses were weighted and conducted using SPSS software for Complex Samples to account for the complex sample design of the NHIS. Weights were produced for persons from the random quarter of adults sampled to take the 2010 'Quality of Life' section and the random half of adults sampled to receive this set of disability questions in the Sample Adult component of the NHIS. The weights account for the complex survey design by adjusting for differential probabilities of selection, nonresponse, and post-stratification, and are designed to produce estimates representative of the non-institutionalized civilian U.S. population.

Hearing

The single short set question concerning difficulty hearing even when using hearing aid(s) gives only a broad indication of hearing problems. Two questions were developed and tested for the hearing domain to provide more detail on an individual's hearing difficulty. These included difficulty hearing what is said in a conversation with one other person in a quiet room, and difficulty hearing what is said in a conversation with one other person in a nosier room.

The WG SS question on hearing identifies almost 2 % of the sample population who have serious difficulty hearing (1.6 % a lot of difficulty; 0.1 % cannot hear at all). See Table 7.1.

Table 7.1 Difficulty hearing/short set question

Difficulty hearing/short set question	Unweighted frequency	Weighted (%)	Valid (%)
No difficulty	14,268	87.2	87.7
Some difficulty	1690	9.6	10.4
A lot of difficulty	279	1.6	1.7
Cannot do at all/unable to do	25	0.1	0.2
Subtotal	16,262	98.4	100.0
Refused/NA/DK	278	1.6	
Total	16,540	100.0	

Table 7.2 Difficulty hearing in a noisy room by difficulty hearing in a quiet room (unweighted counts)

	Difficulty hearing in a Noisy room				
Quiet room	No difficulty	Some difficulty	A lot of difficulty	Cannot do	Total
No difficulty	**11,812**	**2867**	**179**	**6**	14,864
Some difficulty	**123**	**714**	**338**	**11**	1186
A lot of difficulty	**1**	**11**	**107**	**22**	141
Cannot do	**0**	**0**	**0**	**25**	25
Total	11,936	3592	624	64	16,216

The two extended questions were chosen because they measure a gradient of hearing limitation. Table 7.2 shows a cross-classification of the two variables. Those with no difficulty in either situation (noisy or quiet room) are located in the upper left corner and those who are unable to hear in either situation are located in the lower right corner of the table. The task is to create a continuum of hearing difficulty from this cross-classification. Several iterations of cut-offs were tested to obtain the categorization.

Cross-classifying these two aspects of hearing difficulty allows for the creation of a gradient of hearing difficulty where those with *no difficulty* hearing in either a quiet or noisy room or *no difficulty* in a quiet room and *some difficulty* in a noisy room are allocated to the lowest level of hearing difficulty (the lightest shade of gray in Table 7.2). Similarly, those experiencing *no difficulty* hearing in a quiet room but *a lot of difficulty* in a noisy room, or *some difficulty* in a quiet room and *no difficulty* or *some difficulty* in a noisy room are allocated to higher level of difficulty on the gradient. Those experiencing *a lot of difficulty* in a quiet room and *no* or *some difficulty* in a noisy room, or *some difficulty* in a quiet room and *a lot of difficulty* in a noisy room or *no difficulty* in a quiet room and *cannot hear at all* in a noisy room are at the third difficulty level on the gradient. All other response combinations are determined to be in the highest or most severe gradient level of difficulty (the darkest shade of grey in Table 7.2).

In any data collection there will appear certain outliers or inconsistencies. These may be due to coding error, data entry error or response error. It is a challenge to the survey developer, through question design, to keep these errors to a minimum. Inconsistencies appear in Table 7.2: for example, those with *some* or *a lot of difficulty* hearing in a quiet room and *no difficulty* hearing in a noisy room (n = 124), or those with *a lot of difficulty* hearing in a quiet room and *some difficulty* hearing in a noisy room (n = 11). While there may be some reasonable explanation for these response patterns, none appears patently obvious. These 135 individuals (0.8 % of the population) were located within the hearing difficulty gradient based on primary consideration of difficulty hearing in a quiet room and secondarily, difficulty hearing in a noisy room.

Based on this assessment, an indicator of hearing difficulty going from lesser to more extreme difficulty hearing was derived and is presented in Table 7.3.

Recall that the WG SS question identified 1.7 % of the sample as having severe hearing difficulty (*a lot* or *cannot do at all*). Using the hearing gradient, 0.9 % were classified as most serious (class 4) and 3.0 % were in the two combined classes 3 and 4.

The determination of this 4-level shaded gradient was based on several attempts at combining responses, making cut-offs and comparing the resultant gradient with other measures of hearing difficulty, like the WG short set question. It is evident from the table below that while there are instances of inconsistency (those in the lower gradient levels who have *a lot of difficulty* hearing on the short set question or those in the higher gradient levels who report *no* or *some difficulty* on the short set question); the level of agreement between the WG short set question and the hearing gradient is also evident (Table 7.4).

The constructed Hearing Indicator variable correctly classifies all those who respond *cannot do at all* to the WG SS question as most severe (class 4). The majority of those who respond *no difficulty* to the WG SS set question (99.6 %) are classified as 1 or 2 on the hearing gradient. Only 0.3 % of those who respond *no difficulty* to the WG SS question (0.3 % of the sample) are inconsistent. Those who respond *some difficulty* to the WG SS question fall along the spectrum of the gradient and those who respond *a lot of difficulty* to the WG SS question are more likely (66.5 %) to have a higher (3 or 4) gradient than a lower (1 or 2) gradient (33.5 %).

Table 7.3 Hearing indicator

Hearing Indicator	Unweighted Frequency	Weighted Percent	Cumulative Percent
1.00 low difficulty	14,679	91.5	91.5
2.00	1016	5.5	97.0
3.00	356	2.1	99.1
4.00 high difficulty	165	0.9	100.0
Total	16,216	100.0	

Table 7.4 Amount of difficulty hearing (WG-SS) by hearing indicator

Unweighted Count Weighted Row %	**Hearing Indicator**				
Amount of difficulty hearing (SS)	**1.00**	**2.00**	**3.00**	**4.00**	Total
No difficulty	13,658	487	52	7	14,231
	96.5	3.1	0.3	0.0	100.0
Some difficulty	952	471	228	28	1679
	59.9	25.5	13.3	1.3	100.0
A lot of difficulty	35	56	75	105	271
	15.5	18.0	30.8	35.7	100.0
Cannot do at all/Unable to do	0	0	0	25	25
	0.0	0.0	0.0	100.0	100.0
Total	14,672	1014	355	165	16,206
	91.6	5.5	2.13	0.9	100.0

There can be several explanations for inconsistency between the WG short set question and the derived hearing indicator. Hearing difficulties include a range of problems that deal with some specific aspects of the hearing function: the perception of loudness and pitch, the discrimination of speech versus background noise, and the localization of sounds. Background noise is a detractor for hearing and this distraction becomes worse with increasing age and levels of hearing loss. Questions can be designed to capture these specific elements of hearing difficulties; however a generic set of parsimonious hearing questions will not be able to capture all aspects of hearing difficulty.

Pain

While most of the functional domains included in the WG extended set of questions fall discretely into a core domain of functioning or basic activity domain, such as physical, sensory, psychological or cognitive functioning; pain is not contained within a single domain. It represents a symptom of bodily functioning, rather than a basic activity domain, and can be related to any of the other domains of functioning.

Pain is a difficult symptom to measure. There is no readily available, valid biometric that measures or describes pain. It cannot be measured directly in a survey, but must be judged by the individual's responses to questions, which are subjective and influenced by a number of factors including sex, age, education, and other personal factors. It is also a product of culture and condition (Zola 1966). However, it is the subjective experience of pain, taking into consideration the availability and use of medication, that determines the consequences for the person – whether their pain experience impedes their ability to participate in social/life activities.

The complexity of the pain experience cannot be captured in a single question. In earlier rounds of testing, a number of pain dimensions were identified as potentially important indicators of pain, including asking respondents about the frequency, duration and intensity of their pain, as well as asking about the use of medication. The set of questions on pain included in the protocols that were tested in the 2009 WG/BI/UNESCAP cognitive and field testing were intended to capture all of these essential elements (pain frequency, intensity and duration plus use of medication). The intent was to combine these three aspects of pain to form a scale or summary measure of the experience of pain. Initial analyses provided evidence that two dimensions in particular (pain intensity and frequency) were unique and important qualifiers of people's pain experience. These two dimensions are analyzed below using the NHIS data.

Taking an approach similar to that used to analyze hearing difficulty; the extended questions on pain were first cross-tabulated, Table 7.5. Again, several iterations of cut-offs were tested to obtain the categorization.

Respondents who did not report pain in the past 3 months or who experienced pain *some days* of *little* intensity were placed in the lowest category of the pain gradient (lightest shade of grey in Table 7.5). Those who experienced *a lot* of pain *most days* or *every day* were placed in the highest category of the pain gradient (darkest shade of grey in Table 7.5). Two intermediate levels were also identified: those who reported *a little* pain *most days* or *every day*, and those who reported a moderate amount of pain intensity (*in between*) *some days* were located in the next to lowest category of the gradient; and those who reported a moderate amount of pain intensity (*in between*) *most days* or *every day*, or *a lot* of pain *some days* were located in the next to highest category of the gradient. (Note: those responding *never* to the pain frequency question were not asked the pain intensity question or the follow-up probe questions.)

The pain indicator shown in Table 7.5 is presented in Table 7.6. For pain, there was no single short set question to use for comparison. 7 % of the sample reported

Table 7.5 Frequency of pain in past 3 months by pain intensity (unweighted counts)

	Pain Frequency of pain in past 3 months				
Pain Intensity	Never	Some days	Most days	Every day	Total
not asked	**2631**	0	0	0	2631
a little	0	**1442**	**133**	**112**	1687
In between	0	**611**	**213**	**275**	1099
a lot	0	**220**	**139**	**314**	673
Total	2631	2273	485	701	6090

Table 7.6 Pain indicator

Pain Indicator	Unweighted Frequency	Weighted Percent	Cumulative Percent
1.00 low level	4073	66.4	66.4
2.00	856	15.2	81.6
3.00	708	11.5	93.1
4.00 high level	453	7.0	100.0
Total	6090	100.0	

Table 7.7 Pain indicator by pain follow-up probe questions (unweighted counts and weighted percents)

Unweighted Count Weighted Column %	**Pain Indicator**					
Pain Probe Questions	**1.00**	**2.00**	**3.00**	**4.00**	Total	p-value
1. Pain is constantly present	94	221	387	371	1073	
	6.8	27.6	55.5	83.5		<0.001
2. Sometimes pain is unbearable/	63	144	312	346	865	
excruciating	3.9	17.4	44.6	78.4		<0.001
3. When I get my mind on other things,	755	467	302	134	1658	
I am not aware of the pain	54.4	55.6	42.9	27.7		<0.001
4. Medication can take my pain away	733	379	237	117	1466	
completely	53.4	45.7	32.2	23.6		<0.001
5. My pain is because of work	259	146	112	65	582	
	18.9	19.0	16.3	15.0		n.s.
6. My pain is because of exercise	276	124	71	20	491	
	21.4	15.6	11.0	4.3		<0.001

more severe pain (class 4) and 18.5 % of the sample reported pain at the higher range of the gradient (classes 3 and 4 combined).

Results of the WG/BI/UNESCAP cognitive testing indicated several emergent themes related to respondent's pain experiences. These themes were developed into follow-up probe questions that were added to field tests – and the NHIS – in order to investigate themes in a larger random sample of the population. The seven questions are presented in Table 7.7. The follow-up probe analysis should not be interpreted as a validation of the findings. The probe questions do not represent a gold standard, and exact agreement between the probe questions and the pain gradient is not anticipated. The analyses of these questions allows for the interpretation of patterns of responses by a random sample of the population. Two of the follow-up probes reflect pain that is considered severe: pain that is constant or pain that is unbearable (the first two probes in Table 7.7). 83.5 % of those in class 4 (most severe pain) said their pain was constant. At the other end of the gradient, only 6.8 % of those in class 1 described their pain as constant. The finding that near 7 % report constant pain in this level does not necessarily indicate error. Recall that level 1 includes those with *a little* pain *some days*. It is not unrealistic that the pain on those occasions is also constant. The middle classes of pain (2 and 3) follow the gradient correspondingly (class 2/27.6 % and class 3/55.5 %).

A similar gradient was observed among those who describe their pain as, at times, unbearable or excruciating: 3.9 % among those in class 1; 17.4 % in class 2; 44.6 % in class 3; and 78.4 % among those in class 4.

Pain that is controlled by medication or pain that is not severe enough to be in the forefront of a person's awareness ("When I get my mind on other things, I am not aware of the pain" – probe #3 in Table 7.7) displays a different pattern. People at the higher gradients of pain describe pain that may be both less susceptible to medication (23.6 %) and less likely to be easily forgotten (27.7 %). At the other end of the gradient, where pain is less frequent and less intense, it is also more easily relieved through medication (53.4 % among those in class 1) and more easily overcome mentally (54.4 %). The middle gradients of pain (2 and 3) generally fall within the established pattern with decreasing prevalence as the pain gradient becomes more severe.

Pain associated with *work* or *exercise* was meant to investigate responses that were potentially out of scope of the questions' intent; that is, responses that were not intended as indicators of pain associated with disability, since this type of pain is often, though not always, self-induced. However, work-related injuries can result in pain that would be considered within the scope of the questions' intent and associated with disability. Very little variation was seen in the amount of pain associated with *work* across the pain gradient; and those who indicated *exercise*-related pain were more likely to place themselves at the lower end of the pain indicator; those at the higher end of the spectrum were unlikely to include this type of pain. Consequently, this analysis suggests that, while pain associated with *work* and *exercise* may impact some responses, the variation across the pain gradient is not as large as the other probe questions. Since pain related to work can be disabling, the nature of the relationship between this variable and the pain indicator is not straightforward.

Fatigue

Fatigue in the context of the WG extended set of questions is considered weariness or exhaustion that manifests itself physically, mentally, or through the senses – or any combination of those. Like pain, fatigue is a symptom rather than a basic activity domain (such as walking, listening, learning or remembering), but it can strongly influence those basic actions and can be a significant factor considered by the respondent as the relevant cause of the problems with basic actions. Fatigue becomes an important intervening factor in understanding difficulties in other domains of functioning. Of interest is to determine whether people's report of difficulties with fatigue is related to the impact of fatigue on other domains (e.g. difficulty walking or remembering and concentrating) or of only the fatigue itself is considered.

In the extended set of questions, three dimensions of fatigue were identified: frequency, intensity and duration. The cross-tabulation of these dimensions is depicted below.

Respondents who responded that they *never* felt tired in the past 3 months or who experienced fatigue *some days* of *little* intensity, lasting only *some of the day* were placed in the lowest category of the fatigue gradient (lightest shade of grey in Table 7.8). Those who responded that they felt tired *most days* or *every day* at high (*a lot*) intensity or moderate (*in between*) intensity *all of the day* were placed in the highest category of the fatigue gradient (darkest shade of grey in Table 7.8). Two intermediate levels were identified. Those who reported *a little* fatigue *every day* or *most days*, or *some days* that lasted *most* or *all of the day*, or those who reported a moderate level of tiredness (*in between*) lasting *some of the day* were located in the next to lowest category of the gradient. And those who reported a moderate level of tiredness (*in between*) lasting *most of the day*, or those whose level of tiredness occurred *some days* and was moderate (*in between*) lasting *most* or *all of the day* or those with a high level of tiredness (*a lot*) *some days* were located in the next to highest category of the gradient. (Note: those responding *never* to the fatigue frequency question were not asked the fatigue intensity or duration questions or the follow-up probe questions.)

Table 7.8 Frequency of fatigue in the past 3 months by fatigue intensity and duration (unweighted counts)

Level of tiredness (Intensity)	**How long it lasted (Duration)**	**How often felt very tired**				
		Never	Some days	Most days	Every day	Total
not asked	not asked	**2377**				2377
a little	Some of the day		**1448**	**67**	**30**	1545
	Most of the day		**109**	**21**	**5**	135
	All of the day		**16**	**5**	**3**	24
in between	Some of the day		**677**	**82**	**19**	778
	Most of the day		**183**	**75**	**19**	277
	All of the day		**63**	**20**	**16**	99
a lot	Some of the day		**247**	**49**	**29**	325
	Most of the day		**160**	**115**	**43**	318
	All of the day		**92**	**39**	**56**	187
total		2377	2995	473	220	6065

The fatigue indicator is presented in Table 7.9. The indicator shows that about 6 % of the sample reported more severe fatigue (class 4) and 20 % of the sample reported fatigue at the higher range of the gradient (classes 3 and 4 combined).

Four distinct themes emerged from the WG/BI/UNESCAP cognitive testing in Asia and the Pacific, and questions related to these themes were included in 2010 NHIS as follow-up probe questions. These probes were then used to assess the fatigue indicator.

The first two probes in Table 7.10 below capture the intent of the fatigue questions: fatigue that is due to a physical or health-related problem and fatigue that is stress-related. Almost 70 % of those in class 4 (most severe fatigue) said their fatigue is due to a physical or health-related problem. At the other end of the gradient, 18.3 % of those in class 1 described their fatigue as physical or health-related. The middle classes of fatigue (2 and 3) follow the gradient correspondingly (class 2/31.5 % and class 3/38.3 %).

A similar gradient was observed among those who describe their fatigue as stress-related (though the numbers here are small): 1.4 % among those in class 1; 4.1 % in class 2; 5.4 % in class 3; and 8.3 % among those in class 4.

Table 7.9 Fatigue indicator

Fatigue indicator	Unweighted Frequency	Weighted Percent	Cumulative Percent
1.00 low levels	3825	61.9	61.9
2.00	1034	18.0	79.9
3.00	839	14.2	94.1
4.00 high levels	367	5.8	100.0
Total	6065	100.0	

Table 7.10 Fatigue indicator by fatigue follow-up probe questions (unweighted counts and weighted percents)

Unweighted Count Weighted Column %	**Fatigue Indicator**					
Fatigue Probe Questions	**1.00**	**2.00**	**3.00**	**4.00**	Total	p-value
1. A physical or health-related problem	290	340	340	249	1219	
	18.3	31.5	38.3	69.3		<0.001
2. Fatigue results from stress	53	44	51	38	186	
	1.4	4.1	5.4	8.3		0.01
3. too much work or exercise	705	512	394	103	1714	
	49.8	51.1	50.2	29.8		<0.001
4. not getting enough sleep	686	603	532	200	2021	
	49.3	61.7	66.4	53.6		<0.001

The other two probe questions deal with fatigue that is associated with either *work or exercise* (probe 3) or *not getting enough sleep* (probe 4). Fatigue of these types, particularly that related to *work or exercise*, may be self-induced and not necessarily an indicator of disabling fatigue and thus outside the intended scope of the fatigue questions. Fatigue related to *not getting enough sleep*, on the other hand, may or may not be health-related. Unlike the previous two follow-up probe questions, less variation was seen in the pattern of fatigue associated with *work or exercise* and *not getting enough sleep* across the fatigue continuum. Those who reported fatigue at the highest category of the fatigue gradient were significantly less likely to identify *work or exercise* as the cause, while those who indicated fatigue related to *not getting enough sleep* more often located at the moderate levels of fatigue on the gradient (class 2 or class 3).

These two probe questions were asked to quantify the proportion of respondents who report fatigue of this type – responses that might be considered potentially 'out of scope' and false positive. Though the results were statistically significant, the gradient of fatigue was less obvious than with the other follow-up probe questions indicating that fatigue associated with *work or exercise* and *not getting enough sleep* is independent of the constructed fatigue indicator. Furthermore, those in the highest category of the fatigue gradient were less likely to identify *work or exercise* and *not getting enough sleep* as the cause of their fatigue.

As indicated in the matrix (Appendix 1) neither pain nor fatigue are basic activity domains but rather they refer to the outcomes of certain body functions (WHO – World Health Organization 2001) and may impact one or more domains of functioning. Alone, moderate or severe pain or fatigue may not be an indicator of a disability and we await the analysis of multiple domains (for example, the impact of pain or fatigue on mobility) in order to make that determination.

Affect (Anxiety and Depression)

The affect domain deals with aspects of depression and anxiety which are important as indicators of emotional disability. While depression and anxiety are not uncommon occurrences in most people's lives, the challenge for this domain was to find a way to capture emotional or psychological difficulties that go beyond what is considered "normal" or "common".

The WG short set of questions did not include this domain as it was not possible to measure anxiety or depression using a single question (a prerequisite for the short set questions). It should be noted, however, that while a direct question on affect was not included in the short set for this reason, affect may be captured through other short set questions. For example, the cognition question (difficulty remember or concentrating) will capture some aspects of affect. Also people who express difficulty with self-care (washing or dressing) may be reflecting on the psychological effects of anxiety or depression rather than physical upper body functioning.

Because of the survey design that included skip patterns for certain questions, a slightly different analytical approach is used to address the combined effects of multiple questions in the two affect domains. These are presented in the tables to follow.

Anxiety is addressed through measures of frequency (How often do you feel worried, nervous or anxious?) and intensity (Thinking about the last time you felt worried, nervous or anxious, how would you describe the level of these feelings?). In addition, medication is known to be a readily available accommodation that can reduce symptoms of anxiety and it was of interest to know whether or not individuals were taking medication for their symptoms.

The inclusion of the medication question raised an additional challenge to the analyses of this domain. Individuals who report lower levels of anxiety symptom frequency or intensity and who take medication for their symptoms may in fact be reporting the positive effects of medication. Based on the iterative analyses of various cut-offs, it was decided to include those who take medication and report low levels of anxiety intensity and/or frequency in the highest category of the anxiety gradient (see below).

Those who responded that they experienced *daily* or *weekly* anxiety excluding those whose intensity is *a little* and including all those who took medication for their anxiety were placed in the highest category of the anxiety gradient (darkest shade of grey in Table 7.11). Respondents who reported that they *never* felt anxious and did not take medication for feelings of anxiety were in the lowest category of the anxiety gradient (lightest shade of grey in Table 7.11). Two intermediate levels were identified. Those who reported feeling worried, nervous or anxious on a *monthly* basis but did not take medication for these feelings were located in the next

Table 7.11 Frequency of anxiety by anxiety intensity and use of medication (unweighted counts)

Take medication for these feelings	Level of feelings last time felt worried/ nervous/ anxious	How often feel worried/nervous/anxious					Total
		daily	weekly	monthly	A few times a year	never	
Yes	A little	45	57	34	36	16	188
	In between	66	80	34	34	4	218
	A lot	92	33	7	10	6	148
Sub-total		203	170	75	80	26	554
No	Not asked	0	0	0		2449	2449
	A little	134	281	373		0	788
	In between	103	191	138		0	432
	A lot	84	63	20		0	167
Sub-total		321	535	531	0	2449	3836
Total		524	705	606	80	2475	4390

Table 7.12 Anxiety indicator

Anxiety indicator	Unweighted Frequency	Weighted Percent	Cumulative Percent
1.00 low levels	2449	55.5	55.5
2.00	531	12.2	67.7
3.00	415	9.4	77.1
4.00 high levels	995	22.9	100.0
Total	4390	100.0	

to lowest category of the gradient. And those who reported anxiety feelings *daily* or *weekly* of *a little* intensity but also did not take medication for these feelings were located in the next to highest category of the gradient. (Note: those responding *never* to the anxiety frequency question were not asked the anxiety intensity question or the follow-up probe questions.)

The anxiety indicator, defined based on the distribution in Table 7.11, is presented in Table 7.12. The indicator shows that about 23 % of the sample reported more severe anxiety (class 4) and about 32 % of the sample reported anxiety at the higher range of the gradient (classes 3 and 4 combined).

A series of follow-up probe questions were added to the field tests and the NHIS to further elucidate patterns of interpretation that were uncovered during initial cognitive testing:

Which of the following statements, if any, describe your feelings of being worried, nervous, or anxious?

- Sometimes the feelings can be so intense that my chest hurts and I have trouble breathing.
- The feelings sometimes interfere with my life, and I wish that I did not have them.
- I have been told by a medical professional that I have anxiety.

In addition, psychological difficulty can also be measured using the K-6 serious psychological distress scale (Kessler et al. 2003). Each of the six questions that make up the K-6 has five response categories: (0) none of the time, (1) a little of the time, (2) some of the time, (3) most of the time, (4) all of the time. The K-6 has traditionally been analyzed as a dichotomy with scores (summation over the six items) of 13+ defined as serious psychological distress (SPD) and scores of 0–12 as without serious psychological distress.

Probe questions were only asked of persons who reported daily, weekly or monthly anxiety or who reported taking medication for anxiety. Results from the analysis of the follow-up probe questions and supplementary questions on the NHIS are presented in Table 7.13.

Table 7.13 Anxiety indicator by anxiety follow-up probe questions and supplementary NHIS questions (unweighted counts and weighted percents)

Unweighted Count Weighted Column %	Anxiety Gradient					
Anxiety Probe Questions	**1.00**	**2.00**	**3.00**	**4.00**	Total	p-value
1. Sometimes feelings so intense my chest hurts and have trouble breathing		28 6.2	33 6.8	218 21.1	279	<0.001
2. Feelings interfere with life		112 23.2	150 36.0	634 65.4	896	<0.001
3. Told by medical professional that I have anxiety		45 9.2	53 10.6	484 48.9	582	<0.001
Supplementary NHIS questions						
4. K6 Score: Serious Psychological Distress	18 0.5	13 1.8	18 3.3	176 16.7	225	<0.001
5. Unable to participate in social activities	40 1.3	10 1.0	9 1.8	82 7.4	141	<0.001

The first three rows in the table above include the follow-up probe questions that are indicative of some of the negative attributes of anxiety: breathing trouble, interfering with life and a medical diagnosis. For each of the probe questions under consideration, those who had more severe anxiety (class 4 according to the definition) were more likely to report trouble breathing, interference with life activities or a medical diagnosis.

Anxiety can also be associated with serious psychological distress as determined using the K6 scale. As illustrated in the table above, those falling in to the highest gradient of anxiety were more likely to have serious psychological distress (16.7 %) than those in lower gradients. Finally, those in class 4 were observed to be significantly more likely to be unable to participate in social activities. This inability may be due to the effects of anxiety but other causes cannot be excluded. It should again be noted that these additional questions are not designed as gold standards for the purpose of validating responses. They are also prone to error or interpretation. The intent of the follow-up survey questions is to quantify relationships and patterns of interpretation, not the degree of agreement between the anxiety indicator and the follow-up survey questions.

Depression is addressed through measures of frequency (How often do you feel depressed?) and intensity (Thinking about the last time you felt depressed, how depressed did you feel?). As with anxiety, in addition, medication is an available accommodation that can reduce symptoms of depression and it was of interest to know whether or not individuals were taking medication for their symptoms.

As with anxiety, the inclusion of the medication question raised an additional challenge to the analyses of this domain. Individuals who experience lower levels of depression frequency or intensity and who take medication for their symptoms may in fact be reporting the effects of medication. Based on the iterative analyses of various cut-offs, it was decided to include those who take medication and report low levels of depression intensity and/or frequency in the highest category of the depression gradient (see below).

Those who responded that they experienced *daily* or *weekly* feelings of depression excluding those whose intensity is *a little* and including all those who took medication for their depression were placed in the highest category of the depression gradient (darkest shade of grey in Table 7.14). Respondents who reported that they *never* felt depressed and did not take medication for feelings of depression were in the lowest category of the depression gradient (lightest shade of grey in Table 7.14). Two intermediate levels were identified. Those who reported feeling depressed on a *monthly* basis but did not take medication for these feelings were located in the next to lowest category of the gradient. And those who reported depressed feelings *daily* or *weekly* of *a little* intensity but also did not take medication for these feelings were located in the next to highest category of the gradient. (Note: those responding *never* to the depression frequency question were not asked the depression intensity question or the follow-up probe questions and are in the lowest category of the gradient.)

Table 7.14 Frequency of depression by depression intensity and use of medication (unweighted counts)

Take medication for depression	How depressed you felt last time you were depressed	How often feel depressed					Total
		daily	weekly	monthly	A few times a year	never	
Yes	A little	25	39	42	59	18	183
	In between	42	43	45	46	5	181
	A lot	84	34	12	22	6	158
Sub-total		151	116	99	127	29	522
No	Not asked	0	0	0		3506	3506
	A little	41	98	200		0	339
	In between	30	76	89		0	195
	A lot	49	43	38		0	130
Sub-total		120	217	327	0	3506	4170
Total		271	333	426	127	3535	4692

Table 7.15 Depression indicator

Depression indicator	Unweighted Frequency	Weighted Percent	Cumulative Percent
1.00 low levels	3506	75.4	75.4
2.00	327	7.2	82.6
3.00	139	2.5	85.1
4.00 high levels	720	14.8	100.0
Total	4692	100.0	

The derived depression indicator is presented in Table 7.15. According to the depression indicator below, about 15 % of the sample reported more severe depression (class 4) and about 18 % reported depression at the higher range of the gradient (classes 3 and 4 combined).

Also, a series of follow-up probe questions were added to further elucidate patterns of interpretation that were uncovered during initial cognitive testing:

Which of the following statements, if any, describe your feelings of being depressed?

- Sometimes the feelings can be so intense that I cannot get out of bed.
- The feelings sometimes interfere with my life, and I wish that I did not have them.
- I have been told by a medical professional that I have depression.

Probe questions were only asked of persons who reported daily, weekly or monthly depression or who reported taking medication for depression (Table 7.16).

The first three rows in the table above include the follow-up probe questions that are indicative of some of the negative attributes of depression: inability to get out of bed, interfering with life and a medical diagnosis. For each of the probe questions under consideration, those who had more severe depression (class 4 according to the definition) were more likely to report inability to get out of bed, interference with life activities or a medical diagnosis.

Depression, like anxiety, can also be associated with serious psychological distress as determined using the K6 scale. As illustrated in the table above, those falling in to the highest gradients of depression were more likely to have serious psychological distress (40.1 % in class 3 and 4 combined) than those in lower gradients. Finally, those in higher gradients of depression (class 3 and class 4) were observed to be significantly more likely to be unable to participate in social activities. This inability may be due to the effects of depression but other causes cannot be excluded. It should again be noted that these additional questions are not designed as gold standards for the purpose of validating responses. They are also prone to error or interpretation. The intent of the follow-up survey questions is to quantify

Table 7.16 Depression indicator by depression follow-up probe questions and supplementary NHIS questions (unweighted counts and weighted percents)

Unweighted Count Weighted Column %	**Depression Indicator**					
Depression Probe Questions	**1.00**	**2.00**	**3.00**	**4.00**	Total	p-value
1. Sometimes feelings so intense I can't get out of bed		28	14	185	227	
		7.2	12.0	26.6		<0.001
2. Feelings interfere with life		129	67	466	662	
		38.9	52.7	66.5		<0.001
3. Told by medical professional that I have depression		44	29	505	578	
		14.7	25.5	57.8		<0.001
Supplementary NHIS questions						
4. K6 Score: Serious Psychological Distress	24	16	21	155	216	
	0.6	5.3	20.6	19.5		<0.001
5. Unable to participate in social activities	48	7	15	66	136	
	1.1	2.2	11.7	7.9		<0.001

relationships and patterns of interpretation, not the degree of agreement between the depression indicator and the follow-up survey questions.

Conclusions

A single question on difficulty functioning may only yield a very broad indication of the problems a person experiences in that given domain of functioning. However, in some cases a single question can capture all, or most, of the information that is needed to define continuum of functioning in that domain. For example, the single vision question: *Do you have difficulty seeing even when wearing glasses?* is able to capture the full spectrum of visual difficulty encompassing both near and far vision problems. The addition of questions on difficulty seeing across a room or the print in a book or newspaper, while allowing for a breakdown of vision problems by near or far sightedness, would not add information to an overall continuum of vision difficulties.

The two hearing questions, on the other hand, allow for the establishment of a finer gradient of hearing difficulty from minor to severe providing more detail of the hearing experience than is possible with a single general hearing question. In addition, for those domains of functioning where a single question could not be developed (as required for the short set), multiple questions are necessary to describe the entire breadth of the problem (for example pain intensity and pain frequency). The challenge then becomes how best to combine those elements of the pain (or hearing, fatigue, affect) experience to develop a summary measure that describes the continuum of functioning in these domains.

The analyses that were undertaken to arrive at recommended ways to combine information from multiple domain questions are presented in this paper. There may be other ways of combining information from multiple questions, but for international comparisons and reporting, a uniform approach to both data collection – and analysis is demanded. The analytic strategy presented here for selected domains, based on a random sample of the US population, will form the foundation for a generalized approach to defining disability using the WG extended set of questions and pave the way for the reporting of comparable data internationally.

Disability measures obtained using the WG extended set of questions allows researchers to consider the full spectrum of functional limitations from mild to severe in greater detail. For example, people who report only *some difficulty* in one domain of functioning (basic activity or body function domain) could be included in analyses and reporting of disability depending on the purpose of the measure and the goal of the research. Public health specialists may be more interested in the people who have *some difficulty* as these would be important sectors of the population to monitor to ensure that these mild difficulties do not progress to levels that are more severe. Similarly, children identified with *some difficulty* seeing, for example, can be assessed for the need for corrective glasses which would remove the difficulty – leveling the playing field – and give them a better chance at completing their education and succeeding in life. Alternatively, a social protection program might consider only the more severe levels of difficulty as relevant for understanding the need for cash transfers as part of a social protection scheme.

Evidence has shown (Loeb 2013) that previous measures of disability that rely on a medical model approach and that reflect a simple dichotomy: Do you have a disability? With 'yes or no' response options result in very low rates of disability. The approach to measuring disability using the WG extended set of questions will produce higher prevalence rates that reflect a broader spectrum of functional difficulty, including those with mild or moderate limitations as well as those with the most severe difficulties and impairments across a wide range of functional domains.

Data collected using the extended set of disability questions provide the ability to address single domains of functioning – in particular with respect to specific groups of people with limitations in specific domains (special interest groups). In addition, for those domains that include information on assistive devices and technologies (walking, for example) it is possible to assess the impact of the environment on functioning – and to analyze aspects of both capacity and performance. Finally, in combination with the collection of data on allied variables, for example, employment, education, access to health care and other services etc., it becomes possible to assess the impact of functional limitations on different aspects of daily living and social participation. The inclusion of these questions in surveys will address issues pertinent to people with disabilities, such as the accessibility of the built environment, provision of rehabilitation services, and equal access to employment and education.

In addition, the data obtained using these measures provide other opportunities for ensuring that disability is visible and on the policy agenda in an integrated manner. For example, there are currently efforts underway nationally and internationally to mainstream disability data collection – to make disability status part of the routine collection of statistical information through censuses and survey in the same way that information on race and gender are collected. (World Report on Disability 2011) This would allow for the disaggregation of data by disability status thereby ensuring that differences in experiences of disabled versus non-disabled sectors of the population are assessed and better understood. The previous omission of disability status in the presentation of survey data and statistics has been the lack of adequate, comparable measures of disability that can be used to determine disability status and whether those with disability are fully participating in society. The WG short and extended sets of questions provide such measures.

The definition and measurement of functional status or disability in a population will, coupled with the collection of other allied information on, for example employment, education, access to health care and other services and social participation, pave the way for assessments of the equalization of opportunities as specified in the UN Convention on the Rights of Persons with Disability (UN – United Nations Enable 2006) and the Millennium Development Goals (see: http://www.un.org/millenniumgoals/) (UN – United Nations 2002). The list of allied parameters variables above is not exhaustive; and, depending on availability and the specific requirements and goals of the survey in question, more survey data items can be included that would further highlight disparities in these and other areas of participation between those with and those without disability.

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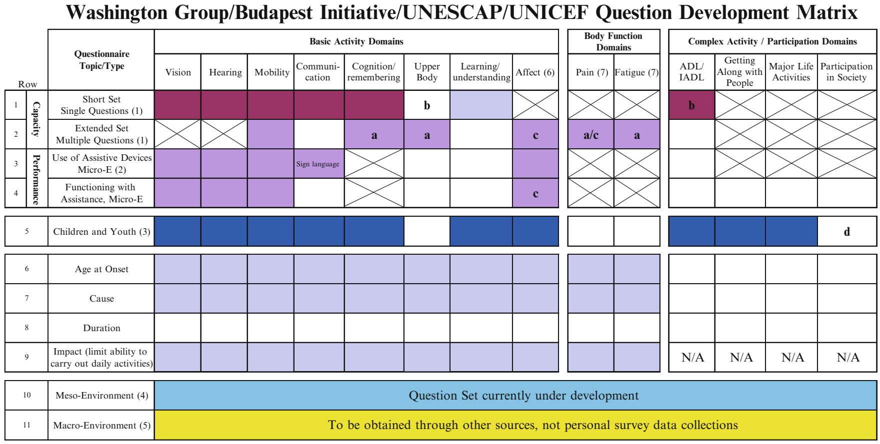
Appendix 1: Matrix

Washington Group/Budapest Initiative/UNESCAP/UNICEF Question Development Matrix



Washington Group/Budapest Initiative/UNESCAP/UNICEF Question Development Matrix

Row		Questionnaire Topic/Type	Basic Activity Domains								Body Function Domains		Complex Activity / Participation Domains			
			Vision	Hearing	Mobility	Communi-cation	Cognition/ remembering	Upper Body	Learning/ understanding	Affect (6)	Pain (7)	Fatigue (7)	ADL/ IADL	Getting Along with People	Major Life Activities	Participation in Society
1	Capacity	Short Set Single Questions (1)	🟥	🟥	🟥	🟥	🟥	b	▨	☒	☒	☒	🟥 b	☒	☒	☒
2		Extended Set Multiple Questions (1)	☒	☒	🟪		🟪 a	🟪 a		🟪 c	🟪 a/c	🟪 a		☒	☒	☒
3	Performance	Use of Assistive Devices Micro-E (2)	🟪	🟪	🟪	🟪 Sign language	☒			🟪	☒	☒		☒	☒	☒
4		Functioning with Assistance, Micro-E	🟪	🟪	🟪		☒			🟪 c	☒	☒				
5		Children and Youth (3)	🟦	🟦	🟦	🟦	🟦		🟦	🟦			🟦	🟦	🟦	d
6		Age at Onset	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨				
7		Cause	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨				
8		Duration														
9		Impact (limit ability to carry out daily activities)	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	N/A	N/A	N/A	N/A
10		Meso-Environment (4)	Question Set currently under development													
11		Macro-Environment (5)	To be obtained through other sources, not personal survey data collections													

SEVERITY is captured in response categories: no difficulty; some difficulty; a lot of difficulty; cannot do it at all

Matrix NOTES:

(1) Measurement is WITHOUT the use of assistive devices or other help WITH THE EXCEPTION OF VISION (glasses/lenses) and HEARING (hearing aids). These are both measured WITH the use of assistive devices and thus do NOT represent true measures of Capacity. Extended Set multiple questions are captured under Performance (Row 4).

(2) Micro environment - technical and personal assistance that follows the person wherever they go (e.g. wheelchair, eye glasses, personal attendant).

(3) Module on Child Functioning and Disability developed as a WG/UNICEF collaboration

(4) Meso environment - the environment beyond the person (e.g. transportation infrastructure, accessibility, service provision at local level, attitudes of others). Meso environmental questions may also be non-domain specific.

(5) Macro environment - that which affects a whole country, such as policies and legislation, general societal attitudes and practices. Macro-environmental questions are NOT domain specific.

(6) Affect includes aspects of psychological functioning: anxiety and depression

(7) Pain and Fatigue are not functional domains (nor are they included in the ICF as such) however they are included here as domains that impact functioning.

🟥 Short set questions

🟪 Extended set questions

▨ Tested in WG/ESCAP project but not adopted

🟦 WG/UNICEF Module on Child Functioning and Disability currently being tested

a No questions on functioning with/without assistive devices

b Upper body short set question is the ADL short set question

c Respondents are instructed to answer according to whatever medication they are taking.

d Under development

ADL (Activities of Daily Living): e.g. walking inside the home, standing from a chair, getting into and out of bed, eating, and dressing.

IADL (Instrumental Activities of Daily Living): e.g. doing chores around the house, preparing meals, and managing money.

Getting along with people: involves interpersonal interactions and relationships (socializing and interacting with others) and includes dealing with family, friends, persons in authority.

Major Life Activities: includes working inside or outside the home to earn an income and support the family or going to school and achieving educational goals.

Participation in Society: includes joining in community/family gatherings, religious/civic activities and leisure/social/sports events.

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Chapter 8
The Asian Testing Experience

Marguerite Schneider and Andres Montes

Introduction

Earlier chapters in this book described the processes of developing measures for disability and why this is important for internationally comparable measurement of disability. This chapter reports on an example of a question evaluation and testing process undertaken jointly by the Washington Group (WG) and the United Nations Economic and Social Commission of the Asia and the Pacific (ESCAP).[1] The chapter focuses on the process undertaken in collaboration with six countries from the region as well as the impact of the collection of disability data as part of the global effort of the WG. The focus is not on the test results as these are reported in other chapters.[2]

This chapter describes and evaluates the process of engagement with six countries in the Asia-Pacific region by the WG in collaboration with ESCAP. This is not an official report from ESCAP but rather a reflection on a process of a partnership between the WG, ESCAP and six ESCAP member countries with outcomes that met expectations of all partners. The WG/ESCAP collaboration arose out of the

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[1] This endeavor was undertaken under the financing of the UN Development Account project ‘Improvement of Disability Measurement and Statistics in Support of Biwako Millennium Framework and Regional Census Programme’ to be referred to as the WG/ESCAP project in the remainder of the chapter.

[2] Further information can also be found at www.unescap.org/stat/disability/Results-Testing-ESCAP-WG-Question-Disability.pdf

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broader aim of ESCAP to improve the collection of disability statistics in the region by working with six member countries and the WG's aim to develop internationally comparable measures of disability. The synergy between these two aims consolidated the programme of work and increased skills and knowledge of the six participating countries.

In summary, the WG/ESCAP project aimed to: (a) raise awareness through regional and in-country workshops; (b) develop standards for cognitive and field testing of questions, and analyses; (c) improve national capacity; and (d) improve knowledge management.

The key activities used to achieve these include regional workshops on census data collection, developing a standard survey question set for cognitive and field testing in six countries, joint result analysis and formulation of recommendations, strengthening in-country advocacy and advisory services, and knowledge management tools, such as dissemination of the project findings at meetings and on the project website, producing a training manual for cognitive and field testing, and developing a regional network of experts.

The Process of Engagement

The process of engagement started with an agreement between the WG and ESCAP as to the purpose and aim of the partnership and project. This was followed by a meeting of 25 ESCAP member countries out of which six participating countries were selected. These six countries were taken through a process of training on cognitive testing, support while they ran their own cognitive interviews and field testing. The cognitive and field testing of the WG Extended Set was followed by a report back to a larger group of ESCAP member countries. The process also included a second round of cognitive testing and analysis, participation by the six countries in the WG annual meetings and initiating a network of disability statistics experts from the participating countries for other ESCAP countries.

Each step in this process is described individually.

Developing the Partnership

ESCAP has undertaken a set of projects to improve disability statistics in the Asia-Pacific region. The first project (2004–2006) focused on improving disability statistics and was primarily a partnership between ESCAP and the World Health Organization (WHO). The WG/ESCAP project, described in this chapter, spanned over 3 years between 2008 and 2010. While both phases of the overall ESCAP project aimed to improve the collection of disability data in the Asia-Pacific region, they differed in that the first phase focused on understanding the framework for collecting disability statistics as set out in the International Classification of Functioning, Disability and Health or the ICF (WHO 2001). The second phase focused on testing survey questions to ensure that the questions are valid measures of disability. Specifically, the second phase or the WG/ESCAP project, undertook cognitive and field testing of the WG's Extended Set questions through training of ESCAP member countries in these techniques.

Discussions were held between the WG secretariat and ESCAP to determine the feasibility of achieving two goals with a single project: improving knowledge and skills of ESCAP member countries in understanding and collecting disability statistics and testing the WG's Extended Set of questions for measuring disability in surveys.

The WG workgroup on extended sets had reached a point in the development of the extended set where these questions required testing. Given the successful international effort on testing of the short set of questions between 2004 and 2006 (Miller et al. 2010), the WG embarked on an effort to test the Extended Set again across a number of countries.

At the same time, ESCAP was looking to continue earlier efforts to improve disability statistics in the ESCAP region. Given the ongoing participation of ESCAP representatives at the WG annual meetings, it was decided to apply for funding to undertake the cognitive and field testing of the WG Extended Set by synergising the needs of the WG for a means to test the extended set and of ESCAP by working with a selected group of countries to build skills and knowledge in disability measurement for statistics.

This synergy resulted in a funded proposal entitled Development Account Project Improvement of Disability Measurement and Statistics in Support of the Biwako Millenium Framework and Regional census Programme. The aim of the project was to further promote better disability data collection by developing standard measurement tools and improving national technical capacity. The project took into account country needs in the region while contributing to the ongoing global initiatives on disability statistics through the work of the WG. This synergy of need created a particularly conducive context for a successful project yielding good testing data for the WG Extended Set and building a network of experts in the field of disability measurement for statistics within National statistical offices.

The WG/ESCAP Project (2008–2010)

The focus of the project was on designing standard question sets for self-report surveys as population measures of disability. The objective of the project was to train participating country representatives to conduct cognitive and pilot testing and analyses of the WG extended set. The results of the cognitive and field testing could thus contribute to an empirical basis for establishing standard survey measurement for disability data collection.

The WG/ESCAP project process comprised two regional workshops, three training and analysis workshops for the six participating countries, individual country visits by consultants and ESCAP staff, a project evaluation, individual country reports, a final overall report on the findings across the six countries, and guidelines for cognitive and pilot testing of disability survey questions. In addition to these project related activities, the participating countries were able to attend a number of the WG annual meetings where they were involved in presenting their findings from the project.

In summary, the strategy of the WG/ESCAP project was to involve many countries at a regional level to start the process, work closely with a few selected countries to develop indepth skills in disability measurement and statistics, reviewing this process with a larger group of countries in a second regional workshop, and establishing a network of experts within the region to provide south-south support for other interested countries.

Regional Workshops

Regional Workshop on Promoting Disability Data Collection Through the 2010 Population and Housing Censuses: 8–10 April 2008 in Bangkok

This workshop was held at the ESCAP headquarters in Bangkok from 8 to 10 April 2008 and was attended by 55 participants from 25 countries representing data producers (more than half were from NSOs), data users (e.g. Ministries of Health), and representatives of persons with disabilities (e.g. non-government and disability organisations).

The focus of the workshop was an effort to build a common understanding of the gaps between what was needed and what was available, and served as an introduction to the second round of work to be carried out as the WG/ESCAP project. Participants were given a survey to complete prior to the workshop in order to identify key areas of focus for the project. The questions asked are presented in Box 8.1.

Box 8.1: Pre-workshop Survey for Participating Countries

1. How relevant is this workshop to the current agenda of national statistical programme in your country?
2. How relevant is this workshop to your professional work?
3. How much do you think this workshop will help increase the technical capacity of your organization for developing disability statistics?
4. How timely is this workshop for the planning of the next population census in your country?
5. How familiar are you with:

    - The Biwako Millennium Framework (BMF)
    - The application of International Classification of Functioning, Disability and Health (ICF) for disability data collection
    - The disability component of the United Nations Principles and Recommendations for Population and Housing Censuses (*Rev. 2*)

(continued)

Box 8.1 (continued)

6. Which topic(s) of the workshop programme do you find most relevant? Please select as many as applicable.
   - User-producer dialogue
   - Introduction of the ICF-based approach
   - Introduction of the global recommendations for census data collection on disability
   - Targeted training on implementing the global recommendations
   - Training on communication skills for advocacy
   - Discussion on advocacy for better disability statistics
   - Discussion on national needs for support
7. What do you expect to gain most from this workshop?

Of the 34 participants who responded to the pre-workshop questionnaire, almost all indicated that the workshop was very relevant or relevant for their current needs at country level and addressed the process of improving the accuracy of disability statistics collected in the region. A number of countries indicated that they were already collecting data using the ICF framework but wanted more training and information on how to develop survey questions.

In the post workshop evaluation, participants reported that the workshop had successfully created awareness of the importance of the ICF-based approach to disability data collection and provided practical training on the implementation of the global census recommendations on disability. The workshop served to introduce the project to a large group of countries and identified some specific country needs for support in both census and survey-based disability data collection. It also allowed for the selection of six countries to participate in the next phases of the project. These six countries were Cambodia, Mongolia, Sri Lanka, Maldives, Philippines and Kazakhstan. Kazakhstan participated as a member of both ESCAP and the UN's Economic Commission for Europe (ECE), and allowed for collaboration to be developed between ESCAP and ECE on the measurement of disability statistics.

While reported as being useful by the large group of participants, this regional workshop remained primarily a theoretical exercise without much practical training in the application of the theory. In order to ensure development of a panel of experts, the WG/ESCAP project focused on a small group of six participating countries. These countries were selected based on their interest, ability to take on the tasks and availability for the project duration. These six countries were Cambodia, Mongolia, Sri Lanka, Maldives, Philippines and Kazakhstan. Kazakhstan participated as a member of both ESCAP and the UN's Economic Commission for Europe (ECE), and allowed for collaboration to be developed between ESCAP and ECE on the measurement of disability statistics.

The regional workshop provided an important starting point and context for the overall project. This was followed by a series of smaller workshops with the six participating countries which are described later. Before we describe these, we discuss the second regional workshop and its purpose and role within the overall project.

Count Us In: Towards Better Disability Measurement and Statistics in Asia and the Pacific: 8–10 December 2009 in Bangkok

A second regional workshop was held after the six participating countries had attended a training workshop and had undertaken cognitive and pilot testing within their own countries.

This second regional workshop aimed at feeding back the results and experiences of the six participating countries to a broader group of regional countries to ensure that lessons learnt were shared beyond the six participating countries. Specifically, the objectives of the workshop were to

(i) increase participants' knowledge on the implementation of cognitive and pilot tests for questionnaire design, by disseminating the results of the cognitive and pilot tests of the WG/ESCAP extended question set to measure disability through surveys and
(ii) further advocate WHO's ICF-based approach for disability data collection through training on census and survey data collection.

Twenty countries participated and preliminary findings from both the cognitive and pilot testing were presented for each of the 10 domains included in the testing process. The questions tested were the draft of the WG's Extended Set of questions and the findings of the testing process provided invaluable data for finalising this Extended Set of questions. Further data were provided by additional testing undertaken by the Budapest Initiative and the Granada Group discussed in Chap. 7 of this volume.

The benefits of this workshop was, firstly, that it presented to the larger group the outcome of the practical application of the theory presented in the first regional workshop. Secondly, the six participating countries were integrally involved in doing presentations at the workshop. They prepared presentations on their experiences in doing the cognitive and field testing and shared some of their own results. The WG and ESCAP training team presented overall results for the six countries.

The process of preparing their presentations ensured that the six country participants reflected on their experiences and through that consolidated their learning from the cognitive and field testing. This consolidation was further developed through other activities, such as participation in the annual WG meetings, as discussed later in this chapter.

Training Workshops on Cognitive and Pilot Testing

From the responses in the 2008 regional workshop and the subsequent interest shown by countries, a smaller workgroup consisting of the six selected countries was constituted to undergo training in cognitive and pilot testing and implement this in their own countries. The purpose was twofold, as stated earlier: to develop expertise within the ESCAP country statistical offices and to provide information on the testing of the WG Extended Set questions.

This section describes the process of training which focused on ongoing and regular contact and training, revision of work, practical exercises and building on the growing skills of the participants.

Three workshops were held with this smaller workgroup: (a) the initial training in February 2009; (b) analysis of cognitive testing interviews in July 2010; and (c) Expert Group Meeting on the Analysis of the Second Round of Cognitive Testing on Disability in February 2011.

Training on Cognitive and Pilot Testing: 16–20 February 2009

The six countries (Cambodia, Mongolia, Sri Lanka, Maldives, Philippines and Kazakhstan) each sent two representatives from their statistical offices to be trained on how to do cognitive and pilot testing of survey questions and specifically for disability statistics.

The workshop focused primarily on training in the purpose of cognitive testing interviews and how to conduct and analyse these. Given the newness of this skill for the participants, the focus was more on why and how to do this question evaluation process, than on how to analyse the results. The workshop was structured around input by key experts from the National Center for Health Statistics (NCHS) in the USA, Kristen Miller and Stephanie Willson, followed by practical sessions of doing the interviews.

Other key ESCAP staff and project consultants (Andres Montes, Ken Black and Marguerite Schneider) provided ongoing support during the training. These members of the team also provided input on the pilot testing component, which was a more familiar skill for the participants, and hence required less input.

The workshop concluded with a completed cognitive testing interview schedule, a process to follow in recruiting the 20 required interviewees in each country, instructions on how to enter the interview narratives translated into English onto the specially developed NCHS database – Q notes, and the process for preparing the pilot testing to be carried out after the revision of the Extended Set based on the analysis of the cognitive testing interviews.

In addition to the 20 interviews from each of the six participating countries, a number of interviews were completed in the USA, Canada, Australia and South Africa. In total around 150 interviews were collected and analysed. The contribution of the ESCAP countries was substantial not only in the numbers of interviews, but also in providing feedback from a context quite different to the USA, Canada, South Africa and Australia.

The process further highlighted the newness of this technique in that the six countries struggled to provide detailed narratives on the interviews and reported finding it quite a difficult task. Nevertheless, the feedback from countries was that they had gained an important understanding of the importance of doing cognitive testing and were keen to develop this skill further not only in the area of disability statistics but for all new survey questions in any topic area. This was achieved through their practical exercise in doing the interviews themselves. The pairing of two people from each country allowed them to observe and support each other while doing the interviews. This was a more immediate source of support compared to communication via email with WG and ESCAP staff.

The analysis of the cognitive interviews took place at the NCHS in May 2009. Unfortunately the country representatives were not able to attend due to lack of project funds for this, but also because of the short time available to get the revisions done based on the analysis, before starting the field testing. The two ESCAP consultants and staff member were able to join the WG team and contribute to the analysis. These findings are reported in the project report and are further described in various chapters of this volume.

The revisions based on the cognitive testing analysis were incorporated into the pilot testing instrument to be administered by the six participating countries. This is described in the section below on country visits for training and support in doing the pilot testing.

As the countries were not part of the initial analysis of the cognitive interviews a process was undertaken to ensure that they became competent in doing this. The country visits afforded an initial opportunity to explain the analysis process, but it was decided that further training was required. This led to the second small work-group training workshop.

Workshop on the Analysis of Cognitive Testing Interviews: 6–8 July 2010

The second training workshop focused entirely on the analysis of cognitive testing interviews to develop a better skills set among the representatives of the participating countries. This was to consolidate their skills and ensure that they would be able to apply the technique beyond disability statistics and be able to train other colleagues in this technique. The need for the workshop arose out of a request from countries for further training. They had clearly understood the importance of the doing cognitive testing but expressed limited confidence in applying the technique fully in their own country contexts. This workshop was held after the second regional workshop.

The workshop included plenary input with much small group work supported by the ESCAP and WG project team. This ensured that countries developed a consolidated set of skills. The interest was evident in that the countries discussed the possibility of doing a second round of cognitive interviews, albeit on a smaller set of questions, to both consolidate their skills and provide further cognitive testing data on the questions that had not been effectively tested in the first round. This process was developed and arranged to conclude with a further analysis workshop in February 2011.

The workshop also included the overall evaluation of the WG/ESCAP project by an external evaluator, who took the opportunity of having the participating countries available for face to face interviews and discussions.

Expert Group Meeting on the Analysis of the Second Round of Cognitive Testing on Disability: 1–3 February 2011

The specific objectives of the workshop were to: (i) discuss the results of the second round of cognitive testing of a question set on disability, in particular on the domains of communication, hearing, affect, pain and fatigue; (ii) further train senior statisticians from Asia-Pacific on the skills required to undertake the analysis of cognitive interviews; and (iii) discuss future areas of work on disability data collection and measurement.

The meeting was attended by representatives from Cambodia, Maldives, Mongolia, the Philippines and Sri Lanka, and resource persons from the National Center for Health Statistics (NCHS) of the United States. Sessions evolved around the analysis of the cognitive test using the web-based software Q-Notes which has been developed by the NCHS for this purpose. The focus was on actively doing the analysis with minimal structured input. Participants followed a three-step approach while discussing the results: (i) within interview analysis, to address basic response errors; (ii) across interview analysis, to observe patterns of interpretation and processes on what questions capture based on interviewees' responses; and (iii) across sub-group analysis, to address potential bias for different group categories. The meeting concluded with a final recommendation on questions to be used in an extended set for surveys.

As a follow-up to ESCAP and the WG's efforts to develop question sets to measure disability, participants underlined the importance of further in-country advocacy to familiarize government ministries/agencies, disabled persons organizations and policy-makers in the use of the WHO's ICF (WHO, 2001) approach to measuring disability.

Country representatives also suggested taking a more strategic approach by including the WG short and extended questions sets as separate modules in their household and labor force surveys as well as in censuses, such as Maldives did in their 2009 Demographic and Health Survey, the Philippines in its 2010 Census and Sri Lanka in its 2011 Census. ESCAP and the WG agreed to support countries in these efforts and to provide them with a framework to analyze and disseminate data obtained through this novel approach.

In Country Training and Support for Pilot Testing: June–September 2009

The second phase of testing of the WG Extended Set of questions was a pilot test in each of the six participating countries. This process was planned using a randomly selected sample of 1000 respondents in each country. The area to be selected was based on the usual stratification methods of the national statistical offices, and typically included at least two types of areas, such as urban and rural. Sri Lanka, for example, selected three strata – urban, rural and tea plantations, and the Maldives selected the main town, Malé, and one island.

In order to prepare for this pilot testing, the two ESCAP consultants, Marguerite Schneider and Ken Black, visited each country for one week, with Andres Montes of ESCAP joining in two of these country visits. The purpose of the country visit was to provide technical support on the cognitive interview analysis and sampling, assisting in training of fieldworkers collecting the field test data, and providing support in discussions with key government officials to develop a better understanding of the need for disability statistics.

The country visits took place as set out below, each consultant visiting three countries and the ESCAP staff member overseeing the project, Andres Montes, taking part in two of the visits (Sri Lanka and Mongolia).

- Sri Lanka: 29 June–3 July 2009
- Maldives: 6–10 July 2009
- Mongolia: 6–10 July 2009
- Cambodia: 3–7 August 2009
- Philippines: 10–14 August 2009
- Kazakhstan: 31 August–4 September 2009

These face to face visits were invaluable in consolidating the knowledge of the country participants, getting a good sense of the realities on the ground, and fostering contacts with government officials within each country. An example of the importance of understanding local conditions is in the responses given to the question on walking and climbing stairs. In the Maldives few of the islands are more than 2 m about sea level and most dwellings are single story making it difficult for people to respond to the question about climbing a flight of stairs. In contrast in Almaty in Kazakhstan, most people live in high rise blocks of flats which often do not have elevators requiring people to climb many flights of stairs on a regular basis. These different contexts influence the way respondents interpret and respond to the questions.

These country visits provided a welcome source of individualised support, while also allowing the consultants to assess particular concerns of individual countries. In the first couple of countries visited, the training allowed the final ‘errors’ in the pilot testing instrument to be ironed out and finalised.

Participation in the WG Annual Meetings (Expand on This)

The participating countries were encouraged and funded to attend the 8th WG meeting held in Manila, Philippines in 2008, the 9th WG meeting in Dar-es-Salaam, Tanzania in 2009, and the 10th WG meeting in Luxembourg in 2010. The results of the WG/ESCAP cognitive and pilot testing were presented at each of these meetings by both the country representatives and the other members of the project team.

The 2008 Manila meeting was organised by one of the participating countries, and representatives from each of the other five countries attended the meeting. This meeting was at the start of the WG/ESCAP project and provided an introduction to the extended set of questions.

By the 9th meeting in Dar-es-Salaam in 2009, the training and data collection for the cognitive and field testing were completed for the project, but only the analysis of the cognitive testing interviews were available. The project countries were each given presentations to prepare and deliver at the meeting. Each country was allocated one domain and they presented the results from their own country for that domain. The WG/ESCAP project team presented an overview of the combined results. One country representative also presented an overview of their experiences in doing the cognitive and field testing.

The field testing results were available for the 10th WG meeting in 2010, and two country representatives were asked again to prepare and deliver the overall results of the cognitive and field testing for the hearing and vision domains. They were also involved in chairing of some of the sessions.

Participation in the WG meetings ensured that the country participants engaged in discussions at an international level, developed their skills of analysis and preparing presentations, and started building networks with other statistical offices beyond the ESCAP region. For the WG, this participation ensured that more countries became involved in the work of the WG and developed further resources for a growing network of experts in disability measurement.

Outcomes of Project

The outcome of the WG/ESCAP project was significant on a number of levels for ESCAP, the WG and the participating countries.

Outcomes for the WG

The project afforded an opportunity to learn and improve methods for question evaluation, and highlight the benefits of implementing a coordinated testing process. Beyond the achievement of the project objectives as set out at the start of this chapter, the project allowed for other issues to be raised and documented. These included: (a) translation issues and the importance of taking into account local context when interpreting findings, as illustrated by the climbing steps question responses in the Maldives and Khazakstan; (b) the importance of the interviewer training in ensuring the collection of quality data especially in the field of disability where the use of negative terminology can significantly affect how questions are answered; (c) the benefits of conducting the analysis in a consistent and standard manner across different sites, and documenting these analyses consistently, as was done for the six countries.

Most importantly for the WG, the project generated extensive validation data for the WG's extended set questions.

Outcomes for ESCAP

The primary objectives of the project for ESCAP were raising awareness, developing standards, increasing capacity in disability measurement and knowledge management.

Raising of awareness was achieved through the regional and in-country workshops and these activities were largely successful as evidenced by the request for further training by the six participating countries, and gradual increasing use of the WG questions for censuses and surveys in the region.

Development of standards was achieved through the different workshops, cognitive and field testing exercises and analyses that looked at both single country and global analyses of the data. The detailed and ongoing training of the six country representatives ensured that they were able to apply a standard approach to cognitive and field testing and analysis. This learning was set out in the Guidelines for Cognitive and Field Testing available on the ESCAP website.[3]

The improvement of national capacity was achieved through the regional and small group workshops and in-country visits by the project consultants. This is evidenced through the individual country reports drafted by the six countries that included their country specific analyses together with the pooled analysis of the cognitive and field testing data for regional and global analyses. In addition, training through the Statistics Institute for Asia and the Pacific (SIAP) provided opportunities for more countries to be trained.

Knowledge management was achieved through dissemination of the experiences during and findings of the project at the two ESCAP regional workshops and at the annual WG meetings. In addition, a report of the findings was prepared and made available on the ESCAP Disability website[4] together with the Guidelines for Cognitive and Field Testing. A regional network of experts is slowly being assembled allowing for strong South-South collaboration and the availability of regional experts.

Outcomes for Countries

The close engagement with the six participating countries allowed for easy exchanges between the six countries and the ESCAP and WG staff. The collegial relationships developed over the repeated workshops, country visits and ongoing email contact coupled with the strong interest and commitment of the six countries allowed for the goals of the project to be effectively achieved. The countries concluded the project with knowledge, experience and a report to use in advocating for accurate and regular disability data collection.

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[3] See http://www.unescap.org/stat/disability/Disability-question-testing-guidelines.pdf

[4] See http://www.unescap.org/stat/disability

Conclusions

The WG/ESCAP project aimed to train people from statistical offices in the region on question performance evaluation and use of disability measures and statistics. This project was successful in providing staff from the six participating countries with a good grounding in methodological issues for survey measurement of disability. This included cognitive testing approaches and pilot testing of questions.

In addition, participating countries were integrally involved in the analysis and write up of the results. Staff from project countries expressed the importance of having acquired these skills and being able to apply them in all areas of their work, beyond disability measurement. Given this positive outcome of the project, these guidelines aim to provide a way to increase the number of people who can benefit from the project.

While the project objectives were achieved, this achievement fell short of influencing policy within countries. However, this is not an unexpected outcome as this will take more time to be achieved. The primary achievement of the project was to develop the skills and knowledge which will lead to better data collection and ultimately improved evidence based policy development in the region.

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Chapter 9
The Challenges of Conducting National Surveys of Disability Among Children

Howard Meltzer

The Demand for Statistics on Child Disability

There is an increasing recognition that there is a need to produce disability statistics on children across the world. On 6 December 2006, the United Nations General Assembly published the final report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities (United Nations General Assembly 2006). Several Articles or sections of Articles in this convention are dedicated to children, as well as the collection of disability statistics.

Article 7, entitled, *Children with Disabilities,* states that “Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.” Article 31 which has the heading, *Statistics and data collection,* states that “Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention”. In order to monitor the implementation of the convention it is necessary to have administrative or survey data which permit the examination of trends.

The desire to integrate disabled schoolchildren and students into main stream education has been taken on board by many governments. OECD (1999) stated that the rights of students with disabilities to be educated in their local mainstream school is becoming more and more accepted in most countries and many reforms are being put in place to achieve this goal. They go on to state there is no reason to segregate disabled students in public education systems. Instead education systems

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Author was deceased at the time of publication.

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need to be reconsidered to meet the needs of all students. However, in order to quantify this progress it is necessary to have statistics on disabled children – not just how many disabled children there are in each country but how many of them are attending school and among these, how many are integrated into mainstream education.

UNICEF (2001) estimates that there are 120 million disabled children in the world. Others place the estimate nearer 150 million (Roeher Institute 2000). The U.N. Special report on Children (2001) estimates that in developing countries approximately half the children become disabled in the first 15 years of life.

The report on the lives of disabled children for the U.N. General Assembly Special Session on Children (2001) also referred to the lack of disability data on children. It highlighted the difficulty in gathering accurate data on the incidence of disability among children and referred to the fact that – countries have used different definitions of both impairment and disability, the quality of statistical data varies widely and too little research has been done on the lives of disabled children.

Why are national surveys on disabled children so important? Just knowing the nature and extent of disability is important from a consciousness awareness perspective – getting it on the political agenda. Obtaining data on children from a very young age is crucial in ensuring the creation or expansion of early year services and that families are supported as early as possible. Having information on school-aged children can act as an incentive to promote their equality of opportunity and improve their access to and services in schools. For older disabled children, about to leave school, the transition to adulthood is a very important stage in their lives and information on barriers on their entry to the labour market is essential so that children can be facilitated to make a positive contribution and achieve economic well-being. For all disabled children, surveys can highlight the burden that society puts on them and the negative attitudes that they may face, primarily social exclusion and discrimination.

Whereas there has been several initiatives focusing on measuring disability and collecting statistics among the adult population (Washington Group on Disability Statistics, European Health and Social Integration Survey, Budapest Initiative, WHO'S Disability Assessment schedule) there has been considerably less endeavours for equivalent information for children and young people. The European Action Plan on disability 2006/2007 describes why mapping the situation of disabled people throughout Europe is difficult: "Definitions and criteria for disability vary according to policy objectives, legislation and administrative standards. Population surveys provide subjective data, affected by differing cultural perceptions in individual Member States. In addition, data focus on the working age population, and exclude children and people living in institutions" (Commission of the European Communities 2005).

There are numerous reasons why the collection of national disability statistics on children within the survey context has lagged behind that of adults. They range from the political context within which statistics on disability are collected, conceptual difficulties in defining disability, methodological challenges in the operationalisation of the selected definition and different approaches to synthesising information from various sources (young people, parents/caregivers and teachers).

Organisation of National Statistics Collections

Government ministries which have responsibility for disability tend to be primarily concerned with employment, pensions, or social affairs and understandably, their main focus is on equalisation of opportunity in the labour market, having a comprehensive and coherent system of disability benefits or promoting equitable access to heath, social, educational and vocational services. Child disability statistics do not fit easily within one government ministry and cut across health, education, social affairs. Hence, considerable co-ordination and political will are required to launch a national survey on children's disability.

Classifications of Disability

Children tend to lag behind adults both in terms of the development of classifications of disability and hence in the epidemiological tools derived from such classifications. The International Classification of Functioning, Disability and Health-ICF (WHO 2001) addresses the broad need for a common language and classification of functioning and disability among adults. Simeonsson et al. (2003) notes that the interaction of developmental characteristics and disability among children represent a special challenge for classification as well as measurement. The publication of the ICF-CY, The International Classification of Functioning, Disability and Health, Children and Youth Version ("WHO" 2007) was a response to the need for universal measures that encompass the components of the ICF for young children that can be used in surveillance, screening and evaluation.

Conceptual and Definitional Issues

One of the main reasons why national surveys on disabled children are far less prevalent than for adults is that disability is far more difficult to define for children.

There are several difficulties in measuring disability specific to children which have repercussions for survey methodology.

Developmental Delay

Children are by their very nature in the process of development. Different activities are regarded as the norm for particular age groups. When should children be expected to walk or to read or to communicate complex ideas? Should any delay from the norm be regarded as a disability? There are also different cultural norms between countries in terms of personal care activities, washing, dressing, feeding, toileting and the extent to which children are expected to help in food preparation, or various household tasks. In the survey context one can ask the parent about the child's capabilities and compare the responses with the normative developmental milestones for children or ask the parents to compare their child with other children of the same sex and age. For some activities it may be difficult for parents to say their child is doing less well than others as it may reflect poorly on their parenting skills.

Capacity and Performance

Having a consensus on the activities expected of children at particular ages only partially helps to meet the challenge of producing comparable disability statistics for children. The issues which have surrounded the measurement of disability among adults over the past 25 year also apply to children: the capacity versus performance debate; whether disability equipment or personal assistance should be taken into account; the length of time the problem has existed or is likely to exist etc. In terms of question wording, parents are asked about what their children can do. In some activity domains, seeing and hearing, walking or climbing, the responses should be valid and reliable. However, questions relating to the child's behaviour (particularly for older children) may be less reliable.

The Influence of the Family

What the child can do, is allowed to do or actually does is dependent on the child's family, particularly for the child's emotional and psychological development (Meltzer et al. 2000). Attitudes of the parent or primary caregiver towards diet, exercise, learning and life-style behaviours are all relevant. Therefore, the functioning of the child cannot be seen in isolation but in the context of the family system. The consequence of this interaction and interdependence is that a survey about disabled children requires as much if not more information about the family – structure, behaviour and attitudes.

Educational Environment

Schools as well as families have a role in the social participation and the social integration of children. A social model of disability which emphasises environmental factors has to take into account the influence of family and school on the child's development. Some surveys, particular those investigating the mental health of children and young people advocate the administration of a supplementary questionnaire among teachers.

The Social Care and Welfare Environment

Children's development is not only influenced by family and school but by the need for and use of health, social and welfare services – who can help the child, in what capacity and at what time? Westbrook et al. (1998) looked at how prevalence estimates and characteristics of children varied by the way that disability is defined. Three definitions of disability were compared by examining parental reports of functional limitation, dependence on compensatory mechanisms, and service use or need beyond that normally expected of children. Using a dataset which identified 1388 children with chronic conditions, they found that the service use definition identified 72 % of the sample as disabled, followed by compensatory mechanisms (55 %) and functional limitations (49 %). Forty-four percent of children were identified by only one component, 36 % by two components in any combination, and 20 % by all three components.

All of these issues prompted Read (2007) to ask the question whether or not it was possible to count the number of disabled children in the UK. From her review she concluded that prevalence rates vary from 5 to 18 % depending on definition or measure, different sub-classifications limit comparisons between surveys, no survey had been designed to cover the whole population of disabled children, data sources were limited by age, geography, size of subgroups and place of residence and very few data sources collected data on social and demographic circumstances of the children and very few surveys took account of how age and development of children may shape functioning and ability.

Survey Procedures

Sampling Children in National Surveys

In order to obtain a robust estimate of the national prevalence of disability among children and young people within a survey context, it is necessary to have a representative sample, particularly representative by the age and sex of the child and the socio-economic circumstances of the family. There are several methods of obtaining a representative sample: carrying out a postal screening of the general population to identify households with children, sampling through schools, using administrative databases and follow-up surveys. There are advantages and disadvantages of each method. Screening by mail allows a vast initial sample to be contacted yet such a method can be time consuming and expensive. Furthermore, response to contact by post can be difficult to obtain. School sampling is an attractive option especially if the child is the only respondent and questionnaires can be administered in classes. However, negotiating access to schools can be problematic. Some researchers prefer the initial contact to be with parents who can then give signed consent to approach the child's teacher. Following up children identified in other national surveys is cost effective but respondent burden becomes a major factor. Using administrative records is the quickest and cheapest method but the records need to be accurate, have full coverage and allow for stratification. However, access to the data as a sampling frame must not breach data protection rules.

Survey Designs

A key decision to be made in deciding how to measure the prevalence of disability among children and young people is whether to adopt a one- or two-phase design, i.e. ask all questions of all respondents or start off with a short screening instrument applicable to all children followed up with a detailed assessment with all screen positives and a sample of screen negatives. There are many advantages of a one-phase approach. Most importantly, detailed information is collected on all children. A sample distribution can be produced on disability domains even though only those with predetermined, above-threshold responses can be regarded as disabled. If the survey's aim is to measure impairments, activity limitations, participation restrictions, environmental factors, service use, and lifestyle behaviours etc., it is important to have this information for all children for comparative purposes. If the survey has a longitudinal element, a one-phase approach allows a large pool of children from which to select controls who could be matched on several characteristics of the disabled children during the first stage interview. On a more practical level a one-phase design is likely to increase the overall response rate compared with a two phase (screening plus full assessment) design; it reduces the burden put on respondents and can be carried out in a far shorter timescale.

The main disadvantage of a one-phase design is cost: the administration is far cheaper in two-stage designs, although the latter is likely to elicit more biases and less precision.

Length of Questionnaire

Wells and Hogan (2003) highlight the issue of interview length (affecting respondent burden and cost) in carrying out national health surveys that have attempted to identify and characterise disability among children. They comment that a large number of items are required to measure childhood disability and that this prohibits their use in general population surveys. By analysing three nationally representative population surveys that contained detailed questions on childhood activity limitations, they were able to demonstrate that it was possible to reduce the number of survey items needed to measure childhood activity limitations and still produce comparable estimates. However, the concise sets of measures did not produce comparable estimates across surveys reflecting differences in the types of questions and differences in the wording of questions found in the original surveys.

Looking at one element of the disability concept from the ICF – participation of children – McConachie et al. (2006) found that to get an adequate measure of this it is necessary to consider the child's dependency on the family, and their changing abilities and autonomy as they grow older. A focus on 'performance' such as whether and how often an activity is taken part in, and to exclude degree of assistance within the measurement scaling was recommended.

Involvement of Children in the Assessment Process

While parental investigation characterised nearly all of the early epidemiological studies of disability among children, more recent studies (especially in the field of emotional and behavioural disabilities), have broadened data collection to include information gathered from parents, teachers, and the children themselves (Meltzer et al. 2000). It is now generally accepted that whenever possible children's voices should be heard. Apart from the benefit of making children feel involved in the research process, information from multiple respondents enhances the specificity of prevalence estimates (Young et al. 1987).

Analytical Issues

One of the problems of collecting information from various sources in different formats, both qualitative and quantitative, is finding the best way to integrate the information which may show a lack of agreement. One method is to accept disability information irrespective of its source. Another method can be described as "case vignette" assessments where detailed case histories are made from several sources including conflicting information and expert assessments are made after examining all information. The collection of this extra information and its processing may act as a financial constraint to conducting research on disability among children.

Ethical Issues

Although there is a growing consensus that research on disability among children should involve the children themselves as much as is appropriate for their age and comprehension, ethical concerns and legal constraints may deter researchers from carrying out surveys on disability among children and young people.

In most European countries, population surveys, even without invasive procedures, require putting the research proposal before an Ethics Committee. This is both labour intensive and time consuming. A key decision is finding the lower age range in which to involve children. Even if one decides on a particular age, say 11 years of age, it has to be recognised that the intellectual capacity of all children is not the same. Some 11 year olds may be functioning intellectually at 8 or 9 years of age.

It is often desirable to interview the child alone. This can cause parents some concern, leaving their child with a stranger, albeit a bone fide interviewer. A technique successfully used by interviewers when parents refused to leave the room was to sit side by side with the child, reading out the questions but then asking the child to key their own answers into the laptop computer.

Although the presence of an interviewer is important for maintaining data quality and response to surveys their presence can influence children's (and parents') answers to survey questions, particularly when asking questions about sensitive topics. Respondents exhibit what is known as a 'social desirability bias' providing answers which they consider to be concurrent with the beliefs of the interviewer or the norms of society in general (Dillman 2000). As well as the interviewer, the presence of other people can also affect the responses given (Bajekal, and Purdon 2001). Scott (1970) noted that children are just as likely as adults to exhibit social desirability bias.

Computer Assisted Self Interviewing (CASI) works much better than paper self-completion methods since research has shown that children have more trouble than adults in following routing patterns through questionnaires (Zuckberg and Hess 1996).

Methodology of National Surveys of Disability Among Children

Owing to the organisational, conceptual, methodological, analytical and ethical challenges in conducting national surveys of disability among children, large scale studies have rarely been carried out. Nevertheless, quite a few countries have done it on one occasion, either linking a children's study to an adult survey or taking advantage of a disability question in the national census to conduct a post-censal survey.

Australia

The Survey of Disability, Ageing and Carers (SDAC) conducted by the Australian Bureau of Statistics (ABS) throughout Australia, from June to November 2003 ("Disability, aging and carer survey" 2003). Children (under 15 years if age) were included in the survey. Personal interviews were conducted with the young adults aged 15–17 years, if the parents agreed. An area sample of private dwellings, covering both urban and rural areas in all States and Territories (except for those living in remote and sparsely settled parts of Australia) was used. There were 17 screening questions which determined disability status. Depending on disability status, age and carer status, respondents were routed through different question structures and modules.

Canada

A sample of the respondents who answered "Yes" to the 2006 Census disability filter questions in Canada were chosen to participate in "The Participation and Activity Limitation Survey (PALS)" (Participation and activity limitation survey 2006). Approximately 9000 children living in private households in the ten provinces and three territories were selected to participate in the survey. The data were collected in the fall of 2006 and winter of 2007. The survey used a separate questionnaire for children. All child interviews were usually completed by a parent or guardian of the child.

Disability among young children (0–4 year olds) was described in terms of delay in development, whether physical, intellectual or other. For children aged 5 and over, PALS identified ten types of disabilities, substituting more specific types of disabilities for developmental delay.

Great Britain

In Great Britain, a large national survey of disability among children (0–15 year olds) was carried in the early 1980s (Bone and Meltzer 1989). Several factors coalesced to mitigate many of the challenges outlined above. First, the survey of disability among children was conducted as part of a government sponsored programme of research looking at the prevalence of disability among the whole population: adults and children living in private households and in institutions. Second, the sample design had a two-phase approach – initially carrying out mail screening of 100,000 households and following up families who screened positive with face to face interviews. However, only parents of children were interviewed in the survey; not the children themselves.

Third, the ICIDH (WHO 1980) which was used as the conceptual framework for the adult survey had to be adapted for its applicability to children. The survey questions included a reference to what was considered as normal for a child of the same age and sex as the sampled child. For children, the notion of what is normal for a particular age was an inescapable basis for the assessment of disability: Twenty domains of disability were included in the survey mostly based on activity limitation. Data were analysed separately for 0–4 and 5–15 year olds.

New Zealand

The 2006 New Zealand Disability Survey provided statistics on the prevalence, nature, duration and cause of disability for children (0–14 years) living in private households ("Statistics New Zealand" 2006). The frame for this survey was created using 2006 Census records. The compilation of the sample frame was made easier by the inclusion of two general questions on disability in the 2006 Census. These questions were included in the census in order to identify a large proportion of the population with disabilities, in order to improve the efficiency of the sample selection for this survey. Separate questionnaires were used for children.

Northern Ireland

The Northern Ireland Survey of Activity Limitation and Disability (NISALD) focussed on the experiences and lifestyles of disabled people in Northern Ireland ("The Northern Ireland Statistics and Research" 2007). The survey covered adults and children living in private households and in communal establishments. Fieldwork for adults and children living in private households was carried out throughout 2006 and was completed in early 2007. Separate questionnaire were designed for children aged 15 or under. A parent, guardian or legal representative of the child was asked to complete the questionnaire on the child's behalf. The definition of disability for the purposes of the NISALD was based on the concepts of the International Classification of Functioning, Disability and Health (ICF).

The screening of the initial sample of households was undertaken on a mixed-mode basis as this was deemed the most effective means of contacting a large number of households. The aim was to conduct the screening questions by telephone where possible and with the consent of the respondent, but where this was not possible or where the respondent had requested otherwise, the screening questions were conducted face-to-face. The child questionnaire included sections on the children's educational experiences, the child's experience of play and social interactions. Transport questions were designed to measure how the child normally gets out and about, and to gauge the child's ability to travel independently if appropriate.

United States

The Bureau of the Census conducted the Disability Followback Survey (DFS) for the National Center for Health Statistics to obtain, inter alia, objective and descriptive information about disability ("Disability Followback Survey" 1994). The survey was a nationally representative sample of the civilian, non-institutionalized U.S. population, both adults and children (under 18 years of age). The DFS was administered to people who were identified as having disabilities through the Phase 1 NHIS-D and also by their responses to disability-related questions in the core NHIS – the screening phase. The children's survey was carried out separately from the adult survey but the questions were asked of a parent or guardian.

A complex set of eligibility criteria was used to identify the mainstage sample based on individuals' responses to the screening questions. "Disability" was regarded as a multifaceted concept which at the analysis stage involved 227 variables and 24 combinations of variables (termed "Disability Hit Flags"). These "flags" included, among other variables, specified medical conditions, receipt of or application for disability benefits, use of assistive devices or prostheses, and ADL, IADL, or functional limitations.

Vietnam

The Vietnam Child Disability Survey 1998 was carried out by the Centre for Information and Statistics on Labour and Social Affairs with funding and technical support from UNICEF ("Vietnam Child Disability Survey" 1998). The survey was conducted from June 1998 to February 1999. A total of 23,040 households in urban and rural areas in 16 provinces were included in the community-based sample survey. A total of 96 household cluster groups in the eight major regions of the country were selected and interviews conducted to estimate the rate of disability among children aged 0–17 years old. The ICIDH was used as the theoretical framework for the survey. There were three kinds of questionnaires used in this survey: (i) a household survey questionnaire, (ii) a survey questionnaire for individual children with disabilities living in households, and (iii) a survey questionnaire for children with disabilities living in institutions. The main aim of the household survey was to identify children with disabilities aged 0–17 years old living in the households who were to be later interviewed in the individual survey of children with disabilities, i.e. to act as a screening questionnaire.

Summary

Although there are sound statistical and policy reasons for carrying out large scale surveys of disability among children, there are also numerous constraints in implementing such surveys. From an organisational point of view there may be numerous agencies responsible for disabled children within government. There are also several operational challenges just in carrying out surveys of children (sampling, ethical issues, involvement of the children, data from multiple sources). More specifically, there are differences in opinion in conceptualising child disability (e.g. adopting a biosocial rather than a medical model, measuring performance or capacity, taking account of the family or not). Although the surveys carried out in

Australia, Canada, Great Britain, Northern Ireland, New Zealand, US and Vietnam demonstrate excellent sampling and survey designs and used well tested questionnaires, the approach and content of the questionnaires (both screening and main-stage) varied considerably.

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Chapter 10
Building a “Module on Child Functioning and Disability”

Roberta Crialesi, Elena De Palma, Alessandra Battisti, and Children’s Workgroup

Introduction

The U.N. Convention on the Rights of the Child (UN 1989) sets out for the first time, in a coherent way, the fundamental rights that must be recognized and guaranteed to all children in the world. These rights are founded on respect for the dignity and worth of each child without distinction of any kind (health, sex, age, race etc.) (art. 2). Furthermore, the U.N. Convention on the Rights of the Child states that a child with disability should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community (art. 23). This requires that the States provide appropriate services for children with disability in order to ensure that “the child’s achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development” (art. 23).

The more recent Convention on the Rights of Persons with Disabilities (CRPD) (UN 2006) dedicates a specific article to children (art. 7). This outlines the States’ obligation to ensure the realization of all rights for children with disabilities on an equal basis with other children, to promote their best interests, and to ensure their right to be heard. The Convention incorporates, within its general principles (art. 3), the respect for the evolving capacities of children with disabilities and their right to preserve their identities. Furthermore, in the development and implementation of legislation, policies and in other decision-making processes concerning issues relating to persons with disabilities, the “States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations” (art. 4).

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On the specific issue of the statistics (art. 31), the Convention invites the States to strengthen the collection and compilation of national data and information about persons with disabilities to enable them to formulate, implement and monitor policies concerning the application of the Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights. States are also responsible for the dissemination of these statistics and to ensure their accessibility to persons with disabilities and others.

In 2011 the U.N. General Assembly adopted a resolution on "Rights of the children",[1] that reaffirms the general principles of the Convention on the Rights of the Child, and provides the framework for all actions concerning children (UN, 2011). This resolution calls upon States to ensure the enjoyment by all children of all their civil, political, cultural, economic and social rights without discrimination of any kind. Moreover, specific attention is put on the rights of children with disability, reaffirming that all children with disabilities should have full enjoyment of their human rights and fundamental freedoms on an equal basis with other children; recognizing that discrimination against any child on the basis of disability is a violation of the inherent dignity and worth of the child. The resolution invites all States to include in the policies and programs for the realization of the rights of the child the relevant provisions for the implementation of these rights also for children with disabilities. It also declares that States shall take measures to collect and disaggregate relevant information, including statistical and research data, in order to identify and address the barriers faced by children with disabilities in exercising their rights.

Although it is clear that the improvement of policies for children with disability requires consistent, accurate and more comprehensive data, the quality and quantity of data available on disability still vary enormously among countries. There is a real need to improve data collection on disability across the world as highlighted in the first "World Report on Disability" published in 2011 (WHO and World Bank 2011). The report stresses that "internationally, methodologies for collecting data on people with disabilities need to be developed, tested cross-culturally, and applied consistently" (page 267), that data need to be standardized and internationally comparable for monitoring progress on disability policies and on the implementation of the CRPD across the world. It underlines the importance of the "International Classification of Functioning, Disability and Health (ICF)" (WHO 2001) as a universal framework for disability data, at both national and international level, in order to "create better data design and also ensure that different sources of data relate well to each other" (page 45). Finally, among other specific recommendations, the World Report on Disability calls attention to the development of appropriate instruments for measuring childhood disability.

The need to overcome the paucity of data on children with disability as well as the scarce cross-country comparability of those data has been confirmed also by the

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[1] A/RES/66/141. The resolution also calls upon States to implement fully the commitments undertaken in the Resolution "Realizing the Millennium Development Goals for persons with disabilities towards 2015 and beyond" (A/RES/65/186 del 2010), and to ensure that children with disabilities are rendered visible in the collection and analysis of data.

United Nations Children's Fund (UNICEF). The 2013 report titled "The State of the World's Children", focused on Children with disabilities, points out the complexity of measuring child disability through population surveys. The Report states "there is a clear need to harmonize child disability measurement in order to produce estimates that are reliable, valid and internationally comparable" (UNICEF 2013; page 68).

The International Classification of Functioning, Disability and Health (ICF) has ushered in a paradigm shift in the concept of disability, adopting a bio-psycho-social model that reflects the cultural changes occurred in recent years in the conception of disability. Disability is no longer considered as an attribute of the individual, rather it "denotes the negative aspects of the interaction between an individual (with a given health condition) and the individual's contextual factors (environmental and personal factors)" (WHO 2001; page 213). Therefore, it follows that every individual, given his or her state of health, can be in an environment with characteristics that could work as facilitators for his functioning or as barriers creating disability.

The new definition of disability changes the approach to be adopted in the design and implementation of social policies and services, and, consequently, the contents of the statistical surveys that provide the information needed to plan and evaluate policies. Translating the ICF concepts into a new operational definition of disability in surveys is not a straightforward task and it requires the development of tools that will measure disability as a result of the interaction between the person's health and their life context.

Since 1995 the United Nations Children's Fund (UNICEF) has helped low- and middle-income countries in monitoring progress in key areas of children's and women's well-being through the household survey "Multiple Indicator Cluster Surveys" (MICS).[2] To overcome the data paucity on childhood disability, since 2000 UNICEF has included the Ten Questions Screen (TQ) in the MICS. By adding this module, MICS has become the largest source of internationally comparable data on children with disability for low- and middle-income countries (UNICEF 2013). The TQ is a validated screening tool (Durkin et al. 1994; Durkin et al. 1995) used in interviewing the primary caregivers of children aged 2–9 years; it requires follow-up medical and developmental assessment in order to yield a reliable estimate of the number of children in a given population who have disabilities. The Ten Questions Screen for childhood disability contains questions on congenital and developmental disabilities, including seizures, speech, cognitive, motor, vision and hearing disabilities. The Ten Questions Screen was, however, developed as part of the International Pilot Study of Severe Childhood Disability in 1984, and its design therefore reflects disability as it was understood and measured at the time (UNICEF 2013). In 2011 UNICEF has begun a process of revision of the MICS methodology for collecting disability data. The necessity to develop a new childhood disability survey measurement has been recognized in order to better reflect the current thinking about disability; in particular with reference to the ICF (child

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[2] For more information: http://www.unicef.org/statistics/index_24302.html

and youth version: ICF-CY) (WHO 2007) as a conceptual framework. Indeed, this version of the ICF is more suitable to describe the specific and unique aspects of developmental characteristics of children and childhood disability (Simeonsson 2009; Lee 2011; Kostanjsek 2011; WHO 2007).

Since 2002 the Washington Group on Disability Statistics (WG) has focused on the development of survey tools to collect basic comparable data on disability. In 2010, it formed a working group responsible for producing a set of *ad hoc* questions on functioning and disability in children. As they shared the same objective, in 2011 the Washington Group and UNICEF established a formal collaboration to develop childhood disability survey measures able to produce cross-nationally comparable data.

Critical Issues in Childhood Disability Measurement

While data collection on childhood disability has generally increased over recent years, these data are still limited and inadequate in terms of description of children with disabilities and their circumstances (Blackburn et al 2010), especially in developing countries (UNICEF 2008; 2013).

This is due to factors such as the lack of priority given to the disability issue in the political agenda as well as the local financial resources available for data collection. In addition, there are other factors more specifically related to data collection. Countries often adopt different methods (administrative records or registers, census, population survey) in collecting information on disability that produce data difficult to interpret, cross-link or harmonize within and across countries. The purpose of measurement, the definition of disability and consequently the approach to measure it are often different. "Each purpose elicits a different statistic and even when the intention is to measure the same concept, the actual questions used differ in ways that severely limit comparability" (Madans et al. 2011; page 3). Several definitions and models of disability have been developed (Altman 2001) and therefore many approaches for measuring disability in the surveys are used, this leads to disparate prevalence rates between and within countries (Mont 2007; Barbotte et al. 2001; Loeb 2013; Loeb and Eide 2006; WHO and World Bank 2011; UNICEF 2013; Schneider 2009). In the various surveys, different components of disability are also investigated with a dissimilar level of details.

While some countries use questions specifically developed to assess childhood disability, others pose the same questions to adult and children alike. Taking into account the reference population, some surveys or censuses pose the questions from birth while others from a certain age, and children are grouped by different age bands for estimating the prevalence. Finally, some surveys adopt mainly a dichotomous answer category, while others use multiple response categories with severity qualifiers, and among these the cutoffs selected to indicate disability may be different.

Moreover, cultural factors (such as differences in values, or attitudes towards individuals with disabilities) may also play an important role as they influence which questions are asked, how they are framed and how individuals will respond to these questions (Groce 2006). Culture may also impact on the measurement outcomes because what is considered as 'normal' functioning varies across countries (Mont 2007; WHO and World Bank 2011; UNICEF 2013). These factors do not currently allow comparable estimates of childhood disability around the world.

When developing a measure of childhood disability to be used in population surveys for cross-nationally comparable data, several factors should be taken into consideration. Some refer to data collection on disability in general – purpose of measurement, definition of disability and alternatives for its operationalization, type of answer categories, space available for the measure – while others are more related to the unique characteristics of the investigated population: children and youth.

Generally, questions designed for an adult population will not be suitable to capture disability among children and youth. Indeed, there are specific issues that make it particularly difficult to measure disability in children. Children are in a constant state of development, transitioning from infancy through childhood to adolescence and young adulthood. This implies continuous changes in their ability to perform actions and activities, especially in the early ages. "In contrast to the relatively stable characteristics of the adult, the evolving characteristics of the child represent a moving target, complicating the task of assessing function and distinguishing significant limitations from variations in normal developmental process" (Simeonsson 2006, page 67). Even if child development experts have identified milestones of development (referring to the age at which most children may be expected to reach certain stages of development) there is variation in the attainment of those milestones of development among children. Therefore, especially among the youngest children, it is not an easy task to distinguish between developmental delay and disability.

While disability among the adult population is more often associated with limitations in physical functioning (mobility, sensory, and personal care - especially with advancing years); in children the main disabilities are more often related to intellectual functioning, emotions and behavior that are more difficult to measure in the survey context. An increase of disability associated with underlying mental health problems is seen particularly in some developed countries. Some mental health problems are not easily identified in the early stages of child development, especially through population surveys, but that should not detract from the need to develop appropriate measures because the consequences of childhood mental health problems invest all areas of an individual's life and can deeply affect the achievements in the field of family, work, social, etc. in adulthood.

Another important issue in the measurement of child disability concerns the survey informant. Generally in population surveys, adults answer questions on disability/health conditions directly, if their condition allows it. Disability measurement for children, on the other hand, takes place through the filter of a parent or some other adult caregiver. The issue related to the quality of self and proxy reports on disability is unresolved some studies conclude that proxy reporting produces increased reports of health problems and higher rates of disability than self-reporting while others find the opposite (Lee et al. 2004).

Several studies have also been conducted to evaluate the age at which children can self-report their health and the impacts on the validity of the findings when parents act as proxies for their children (see Morris et al. 2009). The level of agreement between parent and child depends on the domain assessed; generally good agreement has been observed for domains related to physical functioning and less agreement for emotional domains (Eiser and Morse 2001). Although in principle it would be better to assess disability through child self-report, in a survey setting this would not be reasonable in light of the young age of the potential respondent and the type of impairments that they may have. As the degree of familiarity between an individual and the persons for whom they are reporting may affect the accuracy of the answer (Blair et al. 1991), the parent or the primary caregiver in the household represents the best proxy respondent for questions on children. Indeed, it is recognized that "the closer is the relationship, the more likely that self and proxy reports will agree" (Lee et al. 2004, page 676).

In short, defining and measuring disability in childhood through population surveys is not a simple task as it poses several challenges from theoretical and technical points of view (Blackburn et al. 2007).

Developing a Survey Module on Child Functioning and Disability

Since 2010 a WG working group has been active in the development of a set of questions on child disability to be used as a component of national population surveys or as a supplement to surveys on specific topics of interest (such as health, education, etc.). The group is composed of representatives of national statistical offices from high, middle and low income countries,[3] academics and a representative from UNICEF who joined the group in 2011.

The working group recognized the efforts and achievements that had already been made in disability measurement, and it was deemed useful to collect and review this material, with special regard to data collections related to childhood disability. This documentation provided a basis for the initial discussions on measurement issues and led to the formulation of the working group's objectives.

The following points were agreed upon during early discussions:

– *Conceptual framework*. To use the International Classification of Functioning, Disability and Health for Children and Youth (WHO 2007) as the conceptual

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[3] Representatives from National Institute of Statistics of these countries are or have been involved the group: Italy, Usa, Canada, Australia, Uganda, Philippines, Sri Lanka, Mongolia, Zimbabwe, Oman, Togo, China, Sudan, Mozambique, Ivory Coast, Croatia.

framework, because it provides a common language and standard to classify the components of functioning and disability in children.

- *Purpose of measurement*. In accordance with earlier work of the WG (Madans et al. 2004), the module on child functioning and disability is intended to identify the sub-population of children and youth "at greater risk" than the children of the same age of experiencing limited social participation. A major reason for this choice is the importance of the issue of social participation and equal rights from a policy perspective as illustrated in the UN Convention on the Rights of Persons with Disabilities (Madans et al. 2011) and in the UN Convention on Child.
- *Approach to measurement*. The "difficulties in functioning" approach has been adopted, in accordance with previous WG work. The use of this approach has also been recommended in the World Report on Disability (WHO and World Bank 2011) as a better way to capture the extent of disability. To ensure cross-nationally comparable data, the functional difficulties should be identified in basic actions, by referring to actions that are appropriate to the reference age and not influenced by culture and context factors (WHO and UNESCAP 2008).
- *Reference population*. Initially, it was determined that the set of questions would reference children from 0 through 17 years of age. The workgroup was, however, aware that it may not be feasible to capture disabilities among children less than 2 years of age through population surveys due to the nature of the development process for children of this age.

The further development of the module on child functioning and disability followed through five steps:

1. the selection of appropriate and feasible ICF domains,
2. the development of a first draft of the set of questions/wording,
3. the revision of the question set,
4. the validation process, and
5. the establishment of the analytic properties of the module.

Each of these steps is described in detail below.

1. *Identifying appropriate and feasible ICF domains*

The first step was to select appropriate domains of functioning (according to the ICF-CY). To accomplish this, documentation relating to the measurement of childhood disability and questionnaires on children was collected and analyzed. The questions used in population surveys to capture children with disability were mapped in accordance with the ICF-CY checklists specific to each age group. The coverage percentage was calculated at ICF two-level categories,[4] taking into account whether ICF-CY check list items of each domain had been covered in at least one of the survey analyzed (see Fig. 10.1). This allowed a rough review of the domains already covered in at least one population survey.

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[4] The ICF components considered were Body Functions and Activity and Participation.

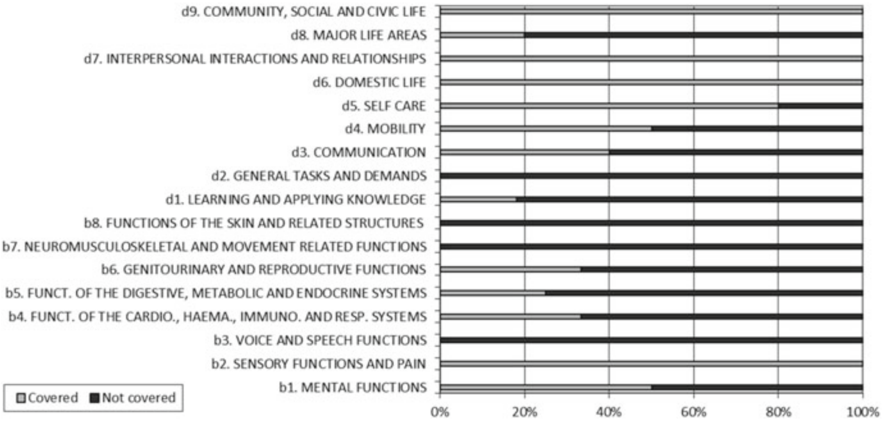

Fig. 10.1 Percentage of domains covered in disability surveys (Scales and surveys considered: The Child and Family Follow-up Survey (CFFS); (LAQ-G) The Lifestyle Assessment Questionnaire; The Activities Scale for Kids, Performance; The LIFE-H Assessment of Life Habits-Children short form; The Participation Activity and Limitation Survey (PALS) 2006, Canada; The National Disability Survey 2006, Ireland; The Northern Ireland Survey of Activity Limitation and Disability, Child Questionnaire 2007; The Multiple Indicator Cluster Survey (MICS) -Ten questions-UNICEF; The National Survey of Children's Health 2007, USA; The Washington Group: short set and extended set.) by ICF Components and Chapters

A document with the list of domains, indicating if they had been covered in a survey, was sent to all group members who were asked to assess the feasibility of including each domain in an international set of questions for children. Group members were asked to consider aspects of relevance, accuracy, clarity and comparability in their review of potential domains. The overall goal was to identify a parsimonious set of ICF-based domains that reliably describes disability in children.

Finally, taking into account the results of this assessment exercise, the ICF domains already covered in the surveys and evidence available from the literature (e.g. Hogan et al. 1997; McConachie et al. 2006; Wells and Hogan 2003), the following minimum set of functional domains was selected: *seeing*, *hearing*, *walking*, *communication*, *learning*, *relationships*, and *playing*. The working group was, however, aware that children experience a wider range of functional challenges than those included in this selection and that it would be important, at a later stage, to include other domains of functioning.

2. *Defining the questions and wording: a first draft*

A detailed review was carried out covering questions that operationalized the above domains in national or international surveys as well as in other test exercises. This review resulted in a first set of questions that were drafted according to the following guiding principles:

- consideration, where applicable, of questions already tested, including those of the WG short and extended sets;
- use of the bio-psychosocial approach when operationalizing questions – focusing on difficulties doing certain activities and avoiding questions that use a medical approach to defining disability (such as asking if a child has a specific disease or impairment);
- use of age-specific questions (applying age bands), because children are in a continuous process of development;
- selection of basic actions in order to ensure that the questions are able to collect cross-nationally comparable data;
- use of response options that capture the severity of the activity limitations. As disability can be conceptualized on a continuum from very minor to very severe difficulties in functioning, it is important to attempt to capture that continuum.
- standardization of the expectations of the proxy-respondents. Because responses are elicited through a proxy (parent or primary caregiver) it was decided, where appropriate, to focus the respondent's attention, when answering about their child, on children of the same age. It was believed that this would give the respondent a point of reference in terms of child development in general and reduce the chance of the respondent making comparisons with children outside of their child's developmental stage.

3. *Consultative process and revisions to the first draft*

In developing the module on child functioning and disability, considerable effort was placed on expanding the consultative process beyond the statisticians and survey methodologists that normally populate the Washington Group.

The first draft-questions covering a minimum set of domains (*seeing, hearing, walking, communication, learning, relationships, and playing*) were presented and discussed during the 11th Washington Group on Disability Statistics, held in Bermuda in November 2011. The meeting was attended primarily by representatives of national statistical offices, but also included representatives from universities or national institutes of public health or other national research bodies or ministries, and a representative from UNICEF. Feedback from participants included: concerns regarding the complexity of the questionnaire due to the several, often overlapping, age bands used (See: http://www.cdc.gov/nchs/ppt/citygroup/meeting11/WG11_Session5_1_Crialesi.pdf); the feasibility of measuring disability in children under 2 years of age through population surveys; and the consideration of questions related to emotional/psychological functioning.

In April 2012, a two-day meeting was organized in Rome (Italy) in order to respond to the input from the previous WG meeting and to provide an updated version of the module to be presented in a technical meeting planned by UNICEF for the revision of the MICS.

At the Rome meeting it was decided:

- to change the minimum age for the questions from 0 to 2 years of age. Despite the recognized importance of early detection of functional difficulties, it is extremely difficult to capture child disability among those less than 2 years of age through population surveys. Among children in this age range the development process is very subjective and culturally influenced, and a developmental delay is not necessarily a sign of functional limitation.

- to simplify the administration of the questionnaire by considering a reduced number of age bands: 2–4 and 5–17 years of age. Initially, it had been thought that a large number of narrow age bands would improve the accuracy of information collected. However, the draft questionnaire based on this approach proved to be very complicated, requiring numerous built-in skip patterns and was quite challenging for interviewers. For that reason, a balance was sought between simplicity and accuracy of the measurement by developing questions specific to wider age ranges.
- to add questions on remembering, self-care and emotional/psychological functioning (emotions, behavior, attention, coping with change).

A new version of the module was presented at the "Technical Consultation on the Measurement of Child Disability meeting" organized in June 2012 in New York by UNICEF. This meeting provided an opportunity to present and discuss the module with a wider audience of experts in the field of child development (pediatricians, developmental psychologists, speech therapists etc.). The consultation provided valuable feedback, and revisions were suggested that focused on: ways to improve the wording of some questions, the use of examples of activity limitation, the addition of alternate versions of certain questions that could be cognitively tested and compared, and the consideration of broader or more restricted age groups for the age bands. The Technical Consultation also proposed that additional domains be considered such as upper body and pain. Finally, a preamble to the module was decided upon: "The next questions ask about difficulties your child may have in doing certain activities….".

At the 12th WG in Bangkok (Thailand, October, 2012), the revised version of the module was presented and discussed as well as the preliminary results from the first cognitive testing conducted in India (see below). It was agreed to proceed with a wider process of validation of the module through further cognitive and field testing. It was also decided that the working group should produce a document that described the technical properties of the "Module on Child Functioning and Disability" and provided methodological guidance for its implementation.

Further revisions to the module followed cognitive testing (see below) and these were presented to subsequent meetings of the WG (Jordan, October 2013 and Argentina, 2014).

4. *The validation process*

According to the WG's validation procedures, the module on child functioning and disability has undergone cognitive testing and field testing (in progress) to determine the quality of the questions and ascertain the cultural understanding by the respondents.

To collect data on disability for international comparability poses important methodological challenges due to the fact that questions are administered in different contexts. Social patterns, beliefs and attitude toward persons with disability as well as differences in language may change the perceived meaning of the translated questions and therefore influence the data reported by the respondents and be sources of systematic measurement error in survey data (Groce 2006; Harkness et al. 2003; Miller et al. 2011).

Cognitive testing is a useful method for identifying patterns of error and patterns of interpretation across countries and socio-cultural groups as well as any problems related to the incorrect translation or their different shades of meaning in the various languages (Miller et al. 2010). Consequently the main goals of the cognitive tests are to determine: (1) if the questions are actually understood according to their intent; (2) if the questions are interpreted consistently across countries/groups; (3) how well the questions perform together as a module in identifying children with functional limitations. The cognitive tests help to understand how the expectations of proxy respondents and their social, demographic characteristics influence the assessment of the child's level of difficulties.

Since September 2012 different versions of the module at various stages of development were cognitively tested in several countries. The first round of testing was conducted in India (Mumbai), United States, Oman, Belize and Montenegro between September 2012 and July 2013. The second round of testing was conducted in the United States in March and April 2014 and a third round of testing was conducted in the United States in August 2014. The cognitive interviews were conducted by research teams in each country with the guidance of the Questionnaire Design Research Laboratory (QDRL) at the National Center for Health Statistics (NCHS) (see Massey et al. forthcoming). Following each round of cognitive testing the module was revised – and re-tested.

Along with this activity, some preliminary field testing has been carried out in India, Haiti and Italy, and by independent researchers in Cameroon, South Africa. The results of these research activities have been considered in the revision of the questions, even though these tests used slightly different versions of the module reflecting earlier stages of its development.

5. *Establishment of the analytic properties of the module*.

Analytic properties of the module will be established based on the results of field testing. It is anticipated that the final version of the child functioning and disability module will undergo a planned round of field testing in several countries.

Field testing is required to gather data from the new module and compare the results with other previously developed measures of child disability, specifically the TQ and the WG extended set of questions on functioning (applied only to children aged 5 to 17). Furthermore, the objectives of the field test will include: identifying difficulties respondent's in understanding the questions and their ability and willingness to answer them under field conditions; testing the flow of the questions as well as the skip patterns and gauging the amount of time needed to complete the survey. In addition, the field test will provide useful information about possible specific needs for interviewer training and a rough estimate of the positive response rate in order to compute the required sample size.

Additional analysis of the data will focus on the distribution of responses in order to pinpoint the threshold for selected indicators; and to compare the proportion of children detected as having a disability across various question sets and the non-response rates as well as missing data. To complete the module evaluation the interviewers' feedback will be considered, especially in order to ascertain whether respondents were hesitant or embarrassed by any of the questions or asked for clarification and/or whether any questions were difficult or awkward to administer. Upon completion of the field testing, the data analysis is expected to provide valuable information to support the understanding of specific domains of functioning and of the overall module.

Conclusions

Disability is a multidimensional, complex and dynamic process. Developing valid and concise measures of disability in the adult population for censuses and population surveys has proven quite a challenge. For several reasons, measuring childhood disability is even more challenging. Developmental milestones are difficult to pinpoint accurately due to the inherent variability in childhood development. A missed milestone does not immediately translate into developmental delay. Responses to questions on child functioning and disability are also, of necessity, filtered through parental/caregiver proxy-respondents.

The Washington Group on Disability Statistics, in collaboration with UNICEF, has worked for the past 4 years on the development of a survey module for children 2–17 years old using the ICF-CY as a conceptual framework.

The approach adopted by the WG and UNICEF in determining disability among children and youth consists in identifying difficulties in doing certain basic activities. Indeed, asking questions on difficulties in functioning in basic action provides useful information "since these actions form the building blocks for more complex activities and, in an unaccommodating environment, can result in disparities in participation" (Madans et al. 2011; page 4). The tool, therefore, is intended to identify the sub-population of children and youth "at greater risk" of experiencing limited social participation than children of the same age.

Considering the importance of producing a parsimonious measure of childhood disability and incorporating this measure in general population surveys - especially where little economic resources for statistical research are available - the current version of the module includes the following domains: *vision, hearing, walking, communication, learning/remembering, emotions (anxiety/sadness), behavior, attention, coping with change, self-care, relationships, and playing*. The questions on vision, hearing and walking detect a large majority of children with sensory and/or physical disabilities, while questions on communication, learning, attention, emotion, behavior, and coping with change may identify children with mental/intellectual disability and/or with emotional or psychological problems. A question on self-care may identify children that have difficulty taking care of themselves independently as the result of impairments in any domain. Questions related to playing and relationships have also been included even though they represent more complex activities, because they are important for a child's well-being and limitations in these areas could have strong negative impacts on child functioning and development.

Not all domains are covered in both age bands selected (children aged 2–4 and 5–17), in particular playing is only included in the questionnaire for children 2–4 years old, while remembering, attention, coping with change, emotions, self-care, and relationships are covered for the 5–17 years old children. This was necessary considering the complexity of measuring functional limitations in some domains due to the level of development in children and other cultural factors. For example, the self-care question is not posed to children below 5 years of age due to the normal variation in the ability of young children to perform self-care tasks (feeding and dressing) and because expectations may vary significantly by culture. The questions on emotions are not asked to children aged 2–4 old; even if young children may deal with many of the same emotions as older children, they often don't know how to share these feelings with others through either words or actions, hence any attempt to ask parents or caretakers about the emotions of these children would yield unreliable results.

Disability is not an all or nothing phenomenon, rather it represents a continuum from no to very severe difficulty. Responses to questions are scaled to cover a range of levels of difficulty, for the most part, *no difficulty, some difficulty, a lot of difficulty* and *cannot do at all*. This allows for the full spectrum of functioning to be captured and makes it possible to select the disability threshold that best suited to the stated purpose of data collection.

Further research activities will improve the questions and address some remaining issues such as the necessity to include other domains or the feasibility of administering the module directly to children (from a certain age) by changing the wording in an appropriate way.

At the time of writing this chapter, the module development is still ongoing, pending the completion of the validation phase and the definition of its analytic properties. Upon completion, the module will be released together with a manual that will provide full methodological guidance to its implementation in surveys. Furthermore, capacity building workshops will be delivered worlwide to build or to strengthen local capacity for collection, interpretation and use of data on childhood disability. The widespread use of the module in surveys will aid in the production of cross-nationally comparable data that, in combination with other data collected on specific topics – such as education or access to service –, can be used to determine the degree of participation in society of children and youth with disabilities compared with those without disabilities. These data will support a country's ability to monitor and assess compliance with the UN Conventions and, over time, their progress towards the full implementation of the rights of children with disability.

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Chapter 11
Cognitive Analysis of Survey Questions for Identifying Out-of-School Children with Disabilities in India

Daniel Mont, Sathi Alur, Mitchell Loeb, and Kristin Miller

Background

The Indian Parliament established the fundamental right to education for all children with disabilities in India by constitutional mandate in 2010 with the enactment of the Right of Children to Free and Compulsory Education Act (known as RTE). This legislation, which provides for free and compulsory education for all children age 6–14 years, specifically includes children with disabilities. This is the first time since independence in 1947 that children with disabilities have been allocated the same rights as non-disabled children to access educational services.

Unfortunately, even with the passage of this legislation it is generally acknowledged that a significant proportion of the millions of children in India still being denied an education are children with disabilities. According to one study, close to

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40 % of Indian children with disabilities are not enrolled in school, compared to between 8 and 10 % of children in Scheduled Tribes or Castes (World Bank 2007). The enrolment rate for all children was over 90 %.

To address this problem the government needs accurate information not only on the number and whereabouts of these children, but the reasons that are preventing them from attending school. To obtain that information, a methodology is required to locate out of school children (OOSC) and identify their reasons for being out of school. When these reasons are related to functional difficulties, it is then important to assess those difficulties and link the children to appropriate services so that they enrol and attend school successfully, within the overall protocols of Sarva Shiksha Abhiyan (SSA), the national flagship programme for education.

Many reasons exist for not attending school. Exclusion may be on the grounds of social prejudice for scheduled castes (SC), scheduled tribes (ST), other backwards classes (OBC) or other minority groups. Other reasons could be that parents desire children to work instead, or that the costs of receiving a quality education are too high, or maybe the lack of proximity to an acceptable school. Also, the reason may be related to functional difficulties children have in seeing, hearing, walking, fine motor activities, communicating, learning, managing their behaviour, etc.

Some functional difficulties may be mild but may still lead to dropping out of school – for example vision problems correctable by glasses. While this is a minor medical condition, it could still have a profound impact on children without access to glasses who as a result of their vision problems have difficulty concentrating, reading and learning, and consequently drop out of school. Other functional difficulties may be more significant and require prolonged therapy, assistive devices, significant adjustments in teaching styles, accessible schools, and other reforms to make the school system more inclusive. In order to deploy resources to get children into school as efficiently as possible it is important to get accurate information on children's functional difficulties and the environmental barriers they face.

A survey could provide a bird's-eye view of these facts but in order to create community networks that can actually reach out to particular children and provide them the services they need, it is important to undertake a complete mapping of OOSC and the reasons for their lack of attendance. This was recognized in the Model Rules under the RTE in Part III, Article 5, which states:

> … the State government/local authority shall undertake school mapping, and identify all children, including children in remote areas, children with disabilities, children belonging to disadvantaged groups, children belonging to weaker sections … (SSA: "Education for All")

ADAPT, a Mumbai based NGO with a 40 year history working on disability issues, was funded by CBM (previously Christian Blind Mission) as part of a project with ADAPT, to map children with disabilities in two political and administrative jurisdictions in order to develop a district level sustainable model of service delivery. Part of the activities included the development and testing of such a methodology. Coincidental with this project, the U.N. Statistical Commission's

Washington Group on Disability Statistics (WG) and UNICEF were collaborating on the development of a module on child functioning and disability for use in surveys and censuses and as part of the UNICEF's Multiple Indicator Cluster Surveys. The questions the Washington Group and UNICEF were developing were thought to be appropriate for the purposes of this Indian project. Therefore, the groups involved decided to collaborate and use the India project as a testing ground for the quality of the childhood disability module.

The proposed mapping methodology tested involves two-steps. The first stage is a mapping instrument administered to all households to identify OOSC and their reasons for non-attendance. This instrument is then used on OOSC to find out their stated reasons for non-attendance and also to identify those who are experiencing difficulties in undertaking basic activities. The identification of children with these functional difficulties is based on the WG questions which target 12 core functional domains. The second stage of the methodology involves sending children identified as having functional difficulties to a second stage follow-up assessment facility for more detailed assessment of their difficulties and for the subsequent identification ofservices that could help them to attend school. This chapter only reports on the testing done on the questions from the first stage of this process. A separate report is available on the field test involving both stages.

The process by which a respondent interprets and responds to a question is complex, and if a survey is not designed properly the responses can be riddled with measurement error that is impossible to disentangle. In order for survey responses to be understood, we must have a good understanding of the cognitive processes that respondents go through in determining their response to different questions. These processes are best elucidated through question evaluation and cognitive interviewing procedures. The WG, with a long history of question design and development experience, has established methodological procedures for question evaluation (see for example, Miller et al. 2010). This methodology was shared with ADAPT staff during a week-long training workshop held in Mumbai in the fall of 2012, conducted by experts from the WG.

The questions were cognitively tested in Mumbai, India, in September 2012 in both English and Hindi. The results are explained in the following sections, including modifications to the questions that were made in response to findings in the early rounds of testing.

We believe that the analyses of the cognitive interview results that are the outcome of the question evaluation process provide a better understanding of the questions – and the responses that they elicit. It allows us to know if the questions produce responses that are deemed within the scope of intended responses – or if they are being misunderstood or misinterpreted. Only through this process can questions be reliably modified to capture what they are intended to capture and avoid the possibility of excessive false positive or false negative results.

Methodology for Cognitive Testing of Survey Questions

Overview

The aim of the cognitive interview study is to investigate how well survey questions perform when asked of respondents; that is, if respondents understand the questions according to their intended design and if they can provide accurate, valid answers based on that intent. As a qualitative method, the primary benefit of cognitive interviewing is that it provides rich, contextual insight into the ways in which respondents (1) interpret a question, (2) consider and weigh out relevant aspects of their lives in relation to the question being asked and, finally, (3) formulate a response based on that consideration. As such, cognitive interviewing provides in-depth understanding of the ways in which a question operates, the kind of phenomena that it captures, and how it ultimately serves (or fails) the scientific goal. Findings from a cognitive interviewing project typically lead to recommendations for improving a survey question, or results can be used in post-survey analysis to assist in data interpretation.

In this cognitive interview study the QUESTIONS are being examined, not the CHILDREN. The study involves a small, purposively selected sample, so there is no reference to variance or standard errors or being representative of the population. No effort is made to estimate the prevalence of disability or the factors associated with disability. Instead, a cross section of different respondents are asked these survey questions and then probed via a qualitative interview to better understand how they are interpreting and answering the question to see if the question is working as intended.

Cognitive testing of questions is now standard operating procedure in the United States and Europe when it comes to survey design, but it has rarely been used in India, or many developing countries. However, 15 countries[1] were involved in cognitive testing of the WG census questions on disability (Miller et al. 2010).

Interviewing Methodology

Traditionally, cognitive testing is performed by conducting in-depth, semi-structured interviews with a small sample of approximately 20–40 respondents. The typical interview structure consists of respondents first answering the evaluated question and then answering a series of follow-up probe questions that reveal what respondents were thinking and their rationale for that specific response. In this regard, cognitive interviews unfold within a narrative format and are often personal and, in comparison to traditional survey interviews, are unique to each respondent.

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[1] Argentina, Brazil, Congo, Egypt, Gambia, India, Kenya, Lesotho, Mauritius, Mexico, Paraguay, Philippines, Tanzania, Uganda, Vietnam.

Through this semi-structured design, various types of question-response problems, such as interpretive errors or recall accuracy, are uncovered—problems that often go unnoticed in traditional survey interviews. By asking respondents to provide textual verification and the process by which they formulated their answer, elusive errors are revealed.

As mentioned above, the sample selection for a cognitive testing project is purposive. Respondents are not selected through a random process, but rather are selected for specific characteristics such as gender or race or some other attribute that is relevant to the type of questions being examined. When studying questions designed to identify persons with disabilities, for example, the test sample would likely consist of respondents with a previously known disability and, to discover potential causes of false positive or false negative reporting, some respondents with no known disability. Because of the small sample size, not all social and demographic groups are represented. Analysis of cognitive interviews does not produce generalizable findings in a statistical sense, but rather, provides an explicit exploration of response processes including patterns of interpretation, which could lead to response error.

Analysis of cognitive interviews is based on detailed interviewer notes. The texts of the interviews are collated by question so that comparisons can be made systematically across all respondents. Several levels of analysis can typically be performed. First, distinct occurrences in which respondents experience difficulty or confusion while answering are identified. Additionally, specific instances or patterns of error are also noted and, most importantly, the particular causes of those errors are identified. In addition to response errors, analysis of cognitive interviews can be conducted to reveal patterns of question interpretation. By comparing each respondent's interpretation to a particular question, patterns can be identified and then examined for consistency and degree of variation among respondents. This type of interpretive analysis does not necessarily illustrate overt response errors, but rather provides deeper insight into the substance or the actual meaning that constitutes the survey data.

Training, Sample, and Interview Selection

The first step in cognitively testing the WG/UNICEF module on childhood disability was to train ADAPT staff on cognitive testing techniques. Because interviews are conducted in the local language – and because knowledge of the local context is critical for obtaining and evaluating qualitative data – it was important that the interviewers had local knowledge. ADAPT staff, primarily educators, attended a workshop that included a description of the current state of measuring disability for international comparison, focussing on the particular difficulty in measuring disabilities in children. Some background was provided on the development of the questions to be tested, in particular that they were prepared in consultation with experts from a variety of backgrounds (such as survey statisticians, paediatricians, speech therapists, and developmental psychologists). These questions were based on functional difficulties, with reference to the child's age cohort (overall 2–17 years, but also specifically 2–4 years or 5–17 years) and were asked to the parents or the primary caregivers. Finally, the workshop included training on cognitive testing procedures. Topics included: background to question evaluation, how to conduct a cognitive interview, a mixed-methods approach to question evaluation that included both qualitative and quantitative methods, issues of sampling, taking notes, analysis, report writing and the use of software developed by the NCHS (Q-Notes). The workshop included the opportunity for participants to test their new skills through mock interviews with program participants and practice interviews with parents of children receiving services at ADAPT.

The original language of the questionnaire was English. Given the diverse nature of the languages spoken in Mumbai, it was seen that most respondents would experience some discomfort with English due to their lack of familiarity with the language. Therefore, the questions were translated into Hindi as it is the national language as well as being easily understood by a majority of the population in Mumbai.

Rather than the translation/back-translation technique that has been popular in the past, the team employed a consensus means of translation whereby groups discussed translation into Hindi and arrived at a consensus that was agreed captured the true meaning of the question. After the initial translation, the questionnaire was reviewed by the participants prior to being tested. The dialect of Hindi used for translation was academic rather than vernacular, which trainees felt would make the questions difficult to understand for common people. Thus the questionnaire was re-translated in the local dialect of Hindi by the participants in the cognitive training workshop. A series of practice sessions highlighted various issues such as an inability to accurately understand some questions due to the lack of concrete examples or examples that were alien to Indian culture. This resulted in the second round of adaptations made jointly by workshop participants and the trainers that included inclusion of culture specific concrete activities.

The process of cognitive testing began with 24 practice interviews followed by 72 interviews with the real, targeted respondents. The practice interviews exercise was useful as these enabled the participants to acquaint themselves with the process, address any clarifications which may arise with respect to the nature of the questions and the procedure of probing. This process yielded some useful insights which assisted in the cultural adaptation of the questions to the context in India.

The final questionnaire (with both the versions-English and Hindi) was formed and cognitively tested over a 7 day period in Mumbai and overseen by the US National Center for Health Statistics (NCHS). All the interviews were conducted at ADAPT's Bandra Centre in Mumbai, which provided transportation and refreshments for respondents coming from outlying areas. Each interview was on average of 1 h duration.

Discussions on selection of the respondents began a month prior to the workshops. Numerous email and Skype discussions were held with the international experts and in-house staff prior to selecting the final list of the respondents. Based on feedback from the trainers it was decided to arrange for one practice interview and three real interviews per trainee/interviewer. For the practice interview parents of students enrolled at the ADAPT Bandra center were contacted and requested for their participation. For the real respondents', ADAPT contacted parents of the Colaba center, Dharavi center, and rural outreach program under the Shiksha Sankalp project and skills development center. ADAPT explained the aim of the workshop prior to registering respondents. It was decided to have as respondents parents of children with different types of disabilities and therefore schools or centers providing services to children with hearing impairments, visual impairments and learning disabilities were contacted for their participation. A similar methodology of informing the organization of the objective of the workshop was undertaken. None of the organizations providing services to children with visual impairment were able to participate. Parents of children with hearing impairments from the Sanskardham School and Cheshire home willingly participated as respondents.

In all there were 96 respondents, 24 were practice respondents (all parents from the Bandra center) and 72 were real respondents (10 from Colaba center, 4 from the skills development center, 12 from the Pelhar center and 14 from the Dharavi centers. Four external organizations provided respondents of which there were 5 parents of children with learning difficulties, 10 parents from Sankardham and 10 parents from Cheshire home and 7 parents from SEC day school.) Four personal friends of staff participated as parents of non-disabled children.

With a view to build capacity among recognized stakeholders in the region, a large pool of ADAPT partners were contacted to participate in the cognitive testing exercise. An attempt was made to contact participants with varied interests in the field of disability. The government agencies working in the area of disability identification as part of their mandate were also contacted. Under the Right to Education act the local authorities (the Bombay Municipal Corporation in the project area) are required to undertake an annual mapping exercise to identify disability whereas the anganwadi worker (community workers) from the Integrated Child Development scheme are also required to do disability identification. Therefore these two agencies were invited to participate in the workshop.

ADAPT being the first organization to test this questionnaire in India, it was decided to have a group of ADAPT staff attend the workshop. When selecting ADAPT staff, again a cross section of staff was selected, namely teaching staff, training staff and therapy staff from across the four centers of ADAPT.

Attendance to all five training days was made mandatory and only those who were able to participate on all the days were permitted to register.

Analysis

Miller et al. (2014) explain that analysis of cognitive interviews involves synthesis and reduction. This process can be conceptualized within five incremental steps:

1. *Conducting interviews*. Collecting the ways in which a respondent interpreted and formulated answers to the survey questions,
2. *Synthesizing interview text into summaries*: detailing how each respondent formulated their answers, including events or experiences considered as well as any difficulties answering the question,
3. *Comparing summaries*: Looking across respondents to identify common themes and to develop a theoretical schema that details phenomena captured,
4. *Comparing themes:* Analysing themes across subgroups to identify ways in which different groups may process questions differently depending on their differing experiences and socio-cultural backgrounds,
5. *Making conclusions:* Making conclusions and recommendations based on the theoretical schema that depicts how each question performs as well as providing explanation for the performance.

Consistent with this model, summary notes were generated from interviews. Summary notes were then entered into Q-Notes, a data entry and analysis software application developed by the US National Center for Health Statistics. The summary notes specified the way in which individual respondents answered every survey question, including each respondent's interpretation of questions and key terms, activities and experiences considered by respondents, and any response difficulties and errors. Next, analysis was conducted systematically across interviews, identifying interpretive patterns (including patterns of response errors) across interviews. Findings from this second level of analysis depict the phenomena captured by each question and allows for the assessment of construct validity.

Use of Q-Notes, ensures a systematic and transparent analysis across all cognitive interviews as well as providing an audit trail depicting the way in which findings are generated from the raw interview data. Without such an analysis, conclusions presented in cognitive interview reports can, without the reader's knowledge, consist of anecdotal reports derived from one or two standout interviews or the general impressions of interviewers.

Experts at NCHS delivered the training on Q-Notes in Mumbai, and also supervised the data entry and reviewed all the analysis.

Testing the Questions

The cognitive testing was conducted in several rounds. After each round the research team conferred to see if there were any major problems in interpretation. When clear problems existed with the questions they were modified to try to rectify these problems prior to next round. For some questions no modifications were necessary.

The testing team prepared a detailed question-by-question review for use by the WG and UNICEF in evaluating the childhood disability questions. This question-by-question review was structured as follows for each question.

1. The purpose for the question is explained. This includes the concepts and conditions that the question is attempting to capture
2. A summary of the response patterns is provided. Various themes in the respondents' interpretations of the questions are discussed to provide a picture of the range and type of responses that could be expected if this question is used on a survey.
3. A summary of response problems is then provided. Discrepancies between the respondents' interpretation and the intended interpretation are highlighted as areas of concern.
4. The question review concludes with an evaluation of the question – is it capturing the intended information, and if not are there recommendations that can be made to improve the question, or, if not, issues that should be taken into account when analysing quantitative data collected using this question.

In some instances where recommendations were made to modify a question, the question was then re-tested to determine if the modification was effective. In general the questions performed well. Most of the questions required no modification, were well understood by the respondents, and their responses were in line with the concepts the question was attempting to capture.

The rest of this section reports on two questions where the value of performing a cognitive interviewing study to improve a question's design or to help in the analysis of future data is demonstrated. The first question is on walking, which was initially misunderstood, but which through the cognitive testing procedure was modified to substantially improve the question's effectiveness. The second question is on emotional difficulties, where cognitive testing, while in this instance not suggesting modifications to the questions, can still provide insight into how subsequent data can be used more appropriately.

In the initial round of testing the questions on walking were:

Children aged 2–4 years

(a) Compared with children of the same age, does [he/she] have difficulty walking? Would you say… *1) No difficulty, 2) Some difficulty, 3) A lot of difficulty, 4) Cannot do at all*

Children aged 5–17 years

(b) Compared with children of the same age, does [he/she] have difficulty walking 500 m on level ground? (That would be about…. [Insert country specific example]) Would you say… *1) No difficulty (skip c), 2) Some difficulty, 3) A lot of difficulty, 4) Cannot do at all*

(c) Compared with children of the same age, does [he/she] have difficulty walking 100 m on level ground? (That would be about…. [Insert country specific example]) Would you say… *1) No difficulty, 2) Some difficulty, 3) A lot of difficulty, 4) Cannot do at all*

Purpose The purpose of these questions was to identify children with varying degrees of difficulty walking. For children aged 2-4, this meant children whose difficulties created barriers to playing, exploring and interacting with their environment and their community in a way that excludes them or impinges on their development. For children aged 5-17, the short distance question was meant to identify children whose level of difficulty in walking (with no assistive devices) would affect their ability to care for themselves and contribute to household chores. The long distance question is meant to identify children who experience difficulties undertaking normal childhood activities outside the home – like attending school, participating in cultural or recreational events, etc. These are children who either need assistance to perform these activities or are incapable because of their lack of mobility.

Response Patterns The reference to distance was subjective and was differently understood by many respondents, which necessitated the need for changing the question to include concrete examples to ensure that the respondents were providing their answers with relatively the same idea of the distances involved.

When explaining how they arrived at their responses about the difficulty their children had in walking, the respondents referred to the degree of support required by the child (full support with the use of mobility aids, partial support with some dependence on walking aids or parents, or no support required-completely independent in walking).

Respondents also referred to different activities to explain their child's ability to walk such as sports activities, and activities such as crawling and hopping to explain the severity of difficulty in walking across various age groups. One respondent stated that her child…

> *… runs, pushes all children aside, jumps. He goes very fast no problem in walking and sometimes falls because he is walking fast. He goes alone to the shops and shows them what he wants. He brings back what is needed from the shops. They give him a sample and he brings the exact ingredient. He does not have any problem with potholes or stairs.*

Respondents also used behaviours which were general across many situations or specific to situations to explain the child's difficulty in walking. Respondents were able to compare the child with other children, and at times also compared the child's walking pattern at different points in time, as mentioned by one of the respondents who reported that her son has no difficulty now, but as a younger child (5–10 years of age), he had difficulty walking as he could not maintain his balance due to his hearing impairment.

> *But currently he has no difficulty, he is a karate champion, and a 2nd degree black belt. He also does swimming.*

References to the behaviours of the child while walking such as crying, being non-cooperative and the child's ability to walk being influenced by his/her physical condition were also made by the respondents, as seen by this response in regards to question b

> *For walking across a room both father and mother have to make him to stand then he is made to walk wearing splints and maximum support for a moment. When standing 15-20 minutes he cries a lot and does not cooperate. It's hard-work for him and for us too. But we do regularly without fail, we are expecting that one day he may stand and walk in front of us.*

Response Problems In general, respondents could easily answer the question for the age range of 2–4 years, but had problems understanding the questions for walking in the age group of 5–17 years as the distances measured (500 and 100 m) were an abstract number for them, which were difficult to understand. This is seen by one of the response patterns, for one of the respondents to questions b and c, for the age range of 5–17 years.

(Question b- 500 m) On asking why does she say 'some difficulty' for the child, the respondent said that last year she walked to 'Lalbaugcha Raja'. The respondent also mentioned that once she has walked to another deity (Siddhi Vinayak temple) with her grandmother. On probing about going to market, shopping, etc. or any other outings, she informed that she has not tried. Where ever they go, they go by car. But, if something is of her liking then she will do it.

(Question c- 100 m) The respondent felt that the child will have lot of difficulty in walking. On asking why she says so, she said *"I feel she will not be able to do that."* On bringing to her notice that she has said she will have only some difficulty in 500 m and lot of difficulty in 100 m, she said that she will be able to walk long distance holding hand like she did in those instances. But on her own, she will not be able to walk so much. The respondent related her 500 m walk to 2 instances earlier and felt she will have some difficulty while for 100 m she thought of her daily activities and skills. There were very few such instances when she had walked so much and she could think of only these two.

Respondents also used the pace of speed, the level of assistance required to explain their difficulty in walking, and the reference to distance was lost. This reference to distance is an important indicator of the severity of the functional limitation in walking (as seen by the Skip pattern provided with the selection of NO difficulty), without which the question does not yield much information.

Another issue to be addressed was the inclusion of a specific example to be understood by all. Considering the diverse nature of the respondents with respect to their educational levels, residence in a rural-semi urban and urban setting, and their access to various facilities such as school, playground, market (in the semi urban and rural areas, the distance between the nearest school and other facilities is much more than in the urban area), having an inclusive example for 'distance' would have led to errors in the quantification of difficulty.

Thus, it was proposed to change the questions to ask whether a child had difficulty walking to a store, and if they did then asking them if they had walking across a room. The idea was that these were examples of a short and a long distance. But this posed problems for two reasons: first, the distance to stores varies in different areas, and also because the respondents often cited problems walking to the store which had nothing to do with distance. For example, they said their child had difficulty walking to the store because of the lack of traffic lights or because their children pleaded for treats and then cried when they were denied them.

In attempt to divert respondents from this type of interpretation, the skip pattern was eliminated and the notion of distance was highlighted. The two questions for older children were (with the same response categories as previously used):

(b) Compared with children of the same age, does [he/she] have difficulty walking a short distance? for example, across a large room?
(c) Compared with children of the same age, does [he/she] have difficulty walking a longer distance? For example, to a store?

With this set of questions, the problem with interpretations disappeared. The notion of relative distance was established in the respondents' minds, and parents were not distracted with issues about traffic, behaviour, or the variance in how far away a store might be. The respondents were able to answer these question with ease and after probing with further questions to get them to describe their child's ability to walk in more detail, it was determined that their responses to the questions accurately reflected the child's difficulties.

Conclusion Keeping in mind the underlying principle of the question, this domain required modifications in each round to ensure that the response was not influenced by ambiguity of the question. Difficulties in walking can be a contributing factor in limiting access to health care and schooling facilities and is hence an important domain to be probed.

The modified question yielded a clear picture of the child's difficulties as a function of the respondent's understanding of the question, and the examples used by respondents showed that in its final form, this set of questions worked as hoped.

In the emotional domain, the question tested was:

Children aged 5–17 years

Compared with children of the same age, how much does (he /she) worry or feel sad? Would you say…*1) The same or less, 2) More, 3) A lot more*

Purpose This question attempts to identify children at risk of having a mental health disability. The aim is to identify children who have mental health issues which are significantly interfering with the child's schooling and social development. This may be a constantly high level of worry, sadness, or anxiety or it may be episodic in nature, but frequent enough and significant enough to make the child at much higher risk of dropping out of school, not participating in family or community life, or even putting themselves at risk of harming themselves. It is not meant to capture the response to a transitory event that the child can recover from, like the anxiety of taking a school entrance exam or the normal grieving process that accompanies the death of a parent, although such an event could be a trigger of a more pronounced problem with worry or sadness.

Response Patterns The conceptual understanding of worry and sadness as understood by the respondents was through expressed behaviours equated with feelings of worry or sadness. Respondents had equated behaviours expressing emotion- such as making a fuss, thinking too much and repeatedly asking questions, hitting, or not being able to perform or participate in activities at home or at school -- to explain the concept of the child being worried. Laughing a lot was equated to not being worried.

One respondent who answered the 'same or less' stated:

> *She doesn't understand emotion. Last week her grandmother died and the mother was crying. She just sat – she knew her grandmother is dead but couldn't show emotion. She cries if mother hits her for just for that moment. She knows if mother has fever – but there are no emotions beyond that.*

This respondent understood the question with reference to the child's expressing socially appropriate emotion at the particular situation to understand the question. Another one who answered the 'same or less' stated

> *She is an introvert as compared to other children of her age, she does not express her feelings. She is very choosey about friends and opens up only after some interaction.*

Respondents also tended to equate worry with other emotions such as being stubborn, sensitive, upset or afraid, suggesting that perhaps worrying per se is an abstract concept for them, and thus they have tried to explain it in the light of other behaviours and emotions which are associated with worry, but do not necessarily imply it.

An important feature to note is that some parents were unable to compare their child to other children, but to explain worry they made references to the child's behaviour on his own terms, as seen by the following response. The respondent answered 'The same or less,' and stated

> *He used to worry about money issues at home. For example, when friends used to pay school or tuition fees on time and his payment of fees was delayed because his father's salary came in late. But now everything is fine and he doesn't worry about anything. He is a cheerful and easy-going boy, who never feels sad during normal times.*

Another respondent answered 'The same or less' and stated that her son was a jolly boy, he always took efforts to make others and himself happy. Previously he used to get angry but currently he has become very caring For example: if his mom is angry or upset he indicates with a smile or tends to ignore. He feels happy with family but feels sad with outsiders, he feels lonely in school as there is a lot of age difference. Here in the same answer, the respondent is referring to the child's own timeline, expression of emotion that is interpreted as worry as well as situations and reasons where the child expresses certain emotions.

Response Problems Though a majority of respondents were able to quantify the child's worry, for some respondents, due to the differing nature of their child's disability, classification by the given categories was difficult. For one respondent who was unable to answer with respect to the given categories stated

> *For everything else I keep him happy. He is only sad about the fact that he cannot walk, and sometimes exclaims 'if only I could walk'… how can I compare this sadness of him being unable to walk to that of other children who are able to walk?*

The respondent feels that the nature of sadness and worry would be different in the case of her child and other children and thus could not be compared. Another respondent who answered 'Not at all' stated

> *The child cannot feel any emotions at all. She laughs all the time without reason. She only cries when hungry or in pain. Otherwise she doesn't feel anything.*

When pressed by the interviewer of her reaction when she is playing with something and that thing is taken away from her, the respondent mentioned that she wouldn't mind and would just sit rocking her body." This suggests that the nature of the child's disability may perhaps influence the respondent's perception of the child's worry. This also shows that non expression of the feelings confuses the respondent about what answer to give for the question.

Conclusion The emotion question is useful for indicating the emotional and behavioural state of the child- an important contributor towards schooling and education. The behaviours which have emerged as themes are useful indicators of the presence of an underlying emotional state of the child which would assist in providing essential resource support, and provide a holistic view of the child with respect to his abilities in the other domains. Since respondents are able to quantify emotions and explain it with reference to other emotions, the current version of the question is recommended, and remains unchanged.

If the purpose of these questions is to work "as a set" to identify children with disabilities as a whole, the issues parents of children with disabilities had in gauging sadness related to their disability is not a problem because those children will be screened positive based on their other disability. The main concern – of false negatives unrelated to disability– did not arise, so this question seems adequate.

Overall Conclusions and Recommendations

Overall, the cognitive interviewing study proved to be a successful endeavour in that it provided important insight into the performance of the child disability module. A research team was trained on cognitive testing procedures, and how to conduct analysis of the results using Q-Notes. The team conducted a large number of interviews – in both English and Hindi – to determine whether the questions worked as intended. The questions were designed to identify children with functional difficulties who have a high probability of being disabled.

Analysis of interviews revealed that the wording of the questions must be adapted to particular languages and cultural environments. It is not adequate to simply translate questions into other languages. They must then be cognitively tested in each language before being rolled out. However, cognitive testing is not expensive.

Taken together as a set in order to identify the overall prevalence of children with disabilities, the questions performed as intended. The only problems were false positives responses in a few domains. Some questions were designed to identify children with cognitive and communication issues associated with activities like learning, socializing, and behaviour management. However, some respondents reported difficulties in these areas that were linked to issues with physical disabilities. This is not a problem if the goal is to determine the overall prevalence of disability, but if prevalence rates by type of disability are desired then researchers must take into account that some of the children with difficulties with both walking and learning (for example), might actually not have cognitive learning disabilities. Also, when it comes to behavioural issues, it is probably more appropriate to use the "A lot of difficulty" cut-off for identifying children with disabilities, rather than the 'Some difficulty.'

The possible problems of over-identification are not important, however, if these questions are used as a screening mechanism to identify children for more detailed assessments. In that case, it is good to cast a net big enough to avoid a significant rate of false negatives.

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Chapter 12
Developing Tools to Identify Environmental Factors as Context for Disability: A Theoretical Perspective

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Introduction

People living with long-term functional limitations are very familiar with the influence of the environment, physical and economic structures, as well as cultural and social attitudes, on their lives. These factors can either restrict or support the individual's full participation in society or have a neutral impact. Our understanding of disability is difficult because of the relational nature of the concept. We have known for a long time that disability is not only located in the individual person, but is also influenced by the situational factors associated with the various roles the individual plays in their life activities (Nagi 1964, 1981). The influence of the environmental factors associated with the situation can vary by participation area, by individual goals and choices, by type of action difficulty causing limitations and other characteristics of the person such as age, gender and race. Though these latter personal factors are seen as a separate area in the ICF (2001), the inclusion of attitudes in the environmental context does not necessarily allow for the separation of attitudes toward disability alone when the person's age, gender or race can confound the social attitudes toward disability (Barnartt 2013).

Many of the theoretical approaches to the environmental impact associated with disability organize the environmental factors at two different levels, the individual and the societal levels. The immediate environment of the individual, including settings such as the home (reflecting the immediate family), the workplace (the specific job

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the person holds), the place of worship (the specific religious organization which the person chooses), locations of civic participation and other similar settings which surround the individual, create micro systems in which the individual is personally involved. The person deals with the physical and material elements of the context as well as the attitudinal responses which are reflected in the interpersonal interaction that take place in these micro systems. The societal or meso level of environment reflects the structure and organization of various systems in the community that provide services, protection, shelter, food and other products, entertainment, and health care for the total population including things like transportation systems, policing, building construction systems, grocery chains and other forms of product distribution and health care systems. The individual is not always aware of the system level of the infrastructural or service constraints although they are hugely influential in dictating disability policy in the various social structures. While it is well recognized that both these environmental areas, individual and societal, can have a great effect on the disabled person's ability to participate in their chosen social roles, we have very little national or international data on the patterns of environmental barriers or supports. So, for example are there similar patterns of transportation barriers for wheel chair users in all parts of a country or only in rural parts? Or from another perspective are transportation barriers for persons in wheelchairs very different from those experienced by persons who are deaf or blind and what are the similarities or differences in participation that those barriers create.

Much of our information and understanding of these environment/person interactions are based on anecdotal stories of personal experience rather than organized data on the general environmental context. Rehabilitation service providers often explore the immediate nature of the context their clients live or work within. In many cases they have developed questionnaires to collect extensive environmental information from their clients but the data collected in this manner, while detailed, is usually focused on one type of functional limitation or impairment. The questionnaires are not often generalizable to differently impaired individuals, to different geographic areas nor to different societal contexts. Rehabilitation service approaches raise important individual issues, but the data they produce is not representative of persons with disability who are not involved in rehabilitation and thus not necessarily applicable for national policy purposes.

Objective of Understanding Environmental Role in Disability

A major objective in research about disability is to understand the lived experience of persons with impairments or limitations and to facilitate their inclusion in Society including the equalization of opportunity to participate in their societies in the way that they would choose for themselves. For example, in the United States for almost 200 years we have identified individuals with some impairments in our national Censuses in order to track different aspects of their existence, age, gender, living arrangements, school attendance, ability to work and in some instances their location in institutions. In actuality since 1830, in the U.S. at least, we have monitored persons with a variety of impairments as part of census tracking of the whole population. However, for all this time we have ignored the impact of environment on that experience mainly because the problem was always situated with the individual. While more recently that error has been rectified, theoretically, we have yet to develop commonly used, reliable measures for national surveys. However, I will note that two European surveys have introduced such items in the past 3 to 4 years. Data collected in studies on aging have had important information about the home environment for some time, and in the case of the Health and Retirement Survey information on the work environment as well, however, for the most part we have missed a very important part of the disability equation by not accounting nationally for environmental barriers and supports in our data.

For years we have identified the person with impairments or functional limitation that put them at risk of having a disabling experience in their everyday life based on their personal limitations, but have not identified anything about the context of that life that helps to create their participation disability. Identifying the person with limitations in their basic actions, such as walking or hearing is only identifying the person who is “at risk” for disadvantage or discrimination and is only one piece of the situational relationship identified by Nagi (1981)or the equalization of opportunity emphasis as identified today by the Convention on the Rights of Persons with Disability (CRPD). The nature of the environmental facilitators or barriers are the other piece of the “disability” so that Type of Risk (person’s limitations) +/− Environmental factors (facilitators or barriers) influences Level of Participation or Inclusion. This formula is applicable to all people, not just persons with disabilities since the type of risk may also be associated with personal characteristics such as race, gender or age in areas where women or non-majority races may be treated very differently and also impact participation. Type of risk can be further broken into meaningful parts such as the interaction of gender and race or gender and disability, but without the environmental component we can only make assumptions about the factors that are facilitating or blocking participation. Therefore the purpose of this discussion of environmental measurement is to identify a way to capture the social policy related environmental facilitators and barriers that most prominently support or prevent participation.

Considering Environment Issues Cross-culturally

Recent national and international legislation such as the American’s with Disabilities Act (1990) and the Convention on the Rights of Persons with Disability (2006) have established a mandate for understanding the role of the environment in disability cross-culturally. Regardless where a person resides, once the individual moves outside of the home to shop for food, visit a doctor, use public transportation, go to school, or work at a job or any of the more complicated activities associated with participation in a social system, examining disability issues needs to be concerned with the interactive nature of the person in the environment, the real crux of disability. In most data collected today, measurement of this interaction is through identifying the activities that reflect ***actual social participation of the person(such as working at a job or going out for dinner) or lack of participation***, ***without any elaboration of the context within which the activity takes place***. While we may know, from measuring basic functioning and simple task activities, what a person brings to the attempt to use their local environment such as public buildings and transportation, we know very little about the buildings or the transportation system itself. The regularity of transportation schedules, the type of vehicles, the routes they travel, the fares they charge, or the experience the individual has with that system all can influence the usefulness of the system for the person. The same is true for the person without a basic action difficulty as well – we have nothing to help us understand what one has to negotiate in order to use the transportation system successfully, **nor** do we have the factors influencing the ***choices*** a person may or may not have about how to use what is available.

There are questions that have been developed, primarily by rehabilitation professionals, to try to get at these more complicated aspects of the environment on social integration and participation, but they are relatively simple and focused on the individual's personal evaluation of the difficulty of the experience or the frequency they have the experience rather than a description of the nature and extent of the problem encountered. While the evaluation of the experience is very helpful, it focuses the resulting data on the *disabling impact of the environment on the person* (level of difficulty and frequency) rather than describing the real nature or scope of environmental barriers or supports in a locale or in an area of participation. That still focuses remedies on the individual requiring their adaptation rather than identifying the barriers specifically so that they can be changed or eliminated. Generally, as well, the questions have been developed for a particular type of limitation, most frequently mobility limitations, and are not necessarily applicable to all types of functional limitations or in all cultures. Additionally most do not include anything about the element of choice. Using such measures gives us some clues about environment, but provides a false sense of having measured the environment when in actuality what has been measured is the impact of the environment on the individual (see Whiteneck 2004).

Contemplating cross-cultural measurement of environmental facilitators and barriers for persons with limitations in basic activities helps create a different perspective for understanding the environmental context. Rather than that dominated by a person's immediate experience, it brings a focus on assessment of broader contextual circumstances. Approaching this problem cross-culturally evokes images from very modern high speed rail transportation in Japan to travel by donkey or mule in Tibet, of one story mud huts in Rwanda to multi-story skyscrapers in Shanghai or steep mountains in Alpine regions to miles of plains in the Caucuses. **It allows one to recognize that the issue is not the sophistication or simplicity of the transportation system or the variety of architectural styles or the various topographies of separate regions, but rather**, ***how what is available works to inhibit or facilitate the participation of individuals with a variety of functional limitations***. It brings the situational circumstances of participation into consideration linking the mode of participation to the context within which it takes place even more closely. In a country where there are no curbs, there aren't any needs for curb cuts. A cross-cultural approach to environmental definition and measurement requires creating an approach that is culturally neutral while at the same time recognizing that physical topography and weather, building structure, means of transportation and culturally approved methods for doing things are what create the barriers or supports we seek to identify. In other words, we **are not** examining the differences between transportation systems or home structures across cultures, **rather we want to know how *<u>the</u>* transportation system – whatever form it may take – works for the population with disabilities within each culture**.[1] Unlike the approach from the rehabilitation perspective which tries to understand the individual environmental experience and solve it or modify it via altering the individual's way of accommodating to the problem or offering tips on building adaptations, we are approaching this problem from a more general viewpoint by using what is experienced to identify the range of possible environmental problems from a population perspective, more similar to creating a profile of structural/cultural elements as they do or don't impact persons with physical, mental and emotional limitations. The question we are addressing does not focus on the differences among specific factor A (for example the specific types of building structures) across cultures X, Y and Z. Rather it addresses the facilitation or restriction of ***common daily activities*** that the society has developed in a particular environmental element (the types of building structures or the form of the transportation system) as experienced by the citizens with disabilities within that particular culture. The unit of analysis is the various types of participation a person commonly engages in rather than the individual although the data is collected from the individual. In other words our objective is to create a profile of the range of accessibility in the various cultures as experienced by a representative sample of the population in that culture that report a variety of functional limitations as defined by the Washington Group short set of questions for international censuses or the WG extended questions. That profile then can be used as an intervening variable to explain levels of participation among the populations with various types of functional limitations.

While such an approach can be accomplished by observation through measurement and testing of every environmental component in every habitable area of a country, that thorough an assessment is neither physically possible nor economically feasible. However, data collected from random population samples can serve two purposes, identifying the individual experience of person X as they attempt to move around and participate in their cultural environment and when the sample is aggregated describing in a general way the type of barriers or facilitators that are encountered in a specific area of participation in a specific culture. That will give us a more general picture of how the culture is accommodating its population with disabilities. Although a respondent will only be able to respond based on their own personal experience with the immediate types of environmental components with

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[1] Ideally we would want to know that information for everyone in the culture since the social structure may provide barriers and supports for everyone in one way or another. However, our first concern is to identify the types of barriers and supports experienced by persons with disabilities.

which they come in contact in their micro systems, aggregating the answers to the questions will reflect the more general representation of the cultural experience of everyone with any type of functional limitations if the survey uses a representative sample of the population. Such a description can then be examined in terms of whether or not the respondents are disabled or not, elderly or by the specific type of functional difficulty they report. It can even be examined in terms of their educational level or in the context of the resources they can bring to the problem if that information is included in the survey. Certainly our expectation is that persons using wheelchairs or other mobility devices will have different areas that create barriers or supports than persons with vision or hearing difficulty. However, there also may be income, age and gender differences as well.

This approach to measuring environment differs from asking questions about the individual's difficulties functioning since humans are the same across cultures in terms of their types of physical, mental and emotional functioning capacities. Cultural differences may dictate that some people walk more than others or that some carry heavy loads on their heads and others on their backs, but we all have what can be considered the same equipment (arms, legs, eyes, ears, minds) and when there is a problem with any of those functions we experience difficulty and or limitations in the same way, inability to see or hear, walk or carry. However the cultural organization of societies exist within a variety of natural environments and weather conditions which create very different problems that have generated a variety of alternative solutions for architectural construction, transportation and other social problems like the distribution of resources and the development of value systems. So when we measure the environment we are no longer measuring similar areas of functioning, but instead very different approaches to what are similar requirements for life: housing, feeding, transporting, educating, employing, protecting, etc.

In the past we have recognized that disability actually is the outcome of personal limitation caused by health conditions and impairments and the impact of those limitations on full participation as allowed or supported by environmental characteristics (Brandt 1997). One element that contributes to disability is the functional limitations a person experiences related to their health condition or injury which they bring to their activities. That is the individually specific element. All humans have the same basic physical, mental, sensory and emotional functioning potential regardless of the culture they inhabit. Some people may have greater or lesser degrees of physical strength, but we can recognize strength or mental ability (or its lack) wherever it exits, whether it occurs in a black man in Africa or an Asian woman in Bangkok. The experience of functional limitation is relatively uniform cross culturally although type of diet or employment in various areas may increase the presence of certain kinds of limitations (onchocerciasis or river blindness a parasitic disease found in sub-Saharan Africa or fetal alcohol syndrome found among Native Americans and in high rates in South Africa). However, the cultural environment, both physical and social can vary widely. Similar levels of physical functioning difficulty can have widely different outcomes based on the environmental requirements of the different situations persons occupy or the various cultures they inhabit. In order to measure the effect of culturally different environments it is necessary to develop measures that can vary with the characteristics of the specific culture, but can also capture the cross national experience of persons with varying levels of functional difficulties. So, for example, assume there are two men with similar mobility limitations due to a spinal cord injury at the 5th vertebrae. The ability to toilet independently for person A, who lives in an accessible new apartment construction (with indoor plumbing, raised toilet seats and transfer bars) in California, will be very different than the ability of person B to toilet independently using an outhouse in Bangladesh. Our objective is to somehow make those very different environmental experiences meaningful components in examining the environmental impact cross culturally. Incorporating the detailed environmental elements **as they relate to an activity** rather than comparing the detailed characteristics of the environmental elements themselves can at least profile the differences. Person A when asked about the accessibility of toileting facilities can report independent toileting capacity as successful based on a supportive environment while Person B can report his independent toileting as restricted due to inaccessible facilities.

Current Forms of Measurement

The various taxonomies associated with environmental contexts for persons with disabilities identify multiple conceptual categories of the environmental components that can provide barriers or supports to persons with disabilities, including such things as building structure, uneven terrain, modes of transportation and attitudes of others. Typically the tools that have been developed for assessing the environment will concentrate on only one or two aspects of the context that have been considered important and measurable. For example, the built environment seems to be an area that can be measured successfully and is frequently used in examination of circumstances of the aging population. However the built environment is one that covers very broad areas of possible participation, the immediate environment of the home, the work environment or the environment of any of the various types of public places, from parks to health provider's offices. Each participation area can have a variety of features including the multiple structural components of the built environment (stairs, elevators, room size, etc), the material aspects within the built environment (lighting, furniture, doorways, etc) and attitudes of other people occupying that same context. It is not possible to encompass all types or all elements of environmental contexts. Therefore in development of measures, decisions must be made as to the level of approach (individual or societal), range of participation environments to be included and the elements within that participation area to be addressed. It is not possible to encompass the complete environmental context in any great detail as demonstrated by Noonan et al. (2009) and Chang et al. (2013) work reviewing the content of a variety of participation instruments. Therefore, decisions about the focus of measurement require very careful consideration.

The orientation of the approach to environmental measurement to this point has also been very focused on the relationship of the individual to his/her environment primarily coming from a rehabilitation or clinical perspective with a focus on outcomes, particularly from the perspective of an individual with a mobility limitation, brain trauma, or intellectual disability. As proposed by Stark et al. (2007) the purpose of the environmental questions they developed were to examine the ecological validity or receptivity of physical features from the perspective of individuals with mobility impairments. Their focus was accessing a building and using it. A very different approach is that of Clark and George who focused on what are called the 3 D's, density, diversity and design, environmental conceptions that are used to represent the built environment in many study areas such as examinations of transportation use, poverty, and crime and violence (Clarke 2005). The focus of measurement in this approach is housing density, the ratio of number of housing units per square mile in each census tract, and land use diversity, measured by the proportion of workers in the tract who commute to work within 5 min. Other aging literature is closely related to a medical approach and concerns about rehabilitation. They examine the household itself and ascertain physical characteristics related to presence of stairs, accessibility of bathroom and kitchen facilities and adequacy of lighting. Finally a fourth frequently used measure of environment for the aging population is associated with the use of assistive devices and personal assistance to mitigate some of the limitation (Agree 1999).

Since we are approaching this problem from a cross-cultural perspective to identify environmental factors and their impact on participation, the strong impact of culture on physical environments and ways to accomplish tasks makes it difficult to create measures that identify similar constructs across various cultures which may use different tools or have very different ways to accomplish a specific task. Getting water to make a pot of soup, for example, may have very different physical and intellectual requirements. In one country, where modern plumbing only requires turning on a faucet to get water from a sink that is situated next to a stove, makes the process very simple compared to other countries (or areas of the same country) where acquiring water requires going to a well, filling a container, lifting and carrying the container with the water back to the cooking area. How do we reconcile those two different experiences and how do we measure the environmental contexts so that we are getting at the environmental barriers and facilitators that are conceptually equivalent? **Or, do they need to be equivalent**? Is it possible, given a particular culture, to identify the nature of physical and social barriers and supports that exist without comparing across cultures to ascertain the similarity or differences among the descriptions of those barriers or supports. In other words, **is it more important to identify specific barriers that exist that have a commonality across all or most cultures or can we examine the <u>common activities</u> (maintaining a family life) or <u>common facilities/locations</u> (shopping areas) or <u>common services</u> (transportation) that exist and develop a country specific profile of the types of barriers or facilitators that are associated with these locations or types of activities**. This is probably easier to do if we concentrate on basic types of activities than if we examine more culturally related activities such as specifics of work situation or the nature of the value system a culture has developed. Thus, for this **initial** attempt at developing environmental measurement, we propose an emphasis on common services associated with the three primary areas of daily activities, maintaining a home, using transportation and using community resources (such as shopping areas, libraries and museums or accessing government services).

Three Approaches to Measurement

Having examined the environmental question sets that have been developed to this point, we identified three approaches to this task. The first approach is a ***structurally descriptive*** one. Keysor, Jette and Haley have used this approach in the HACE instrument (Keysor et al. 2005). This instrument, which is asked of individual respondents, focuses on the self reported description of mobility related characteristics of the home (such as the presence of stairs), community and transportation system (such as whether or not transportation is close to the home), use of assistive devices, and appraisal of attitudes (attitudes of people in the community in general). Another version of the descriptive form of instrument was developed by Stark (2007) and focuses on community receptivity which through a rank ordered checklist (CHEC) can be administered in the community by health professionals or community members and does not require respondents or questions. The Clark and George (2005) approach which describes the density, diversity and design of the environment is another version of a structurally descriptive approach that is less focused on the individual barriers or supports but provides a better description of the area ambience or safety. None of these examples reflect the personal experience of the individual with mobility limitations but all can document the potential general accessibility depending on the nature of limitations. As such the descriptions are a valuable tool for rehabilitation professionals in order to understand what skills need to be addressed to improve patient mobility or safety. Depending on how extensively the structural reviews are completed, it is possible to conceive that such reviews can document either all the public structures in a town or alternatively all the locations for certain kinds of activities such as eating out or attending a movie. However, the possibility of completion of such reviews in every town and city within a nation or culture are less certain.

The second approach to measuring the environment is also found in rehabilitation literature and focuses on the ***personal experience*** with the environment based on level of difficulty and frequency and the evaluation of that experience which represents the *person/environment interaction score*. Whiteneck's (2004) work with the CHIEF combines a measure that identifies the frequency a particular difficulty or problem is experienced in the environment with an evaluation of the level of that problem. As an example, the question about transportation asks "In the past 12 months, how often has the availability of transportation been a problem for you? Daily, weekly, monthly, less than monthly, never." It is followed by a question asking "When this problem occurs has it been a big problem or little problem?" The answers provide a combination of frequency and intensity descriptions of the problems the person experiences when interacting with the transportation environment . In **actuality the resulting score** (created by combining both responses) **is a measure of the level of difficulty based on the person/environment interaction as defined in the IOM as the displacement in the environmental mat** (see Fig. 12.2 in Appendix depicting that relationship). The amount of displacement in that mat represents the amount of disability that is experienced by the individual and this combination of questions provides an approximation of that construct. Of course additional characteristics of the person, their resources and the participation circumstances can also interfere further or can reduce the level of disability the person experiences.

In the work of Gray, Hollingsworth, Stark and Morgan (2006) there is a similar combination of identifying an environmental element as an influence on participation and the evaluation of that experience with the environment element. In this instance, however, the respondent can identify the environmental element as an influence that is either *helpful* or *limiting* and can also provide an indication of the frequency so that a score can include both positive experiences as well as negative ones. Questions from Gray (2008) include home and community environmental components and also information about community destination access. A representative question from the Gray et al. (2006) instrument asks: "In your home, do the following influence your participation activities? Stairs? Yes, No, NA." If the answer is Yes the following questions are asked: "How much? (Help a lot, help some, limit some, limit a lot – provides level of difficulty or helping) and How often? (Daily, Weekly, Monthly, Less than monthly – provides a frequency measure)." Once again there is a combination of frequency and intensity of the experience only this approach provides a scale that ranges from positive to negative rather than just a negative descriptor. The result of the combined measures of how much and how often in this instrument is another version of displacement in the environmental mat. Both are good approximations of the severity of disability that the individual with a limitation in a basic action experiences in their immediate environment. The resulting data provide important information for the rehabilitation process by identifying where in the environment the individual patient experiences problems (or in Gray's study also support), the disabling effect the person experiences as a result of the problem and the intensity of that effect. However rather than creating a measure of the environment, the resulting measurement is a descriptor of the person /environment interaction and in many instances the environmental element is a generalized component of the environmental context. The *person/environment interaction* type of measures provide the frequency and level of problem created by the environmental focus of the question. It either provides the level of barrier as specified in the first set of questions or the level of barrier to level of support experienced in the environment as represented by the second set of questions. The resulting score created by the questions reflects the level of disability created by the combination of the person's limitations and the environmental barriers or supports. These measures do not profile the environmental context so that factors found in all homes or transportations systems can be identified as detrimental or supportive of the needs of the population with disabilities. However it can indicate the average experience of individuals with limitations in the local transportation system or in their home. However, it tells us more about the mico context of the most common locations of the individual and less about other factors that impact their broader participation.

The third approach to measurement focuses on a ***person's participation level*** and can include environmental characteristics that act as barriers or supports. Such measures can be found in national surveys both in the United States and Europe. This approach focuses on *various types of participation* and allows the respondent either to describe the barriers or facilitators that interfere or support their participation in an activity that takes place in a building structure or in conjunction with various service systems or various role activities. Alternatively, environmental characteristics along with other personal characteristics are used as elements that the person can report as preventing participation. In some instances the approach has also included some indications of participation choices or preferences the respondent may have.

The United States example of environmental questions took place in the 2002 National Health Interview Survey and focused on barriers that might limit or prevent activities at home, school, work or in the community. Questions allowed the respondent to identify a number of possible barriers that limited activities in those different contexts. An example of the question related to the home situation asked: "Thinking of your home situation do problems with any of these things on the list now limit or prevent your participation in home activities or household responsibilities? Yes/No." This was followed by the question: "Which ones?" –This allowed the respondent to choose any number of responses from the following list: Building design (stairs, bathrooms, narrow or heavy doors); Lighting (too dim to read, signs not lit, too bright, too distracting); Sound (background noise, inadequate sound system); Household or workplace equipment hard to use; Crowds; Sidewalks and curbs; Transportation; Attitudes of other people; Policies (rental policies, eligibility for services, workplace rules); Other barriers; Refused; Don't know. A follow up question included the frequency with which a person/environment interaction factor occurred asking about how often these things limit or prevent respondent's participation in home activities? "Would you say always, often, sometimes or rarely." This followup measure can be interpreted as representing a level of severity of the combined factors identified, but not of any single factor. So if a person indicates that both building design and lighting limit or prevents participation, it is not clear if one or both are of equal or different levels of barriers.

While the answer categories in the U.S. questions are probably inadequate to get at all the meaningful possible barriers and ignore the supports that also may be available, it does begin to identify the key environmental factors that create limitations for the individual in a specific participation area. When aggregated across individual's this could begin to document national patterns of the types of environmental context problems experienced in a variety of contexts without focusing on the individual interaction with the environment (Altman et al. 2014). The inclusion of the frequency question does also give at least a piece of the person/environment interaction aspect as well. So an aggregation may show that 30 % of persons with mobility disabilities indicate that building design in the home limit participation in household responsibilities, while 15 % of all persons who report a functional limitation report that attitudes of persons in the home environment are limiting of their participation in home activities. However since the questions don't identify the frequency of each type of barrier, we can only identify the proportion of the population with disabilities who always have barriers within the home compared to those who have barriers less frequently.

Additionally, there are two European surveys that now use participation questions which get at environmental elements, but in a somewhat different manner. These questions seek to identify many possible barriers to various forms of participation and incorporate not only physical environment barriers, but financial and personal barriers as well. The first survey that includes these types of questions is the European Health and Social Integration Survey (EHSIS) which focuses on a variety of social, work and leisure activities. An example of one of that survey's questions is as follows:

- I would like to ask you about hobbies or interests that involve spending time with other people, for example, belonging to a club or association, or taking part in sporting or fitness activities.
- Is there anything which prevents you from pursuing hobbies or interests whenever you want to?
  - Financial reasons (lack of money, can't afford it)
  - Too busy (with work, family, other responsibilities)
  - Lack of knowledge or information (about what is available)
  - A longstanding health condition, illness, or disease
  - Longstanding difficulties with basic activities (such as seeing, hearing, concentrating, moving around)
  - Lack of convenient or available transport
  - Distance (to venue)
  - Difficulties accessing or using buildings
  - Lack of self confidence or attitudes of other people or no one to go with
  - Other reasons
  - Don't want a hobby or interest
  - No, nothing prevents me from pursuing hobbies or interests whenever I want to.

Although this format allows a respondent to identify some environmental barriers both in physical structure, transportation services and economic barriers such as lack of adequate financial resources, it also allows the respondent to include the contribution of their health conditions or basic action limitations.[2] While this does

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[2] The authors of this paper were not able to reconcile their difference in opinion about the inclusion of health conditions and functional limitations as well as environmental characteristics as answer categories before the second author passed away. Therefore both approaches to these answers are included here for the reader to come to their own conclusion.

directly approach the issue of whether the respondent should consider their health condition or functional limitation or the environmental factors raised by Noonan et al. (2009) and Dubuc et al. (2004), should the answer categories include both or should the impact of health condition and environment be examined with separate questions? However the second author has noted that the ICF is based on a biopsychosocial model and felt that one cannot look at a person/environmental interaction without looking at the characteristics of the individual as well as the characteristics of the environment. Obviously this is an area that needs further research.

The additional answer category "Lack of self confidence or attitudes of other people or no one to go with" mixes personal characteristics, attitudes of others and lack of company into one category and while all are possible deterrents to the activity, the combination into one category is confusing for interpretation by the respondent and for analysis purposes. However, this approach does allow the respondent to incorporate some objective and subjective elements of participation noted by Chang and Coster (2014) through the choice element included in the responses allowing the respondent to indicate not wanting to do the activity and also allowing the respondent to indicate that such an activity is not prevented if wanted. Two additional questions allow the respondent to indicate that lack of assistive devices or personal help are additional factors preventing or limiting the activity.

The second European survey with similar questions is the Life Opportunities Survey (LOS) from the Office of National Statistics in England. This survey is much more detailed than the EHSIS although it uses similar categories to document the barriers to activities. It also allows respondents to indicate that they do not need or want to do the activity. Actual questions related to a similar subject to the one indicated above in the EHSIS asks about community, leisure and civic life:

- In an ideal world, where you were able to do whatever you like, which of the things on this card would you be interested in doing? (code all that apply)
  - Going on holiday
  - Visiting friends
  - Spending time with family
  - Playing sport
  - Charitable or voluntary work
  - Going to a museum or place of historic interest (country home, castle, etc.)
  - Going to the theatre, cinema or other arts activity
  - Going to the library or archive
  - None of these
- Looking at the card again in the last twelve months, which things have you done as much as you would like? (Same choices)
- What is stopping you from going on holiday (more)? (Code all that apply)
  - Too busy/not enough time
  - Too expensive
  - No one to go with
  - Fear of crime

- Fear of crowds
- Lack of availability
- Lack of help or assistance
- A health condition, illness or impairment
- A disability
- Attitudes of other people
- Difficulty with transport
- Difficulty getting into buildings
- Difficulty using facilities
- Caring responsibilities
- Feel that I am not welcome
- Do not need or want to
- Other reasons (please specify)

The questionnaire continues asking more detailed questions separately about the seven additional activities asked about in the first question, visiting friends, spending more time with family, etc. But once again we find that physical condition/illness and disability are included as a barrier, as well as psychological aspects of participation associated with "fears". The lack of assistive devices is not addressed, but the lack of assistance from others is incorporated into the answer categories.

Several issues associated with these extensive sets of questions regarding participation as sources of information about environmental issues are raised. First, while the psychological frame of mind (separate categories in the LOS) can contribute information about barriers in the combined form noted in the EHSIS (mixing personal characteristics, attitudes of others and lack of company into one category) makes the usefulness questionable. Another issue, not resolved in this paper, involves the combination of personal health characteristics with environmental barriers in the answer categories. We assume that functional limitations have been captured elsewhere within the survey with the WG short set and/or the extended set, so the biological component is already known. If "other reasons" are included among answer categories, that offers an outlet for the biological component if respondents feel the biological component is primary to not doing the activity. However, we would note that other biological characteristics that can impact participation such as age, race and gender are not included and are probably allowed to be captured elsewhere. Testing the questions with and without the biological components may be one way to explore this issue. For the moment we will leave the point to the reader to decide for themselves.

Table 12.1 provides examples of the questions used to depict various environment areas that have been used by researchers. It gives examples from both descriptive applications and respondent interviews about experiences and participation.

Table 12.1 Examples of instrumentation to examine environmental aspects

Source	Structural barrier description		Personal experience with barriers/ supports		Participation description	
	Immediate surroundings	Extended surroundings	Describe experience	Evaluate experience	Description of barriers	Other information (frequency/choice)
Natural environment						
Gray et al. (2006)				In your community does summer weather (heat and humidity) influence your participation in activities? help a lot, help some, limit some, limit a lot		
Whiteneck (2004)			In the past 12 months how often has the natural environment – temperature, terrain, climate – made it difficult to do what you want or need to do? (Daily – Never)	When this problem occurs has it been a big problem or a little problem?		

(continued)

Table 12.1 (continued)

Source	Structural barrier description		Personal experience with barriers/ supports		Participation description	
	Immediate surroundings	Extended surroundings	Describe experience	Evaluate experience	Description of barriers	Other information (frequency/choice)
EHSIS					Is there anything which prevents you from leaving you home whenever you want to? Choose all that apply – however only one answer category refers to natural surroundings: 7. Unsuitable surroundings (such as hills, slopes, steps, footpath design)	May I just check does the lack of personal help or assistance prevent you from leaving your home? (yes/no) Does the lack of special equipment prevent you from leaving your home whenever you want to? (yes/no)
Intersection of natural and cultural environment						
Built environment						
Keysor et al. (2005)	How many steps are at the main entrance of your home?	To what extent does your local community have public transportation that is close to your home?				
Gray et al. (2006)			How frequently you encounter the home feature (stairs): Daily, Weekly, Monthly, less than monthly	How much home feature (stairs) influence participation in activities: help a lot, help some, limit some, limit a lot		

Whiteneck, Harrison-Felix et al. (2004)			In the past 12 months, how often has the design and layout of your home made it difficult to do what you want or need to do? (Daily to never)	When this problem occurs has it been a big problem or a little one? (Little, Big)		
NHIS in the U.S. (2002)					Thinking of your home situation, do problems with any of these things on the list now limit or prevent your participation in home activities or household responsibilities? Flashcard: 1. Building design;[a] Lighting; Sound; Household equipment hard to use; Crowds; Sidewalks and curbs; Transportation; Attitudes of other people; Policies; Other barriers	How often do these things limit or prevent your participation in home activities? Would you say always, often, sometimes or rarely?

(continued)

Table 12.1 (continued)

Source	Structural barrier description		Personal experience with barriers/ supports		Participation description	
	Immediate surroundings	Extended surroundings	Describe experience	Evaluate experience	Description of barriers	Other information (frequency/choice)
2011 EHSIS – In Europe					Thinking of all the building you want to use is there anything which prevents you from using them whenever you want to? Flashcard: Difficulties parking; difficulties getting into or out of buildings; Difficulties inside buildings; A longstanding health condition, illness or disease; Longstanding difficulties with basic activities; lack of self confidence or attitudes of other people; other reasons; No nothing prevents me from using buildings whenever I want to	May I just check does the lack of personal help or assistance prevent you from leaving your home? (yes/no) Does the lack of special equipment prevent you from leaving your home whenever you want to? (yes/no)

[a] See text for descriptive elements associated with the various categories

Narrowing the Purpose of Data Collection

How do these approaches address the need for environmental measures? The focus of the examples provided is on either the impact of the environment on the individual (difficulty and intensity as defined above), a mostly physical description of the environment in which the individual is doing their functioning (HACE questionnaire), or a description of the environmental barriers experienced in specific participation areas. The issue becomes what is our purpose for the data collection about environment? Do we want to document the magnitude or intensity of the person/environment interaction in various countries across the world or do we want to document/measure/describe the environment as an independent factor as it is experienced by the population with disabilities in various cultures to identify areas where improvements are necessary. When we document characteristics of the individual experience of the environment based on difficulty and frequency we describe the person/environment interaction without necessarily ascertaining exactly what aspects of the environment create the problem or provide the support. If we have persons with disabilities identify the environmental locations that give them trouble and indicate what characteristics of that environment cause the problem or facilitate access we get less information about the level or intensity of the environmental problems for the person, but more information about the location and characteristics of the environment that create problems in various cultures. However, the mapping of environmental barriers/facilitators even with an extended set of questions is very difficult since space limitations, costs and respondent burden will limit the range of questions that can be asked. Instruments used in clinical situations, which focus on the personal impact of environment are just too long for general survey purposes. Asking environment questions in a survey context requires a serious examination and narrowing of the purpose of the questions because of the necessity of a limited number of questions. Identifying barriers to participation as done in the EHSIS and LOS shows a more direct relationship between the variety of barriers and participation, but with multiple answer categories, it is hard to separate the most important barriers from those of less importance or less frequently experienced.

Hierarchy of Environmental Contexts and Participation Roles

If we consider how we live our lives, we recognize a hierarchy of contexts that can influence participation and the range of venues in which participation takes place. The contexts of concern radiate out from the person's living space to the areas where their most distant travel will take them. In some instances the range is very small and limited; in others it can eventually include international travel. For most it takes place primarily in their native community and possibly nearby communities (see Fig. 12.1). The most basic level of that hierarchy is the home context, the place where the individual does most of their living, eating their meals, sleeping and

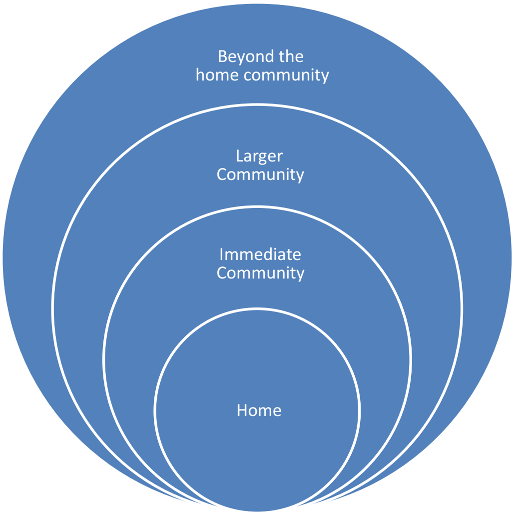

Fig. 12.1 Hierarchy of participation contexts

participating in family relationships. One can think of these contexts in several ways, first focusing on the physical situation, meaning the size and shape of rooms, the lighting, the availability of water or heat, or the presence or absence of stairs and so forth; a second way of thinking about it is in terms of the social actions that take place in those physical environs including the activities that take place in the space, the kinds of things that can or cannot be accomplished in the space or the possible interactions with others in the space. We can also think of the material environment as it relates to life activities, cooking, eating, bathing, sleeping, interacting with family and friends. In some instances it will not be easy to separate the physical environs from the social/cultural way of doing things which will make measurement more difficult. In terms of measurement of these experiences across architectural styles, room and building sizes and comfort, one wants to think not so much about room size, existence of multi levels or number of rooms, but of the ability to accomplish activities within the space that is available and as it is constructed including material objects used within the household. It may be that a person cannot access all the rooms in a home, but can they accomplish all the activities in which they want or need to participate within the rooms they can access?

The next level of engagement is the immediate community surrounding the home. The various activity spaces – work, school, recreation, acquisition of consumer products, service provision, all require the same examination of the physical structural environment that was established in the home. However the environment outside the home may or may not include paved areas, streets with traffic or close neighbors. Distances between the home and places of work or school, community centers and churches, or shopping and service provision may vary in some instances requiring some form of transportation. For that reason the need for transportation and the types of transportation available become an important additional piece for understanding the environment.

The final element of concern in this first approach to understanding and measuring environment on a cross-cultural basis is the presence or absence of discrimination or negative attitudes that exist in the social environment in which the person with disabilities engages. Though it would be difficult to identify all social interactions and interpret the negative attitudes that may exist in each one, it probably is important to at least get some perspective on how widespread discrimination is in a particular culture.

There also is what can be considered a hierarchy of participation roles. Self care is probably the primary role a person must play in order to maintain existence. When a person has a problem maintaining self care they are much more likely to experience significant barriers in other forms of participation as well. Additional participation roles include family roles, shopping roles, home maintenance roles, work roles, extended family roles, friendship roles, citizenship roles, religious roles and others. However, the important thing about the participation role hierarchy is that it is organized by personal choice so that while we can hypothesize a generalized participation role hierarchy, it will only be an approximation of what is found with individuals in the population based on their personal choices. In order to capture the participation/environment interaction it will be essential to consider these two hierarchies, environmental space hierarchy and role participation hierarchy.

Contextual Overlap

It is necessary to also note that in some instances there is an overlap of environmental problem areas in multiple participation contexts. One such overlapping area is transportation since ability to get around in a community may influence consumer roles, work roles as well as leisure activity forms of participation. Another area of overlap can be associated with personal income levels and the important role that resources play in the ability to participate in numerous types of activities, not only because of the cost of the activity itself, but the cost of transportation, the cost of assistive helpers or the cost of equipment. It may be that the aspects of a specific form of participation that can be overlapping with many other forms of participation should be addressed separately in a questionnaire in order to provide additional answer space to incorporate a greater variety of other forms of support or barriers.

Discussion

There are three possible approaches to environmental measurement – the personal difficulty with the environment which is reflective of the respondent’s situation acting in that environment – or a descriptive profile of the built environment/transportation system of the culture that provides a map of the typical locations/resources available in the country – or an examination of barriers and supports that are experienced in specific participation situations. The first allows us to capture the lived experience of disability in a wide variety of persons with limitations or difficulties. The second would provide some key focus areas of the environment in which important participation takes place and provide a general description of the facilitators or barriers that those environments provide. This can be a general documenting of how the individual experiences the commonly used areas of environment and how well those environments fulfill the needs of the general population with disabilities. The third, focusing on the activities which are common across cultures (important life activities) and aiming for a general level of data would avoid the biggest cultural differences among countries and allow us to talk about home architecture, architecture in public spaces, transportation systems and possibly a broad view of discrimination without the complication of cultural differences. If we take this more general view of the environmental system it will allow us to use some of the intra-country details of the transportation system or the home architecture to help respondents to understand what we are asking in the questions but without making those detailed comparisons across countries. For example if we ask about steps in homes in a culture where there are generally steps used, that particular detail can be replaced in cultures that rarely use steps with another more commonly encountered problem area that requires similar functioning capacity such climbing up an incline. The same kind of substitution is possible when asking about transportation. If a country does not have subways or bus systems and instead use horse or human drawn carts, that detail can be included. The cross-cultural comparison will focus on the more general aspects of the transportation system such as the cost or frequency when it is available, whether the vehicles are accessible or even whether transportation is available to the places that respondents want to go. The country could use the data relevant for their cultural way of doing things for within country analysis while we would have to develop a format for the between country comparisons. The comparison result would take the form of a statement indicating the general area of the problem as opposed to the specifics. So while in one country lighting in the home may be based on a fire or oil lamps while in another country it is based on intermittent electricity and in a third country it is based on regulated electricity (some form of rationing), the countries would be compared on whether or not lighting in the home was or was not considered as something that limited or prevented the disabled individual's participation in family life. The nature of the type of lighting in that approach is not a comparison element.

In order to develop a useful tool for measuring the environmental context it will be important to identify forms of participation that are common in all cultures such as eating/feeding, laundry, and shopping requirements in maintaining a household; various forms of education; religious membership and attendance; and a variety of social and leisure activities such as visiting friends, attending sports events or movies, going on holiday. Transportation is an important factor across participation areas and probably should receive its own question. While work activities may be too complicated to measure initially, receiving health care maybe an important area to examine since most persons with disabilities probably have a need for that service. Another area that has seen little examination of barriers for persons with disabilities is associated with safety and emergencies.

It is also important to note that the environmental factors influence everyone in a population, not just persons with disabilities. It would be preferable that the total population surveyed be asked the environmental questions so that the environmental elements can be identified accurately as limiting the entire population or limiting the population with disability to a greater extent.

Appendix

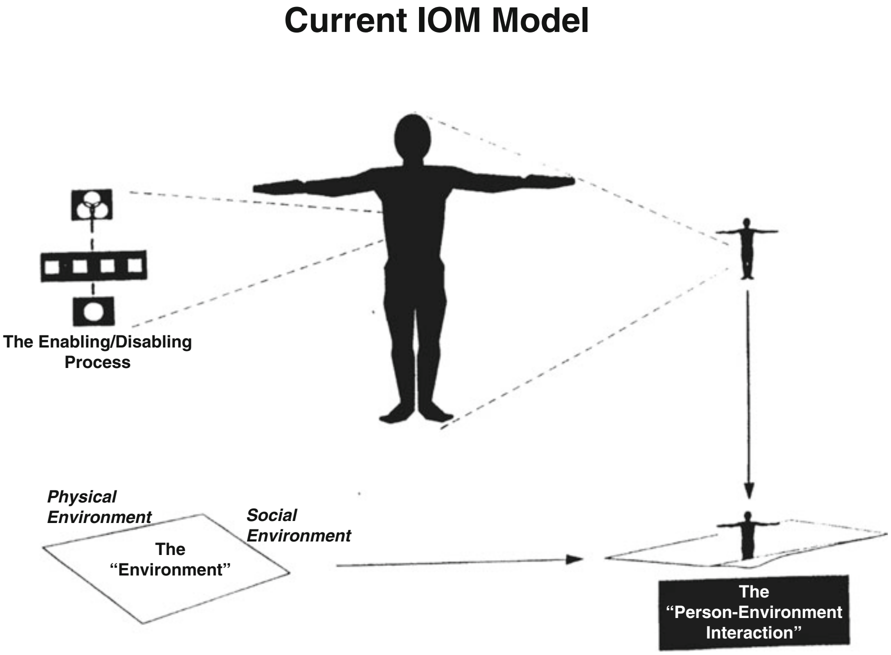

Fig. 12.2 Source: Brandt (1997)

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Chapter 13

International Comparisons of Disability Prevalence Estimates: Impact of Accounting or Not Accounting for the Institutionalized Population

Emmanuelle Cambois, Carol Jagger, Wilma Nusselder, Herman Van Oyen, and Jean-Marie Robine

Background and Hypotheses

The Limits in the Population Survey Coverage

Most health and disability surveys are based on samples representative of the population living in private households (household population or HP). In other words they exclude the institutionalized population (IP), i.e. those living in collective households such as nursing or health care institutions, homes for the elderly, communal homes, etc. The IP definition and boundaries are country specific, depending on the circumstances in which people live together and the availability of institutions. To include people in institutions in a population survey proves complicated at every stage, from creating the sampling design and constructing questionnaires that are strictly comparable to those designed for private households, to gaining access

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to residents and interviewing them. Extending a survey beyond private households is costly and therefore is rarely done. Excluding the institutionalized population obviously raises the question of the representativeness of the private household sample compared with the total population (TP) and, depending on the topic to be addressed, the representativeness of the data collected. This is particularly problematic when it comes to analysing topics which are related to the probability of living in or outside the household; for example, population health status since poor health and impairments are major determinants of living in institutions, depending on the health care system and supply of health-related institution.

The few surveys that have been included both residents of institutions and private households, such as the one conducted in France around the year 2000, have shown significantly higher prevalence of disability in homes for the older population, nursing homes/care institutions (Mormiche 1999; Cambois et al. 2005; Mormiche 2000) and prisons (Desesquelles 2005) compared to HP, particularly for the youngest age groups. So it is likely that the measurement of health or disability taken solely from the HP underestimates health problems in the TP though it is rare that one has the appropriate data to accurately assess the gap.

The degree of the impact that this difference would have on a health indicator for the TP is therefore uncertain. One could assume that the impact is small due to a trade-off between the size of the excluded population and the magnitude of the excess health risk. Where the excluded population is small it is likely to significantly differ from the HP, but its small size means that the impact on the overall indicator will be small. Where the excluded population is large, it is likely to differ less from the HP so the bias will be small. This would imply that in the end the bias due to the hypothesis that HP data are representative of the TP may have little impact on conclusions regarding time trends or disability differences between countries. This variation is also true regarding different age groups within a country. Living in medical institutions at young ages is generally extremely rare and driven by a disability which makes impossible to stay at home; the high disability prevalence in the IP induces a large differential with the low disability prevalence in HP: but the impact on the TP prevalence is reduced by the fact that the percentage of young people in institutions is small. At older ages, in countries where an IP is also rare, the situation should be similar to the one for younger ages with an expected small impact on the TP estimates. In countries where the IP at older ages is large, and therefore could have more weight in the TP prevalence, the population is more heterogeneous because disability is not the only determinant of living in institutions; the differential between IP and HP prevalence is reduced and so exclusion of IP is expected to have a small impact on the TP estimate.

Constraint for International Comparisons

In the context of harmonization of health data, it is important to document the bias associated with the representativeness of the survey population and the impact of the various options available to adjust the TP estimates, as such differences may hamper comparability. When international comparable data is available,[1] the gap between the TP and the survey population is more complex.

The boundary between HP and IP depends on national (and regional) patterns of institution use and supply. This results in variation not only in the proportion of the population in institutions and therefore excluded from the general surveys, but also in the health difference between those living in households and in institutions. Where there is a relatively small institutionalized population, either because of supply constraints or less demand, the population they accommodate is likely to be highly selected and different from the HP, particularly in terms of health status. Where there is a large institutionalized population, institutions will accommodate a larger and more varied population which may differ less sharply from the HP. National situations vary, and with them the extent of the expected bias in a measurement of the TP health status based on a representative sample of the HP (see annex Fig. A.1).

In addition, whilst the proportion of the population covered by the survey is often known, data on the distribution of the excluded population between different types of institutions are not always available. Even where detailed statistics are available, some categories of dwellings in the published tables (such as “religious institutions” and “other institutions”) are hard to classify as health related institutionalized population (IP_{HR}) or non-health related institutionalized population ($IP_{N\text{-}HR}$). In some contexts, religious institutions contain residents who have (financial, health, social) difficulties living in private household rather than religious people. At older ages, health and disability may be reasons for residence in such institutions. And the characteristics of institution’s residents may also vary with age (as in “religious institutions” for instance where the reason for living in these institutions can vary across ages from sheltered accommodations to nursing homes). At younger ages, living in an institution is much more related to school and college or work than health-related housing.

The definition and boundaries between health related and non-health related institutions therefore vary largely with the national context and by age. Furthermore, depending on the national context or age, another issue is the distinction between permanent and temporary institutional residence. Each country might have specific reasons for considering a household member to be part of the household or living in institutions depending on the type of stay (long or short, regular or episodic, week days or all week, etc.). This makes identification even more complex, since it is dependent on country specific (age-specific) contexts.

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[1] This is already the case with a number of International surveys based on household population: the European survey on health and retirement (SHARE) which is comparable to the American Health and Retirement Survey (HRS) and the English Longitudinal Study of Ageing (ESLA); the European Study on Income and Living Conditions (EU-SILC).

Options to Deal with the Population Excluded from the Survey Coverage

There are a range of options to provide population estimates of disability prevalence, adjusting for the population excluded from surveys, as mentioned for example by Freedman and colleagues (Freedman et al. 2002). In most cases analyses are based on data from HP on the assumption that the limited representativeness for the IP will not invalidate results. Often, this hypothesis is justified by the proportionally small size of the IP. According to this hypothesis, the overall prevalence of a given health problem in the HP may be considered representative of the prevalence in the TP. However, when focusing on sub-populations where a higher proportion are living outside private households, for example older people, or when the topic addressed is a potential criterion for moving into an institution, such as disability, this hypothesis poses problems.

When additional information on institutions is available, other options may be applied. Some studies considered a selection of institutions where ill health is over-represented for which the disability prevalence is known (Crimmins et al. 1997; Erickson et al. 1995; Robine and Mormiche 1994). This option requires detailed information on the type of institution; it also requires information on the health of the residents based on special surveys which enable estimation of a institution-specific excess risk of disability, compared to that is observed in the HP. This latter information is scarce, even if it can be more frequently produced than the strictly comparable HP and IP surveys.

An alterative and more commonly applied option was proposed by Sullivan. In his aggregate "disability-free life expectancy" index, Sullivan suggested that to avoid underestimating impaired health by not accounting for IP, estimates should be adjusted by assuming that the entire population of health-related institutions (IP_{HR}, comprising residents of homes for the disabled, nursing/care homes and homes for the elderly population) have disability (Sullivan 1971). Although this hypothesis may be justified since such institutionalization is in itself a reflection of some degree of disability (difficulty to live alone in a private household), its validity depends on the type of health or disability indicator addressed. For widespread disability such as common functional limitations, Sullivan's hypothesis will be close to the measurable reality in such institutions, but for severe disability, the assumption that all residents are disabled will overestimate the overall prevalence. Furthermore, Sullivan's solution concerns the IP_{HR}, so it is essential that health-related and non-health related institutions population ($IP_{N\text{-}HR}$) within the population not covered by the survey sample are distinguished.

Classification between health-related and non-health related institutions is not straightforward. Therefore, the latest option to adjust for the population excluded from surveys is to counterbalance the underestimation of the estimates by applying Sullivan's proposal to the whole IP. This overestimates the TP disability prevalence, especially where the proportion of $IP_{N\text{-}HR}$ among the IP is high but, when accurate statistics are not available, it provides an interval for the TP estimates using the two extreme estimates as limits.

Assessing the Impact of the Adjustment Options

Here we aim to assess the magnitude of the bias to disability estimates by applying three hypotheses to HP based surveys. The data from a French disability survey conducted in 2008 and 2009 among the HP and IP_{HR} populations are explored. These data give the share of the population living in health-related institutions and comparable estimates of disability for both the HP and IP_{HR} as well as the resulting estimates for the TP. These data also enable us to test the bias inherent in an estimate that uses only information gathered from the HP. To do this, we compute TP disability estimates using the three options based on hypotheses to account for disability in IP: *H1* assumes that the data from the HP surveys are representative of the data for the TP (providing the lowest disability estimates); *H2* considers that the entire population excluded from the survey (IP) has disability (providing the upper limit of the estimate); *H3*, where the IP_{HR} information is available, following Sullivan's solution and assuming that all the IP_{HR} residents have disability. The three estimates (presented in percentages and numbers of people with disability) are compared to the observed figures based on the French disability survey conducted both in HP and IP_{HR} population samples.

In a second stage, we present the situation in three European countries and examine the differences in the estimates made under each of the three previous hypotheses. We focus on France, Italy and the Netherlands, for which we had information regarding the percentage of the IP population in health-related institutions and which differ sharply in their distributions (IP_{HR} and $IP_{N\text{-}HR}$). This gives a range of estimates for assessing the extent of the bias in each country's configuration. With these analyses the impact of each hypothesis on the disability prevalence estimate for the TP (percentage and numbers) can be measured as well as the extent to which each hypothesis modifies the between-country differences.

These two stages, based on the French data and on the European ones, lay the basis for discussing the validity of the hypotheses.

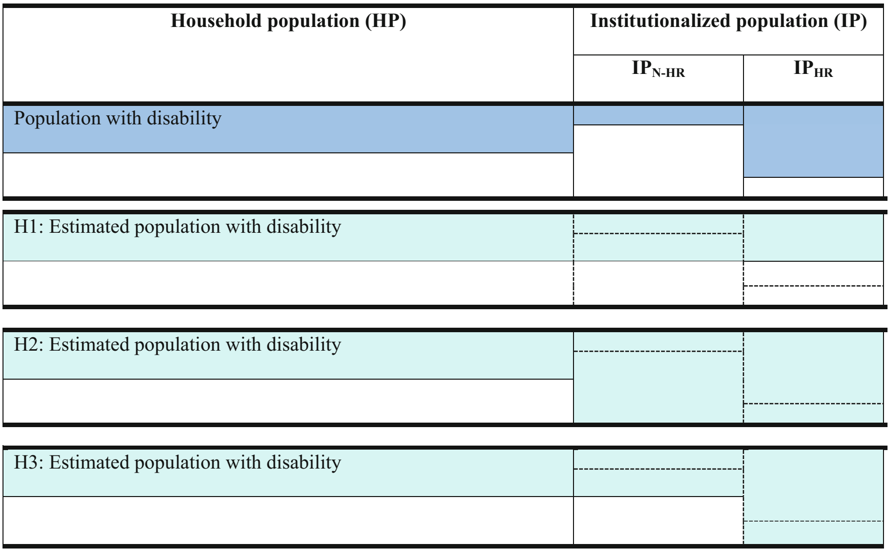
Data and Methods

Disability Prevalence Estimates Based on Three Hypotheses

The survey data give the prevalence of disability in the HP. The census or population registry data provides the relative proportion within HP and IP as well as the distribution between IP_{HR} and $IP_{N\text{-}HR}$. We assume that the IP both includes the IP_{HR}, where disability prevalence is higher than in the HP (since impaired health is the criterion for going into this type of institution), and the $IP_{N\text{-}HR}$ where the disability prevalence is equivalent to or lower than that of the HP (Table 13.1). Estimates of TP prevalence obtained using the hypotheses are compared as follow:

- H1. The data from a given HP survey are assumed to be representative of the TP. The disability prevalence obtained from the HP survey by age group is

Table 13.1 Observed and estimated population with disability in private household population (HP), populations living in health-related (IP_{HR}) and non-health related ($IP_{N\text{-}HR}$) institutions according to three hypotheses for disability prevalence in the IP



applied to the population as a whole. H1 estimate provides the lower limit of the TP population estimates interval.

- H2. The disability prevalence from the survey by age group is applied to the HP only to obtain the HP population with disability to which is added data the entire population living in institutions (IP) considered as having disability. H2 estimate provides the upper limit of the TP population estimates.
- H3. Where the data allow, Sullivan's hypothesis is used. This is a refinement of H2. For the population living outside private households (IP), the population in health-related institutions IP_{HR} (nursing/care homes, homes for seniors and homes for the disabled) is distinguished. The disability prevalence from the HP survey is attributed to both HP and $IP_{N\text{-}HR}$. To this result is added the entire IP_{HR}, who are all regarded as having disability. The H3 estimate should be the closest to that observed when comparable data are available for the HP and IP_{HR}.

We first test the three hypotheses using detailed French data. Then, we extend this by using data on disability from the survey EU-SILC (European Statistic on Income and Living Conditions) for France, The Netherlands and Italy in order to assess the variation in the impact of the three hypothesises according to the national context. These countries were chosen to illustrate the diversity of situations between countries: different degrees of detail in the available data, different distributions by age between household and institutional populations and different ways of classifying institutions.

In publications from statistical offices, IP_{HR} and $IP_{N\text{-}HR}$ cannot always be clearly distinguished. For this study, we obtained detailed data for the three countries where health-related institutions could be clearly identified as accommodating people for reasons of impaired health or loss of independence (from the French statistical institute INSEE from France based on the 1999 population census, from the Italian ones ISTAT based on the 14th population census and from Statistics Netherlands *Statline* based on the municipal population registries). However in some cases, identification of IP_{HR} was not straightforward. We then also defined as IP_{HR} collective dwellings where residents would be more likely to be in poor health than in HP, such as religious institutions defined as religious nursing homes. In France religious institutions can provide a high proportion of accommodation for the elderly population who no longer live alone. However, this might not be the case for other countries.

The French Example

The survey on disability and health (Handicap-Santé or HS) provides comparable information from samples of the HP (in 2008) and IP_{HR} (in 2009) (Bouvier 2009). The samples were large: 29,000 persons in the household sample and 9000 in the institution sample (see Annex, Table 13.A1, for numbers concerned). The questionnaire included a disability indicator, the Global Activity Limitation Index (GALI). The GALI is one of the three questions in the Minimum European Health Module, now used in many surveys. Respondents are asked “For the past 6 months at least, to what extent have you been limited because of a health problem in activities people usually do?” (Cox et al. 2009). The response categories are “Not limited”, “Limited” and “Severely limited”. For this example we consider both “any limitations” and “severe limitations only” to allow assessment of whether the severity of disability affects the impact of the tested hypotheses.

To classify the IP, we use data from the 1999 French census which breaks down the population by type of dwellings. The 95 % confidence intervals associated with the prevalence are calculated for each age group, for the HP and for the IP_{HR}. Confidence intervals for the TP disability prevalence are deduced by taking account of the distribution of the population among HP and IP_{HR}.

The European Example

Population Structure by Household Type

At the European level, statistics from population censuses or population registries conducted around 2000 give the HP as a proportion of TP and some distinguish between types of institutions and between IP_{HR} and $IP_{N\text{-}HR}$. In this study we present the distribution among HP and IP in France, Italy and the Netherlands. For these countries we obtained detailed information on types of dwellings. The overall data are from Eurostat tables and the detailed figures from each country’s statistical institute. Figures are given for total population (men and women together), by 5-year age group and by major age groups (15 and over, 65 and over, 85 and over). For Italy, the detailed figures are given by 10-year age groups except the youngest ages (0–24 years).

Disability Data

The EU-SILC survey conducted in the 27 European Union member countries included the GALI question for disability measurement.[2] In this exercise, we do not distinguish the level of severity of the limitations considering only the overall activity limitation prevalence "Any limitations". We use the 2005 survey data, taken from the EHLEIS European joint action website (www.eurohex.eu) (see Annex, Table 13.A2, for EU-SILC sample sizes). Figures are shown for total population aged 16 and over, by 5-year age group (assuming that the prevalence for age group 15–19 is equal to that for the 16–19 age group), then for age group 15+, 65+ and 85+.

Results

Activity Limitation Prevalence in HP and IP in France

For 2008 in France, the prevalence of activity limitation in the HP reaches 25 % in the population aged 15 and over, 53 % for those aged 65 and over and 81 % for people aged 85 and over. The data from IP_{HR} give prevalence of 82 %, 87 % and 88 % respectively. As expected, whilst activity limitation is already fairly widespread among HP, it affects a even higher proportion of those living in the IP_{HR} (Fig. 13.1).

The prevalence increases sharply with age, but less so in IP_{HR} since the prevalence is high from the earliest age. For severe activity limitations, prevalence in the HP is 11 % for people aged 15 and over, 26 % for people aged 65 and over and 52 % for people aged 85 and over; in IP_{HR} they are 59 %, 63 % and 63 % respectively.

The HS survey figures thus provide the basis for measuring the relationship between activity limitation prevalence in the HP and IP_{HR} (Fig. 13.2). Because disability is relatively rare among young people, for the 20–24 age group the IP_{HR} differ sharply from the HP, with a prevalence ratio of 6 for all limitations and of 15 for severe limitations. These very high excess risks concern only a small section of the TP, selected on the basis of health problems and disability.

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[2] The GALI question is included in both the EU-SILC and the HS for France; figures from these two sources are not directly comparable because their survey protocols were very different, but in the context of our exercise the populations the indicator identifies in each case seem very close.

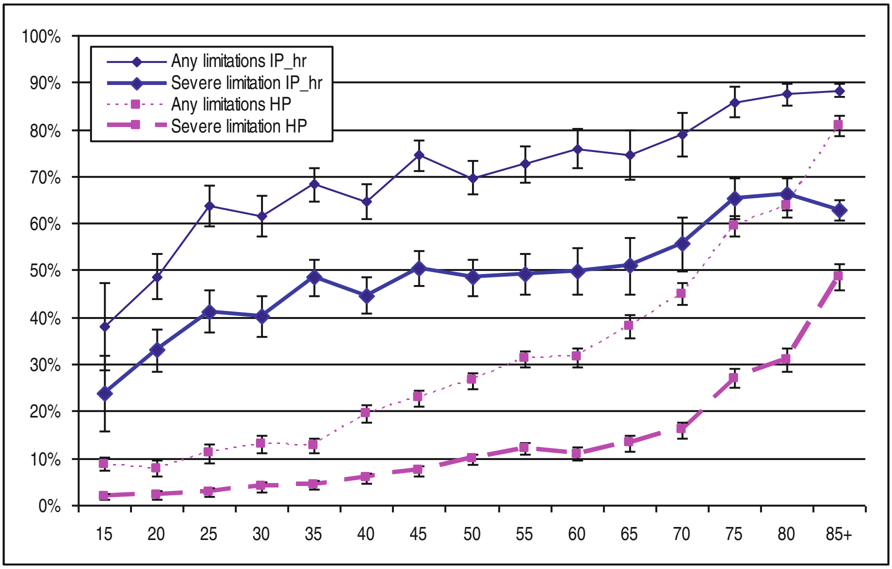

Fig. 13.1 Observed prevalence of "any activity limitation" and "severe activity limitation" in the French private household (HP) and health-related institutionalized (IP_{HR}) populations by age groups. French HS survey (2008–2009)

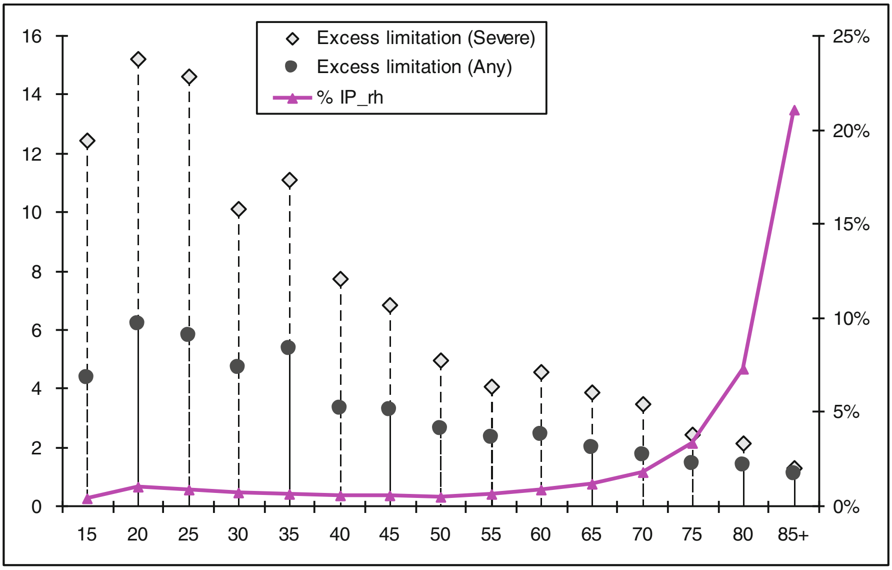

Fig. 13.2 Excess risk of "any activity limitation" and "severe activity limitation" French health-related institutionalized population (IP_{HR}), compared to prevalence in French private household population (HP) (ratios) (French HS survey, 2008–2009) and % of the IP_{HR} within the total population (TP) (1999 population census). Men and women aged 15+

Because institutionalization and disability are frequent in older age groups regardless of place of residence, there is less difference in the prevalence between the HP and IP_{HR} than among the young; but prevalence is still higher in IP_{HR}, particularly for severe disability. Figure 13.2 shows the trade-off between the magnitude of the excess risk of activity limitation in the IP_{HR} and the proportion of the TP concerned. To calculate the prevalence of "any limitation" and "severe limitations" in the TP, the HP and IP prevalence measured by HS survey are applied to the HP and IP populations of the 1999 census. To these values, we add the estimates obtained using the HP prevalence and each of the three 3 hypotheses for including the IP. The measured prevalence lies between those estimated with H1 (which takes no account of excess disability in institutions) and with H3 (which assume all excess disability in institutions). Taking "any activity limitations", the estimates are very close to the observed values (Fig. 13.3).

The gaps are wider for severe disability, particularly at advanced ages, for which the different hypotheses give significantly different estimates: the hypothesis that all institutional residents have activity limitations is much further from reality for severe limitations than for moderate levels. H2 and H3 estimates are very similar at older ages due to the fact that institutions for the elderly population are almost all health-related institutions; this is not the case at younger ages when the distinction between IP_{HR} and $IP_{N\text{-}HR}$ makes a difference. Calculating the prevalence in the TP at different ages, only the prevalence of severe activity limitations for ages 85 and over differ significantly between hypotheses (Table 13.2). Estimates based on H1 are below the measured prevalence, but the difference is not significant: the estimate falls within the confidence interval. Only for the severe activity limitations in age group 85 and over, are the H2 and H3 estimates significantly higher than the observed and the H1 values.

Variation in the Numbers of Persons with Activity Limitation by the Hypothesis Adopted

According to the 1999 population data, around five million French people aged 65 and over had activity limitations; of these, about half had severe limitations (Table 13.3). H1 underestimates this figure by about 85,000 (0.9 % of TP) and H2 overestimates it by about 83,000 (0.9 % of TP). H3 with a 70,000 (0.7 % of TP) overestimation is closest to the observed value and this overestimation is linked to the fact that the prevalence of activity limitation in the IP_{HR} is not 100 % as the hypothesis supposes. For severe limitations, the error margin is wider because the observed disability values are further from the 100 % applied to institutions in hypotheses H2 and H3. In this case H1 is closest to the measured value, irrespective of age group.

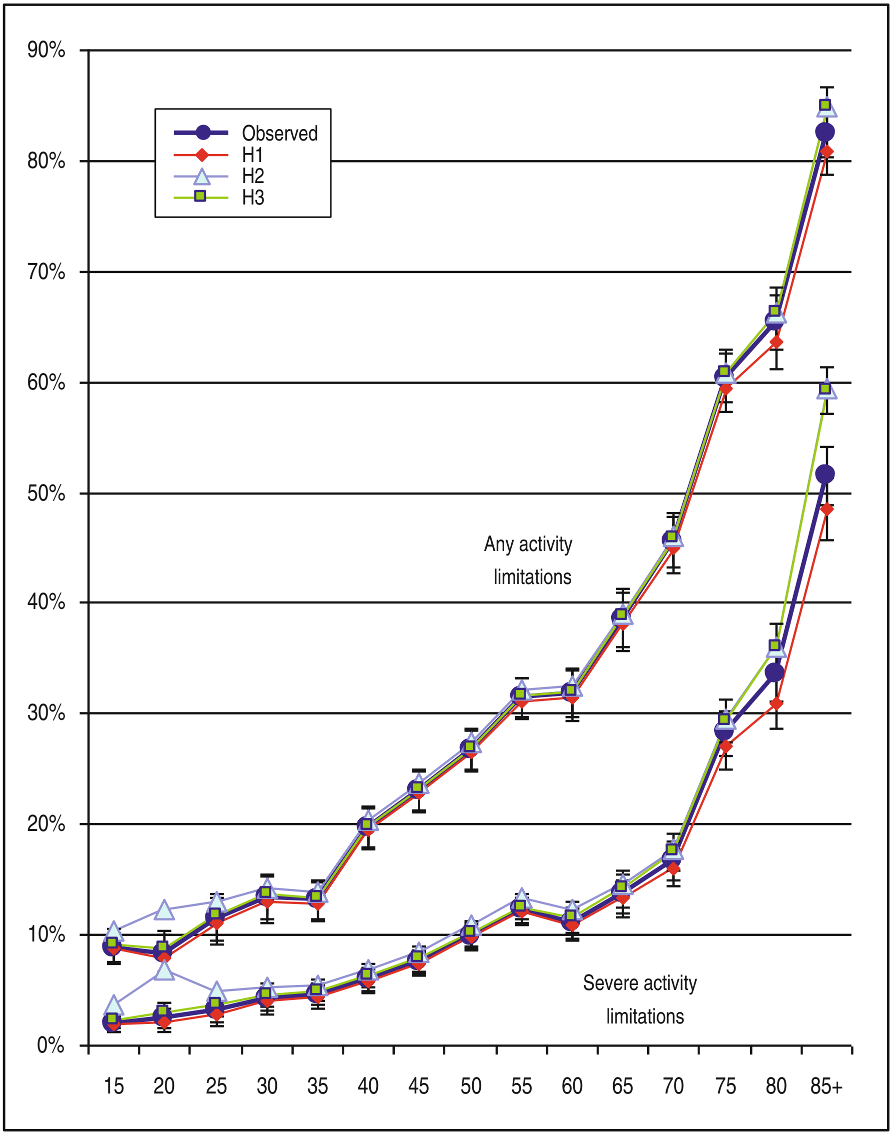

Fig. 13.3 French observed and estimated prevalence of "any activity limitation" and "severe activity limitations" based on data from the French HS survey and the three hypotheses for including the institutionalized population

Table 13.2 French observed and estimated prevalence of "any activity limitation" and "severe activity limitations" based on data from the French HS survey and the three hypotheses for including the institutionalized population

All limitations	Observed (%)	H1 (%)	H2 (%)	H3 (%)
15+	25 [23–27]	25 [25–26]	27 [25–30]	26 [24–29]
65+	55 [52–59]	53 [52–54]	56 [53–59]	56 [53–59]
85+	82 [80–84]	81 [79–83]	85 [83–87]	85 [83–87]
Severe limitations	**Observed (%)**	**H1 (%)**	**H2 (%)**	**H3 (%)**
15+	10 [9–11]	10 [9–10]	12 [10–13]	11 [9–13]
65+	26 [23–29]	24 [23–25]	28 [25–30]	28 [25–30]
85+	52 [49–54]	48 [46–51]	59 [57–62]	59 [57–62]

Table 13.3 Numbers of French persons with "any activity limitation" and "severe activity limitations" based on data from the French HS survey and differences with the three hypotheses for including the institutionalized population (HS survey 2008–2009 and 1999 population census)

		DIfferences between the number estimated by H1, H2 and H3 and the number observed with the data (HP + IP)		
All limitations	Observed (a)	(Number H1) – (a) (%TP)	(Number H2) – (a) (%TP)	(Number H3) – (a) (%TP)
15+	12 156 439	–199 634 (–0,4%)	+ 545 827 (+ 1,1%)	+ 162 527 (+ 0,3%)
65+	5 275 353	–84 151 (–0,9%)	+ 82 762 (+ 0,8%)	+ 70 936 (+ 0,7%)
85+	1 173 351	–22 348 (–1,6%)	+ 35 451 (+ 2,5%)	+ 34 970 (+ 2,5%)
Severe limitations	Observed (a)	(Number H1) – (a) (%TP)	(Number H2) – (a) (%TP)	(Number H3) – (a) (%TP)
15+	4 726 681	–192 840 (–0,4%)	+ 792 623 (+ 1,6%)	+ 337 438 (+ 0,7%)
65+	2 443 369	–119 295 (–1,2%)	+ 216 943 (+ 2,2%)	+ 193 964 (+ 2,0%)
85+	732 250	–42 042 (–3,0%)	+ 113 481 (+ 8,0%)	+ 110 967 (+ 7,8%)

For the Population Aged 85 and Over, Estimates Are Sensitive to the Hypotheses

As expected, H3 is slightly better than the two other hypotheses for the 15+ and 65+ age groups taking all activity limitations regardless of severity. The French estimates for the most advanced ages (85+) are more sensitive to the hypotheses than those for younger age groups and H1 gives the result closest to the measured prevalence, particularly for the population with severe limitations. H2 (applying a 100 % prevalence to the entire IP) considerably overestimates both prevalence and the numbers of persons with disability. Given the prevalence and the confidence intervals applied, where there is a lack of data to distinguish between IP_{HR} and $IP_{N\text{-}HR}$, H1 seems to be preferable to H2. When such data are available, the measured values fall between the estimates of H1 and H3, these two providing a refined margin for taking account of under- and over-estimation of prevalence.

Table 13.4 Institutionalized population (IP), population of health-related (IP_{HR}) and non-health related ($IP_{N\text{-}HR}$) institutions as percentage of total population (TP) France, Italy and the Netherlands (Population censuses and registry, circa 2000)

The Netherlands	%IP	$\%IP_{HR}$	$\%IP_{N\text{-}HR}$
15+	1,6	1,3	0,3
65+	6,2	5,9	0,3
85+	24,1	23,6	0,4
Italy	**%IP**	**$\%IP_{HR}$**	**$\%IP_{N\text{-}HR}$**
15+	0,8	–	–
All ages	0,7	0,5	0,2
65+	2,1	2,0	0,1
85+	7,2	7,1	0,1
France	**%IP**	**$\%IP_{HR}$**	**$\%IP_{N\text{-}HR}$**
15+	2,5	1,6	0,9
65+	5,5	5,3	0,2
85+	21,2	21,0	0,2

European Estimates

Population Distribution by Type of Institution

The three countries were selected because of their vastly differing HP and IP distributions. Whilst Italy has fewer than 1 % of persons aged over 25, living outside private households, this figure rises to 1.6 % for the Netherlands and 2.5 % for France (Table 13.4).[3]

Overall, the difference between Italy and France and the Netherlands is largely explained by the figures for the 65+ age group: at these ages 5.5 % of the French and 6.2 % of the Dutch no longer live in private households, compared to only 2.1 % of Italians. France stands out as having a greater proportion of young adults living outside private households (Fig. 13.4). Thus the Netherlands have a smaller proportion of their overall population living outside private households than the French despite a higher proportion of the oldest age group living in institutions.

Figure 13.4 shows the distribution of types of institutions in each country. The figures for the three selected countries illustrate the lack of precise definitions or data on the resident populations and how difficult it would be to apply a systematic, uniform rule across multiple countries for separating IP_{HR} from $IP_{N\text{-}RH}$. For instance, the figures for the Netherlands clearly show the different types of accommodation for persons with impaired health or disability, but give less detail on other types of

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[3] To put these countries in perspective see Annex, Figure A1, for HP/IP distribution by age group for 13 European countries).

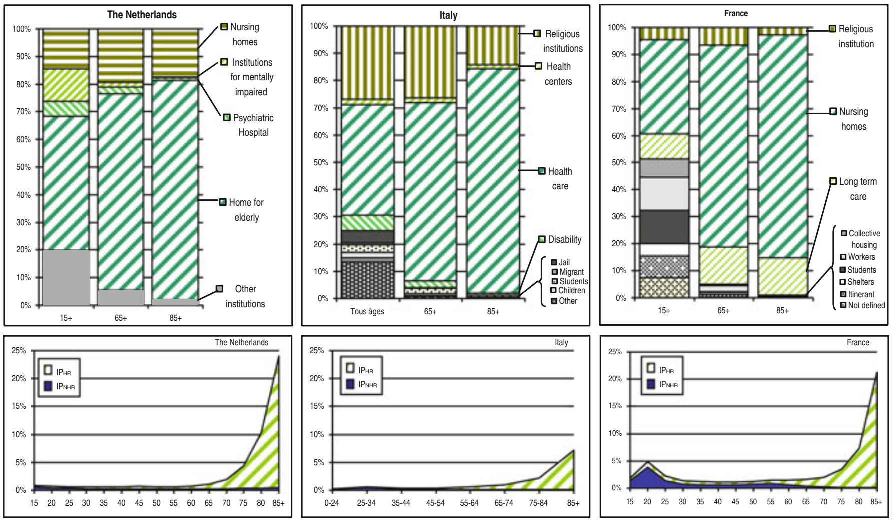

Fig. 13.4 Institutionalized population distribution by type of dwelling for population aged 15 and over (25 and over for Italy) and distribution between health-related (IP_{HR}) and non-health related institutionalized population ($IP_{N\text{-}HR}$) by age group (France, Italy and the Netherlands (Population censuses and registry, circa 2000))

institution for younger people, ages at which fewer people are institutionalized in the Netherlands than in France or Italy. In the Netherlands institutions for the elderly account for a high proportion of the IP and are different to nursing homes. This suggests that they are a more commonly used form of residence than in the other countries with a population more similar in nature to the HP than to the IP_{HR}.

Despite the lack of definition, to proceed in the exercise, a somewhat arbitrary division has been made between $IP_{N\text{-}HR}$ and IP_{HR} for some collective household categories to allow the Sullivan hypothesis to be applied. Institutions regarded as health-related for the purposes of this study are indicated in the figure by diagonal shading.

Disability Prevalence in the Netherlands, Italy and France

Among those aged 15 and over living in the HP in the three countries, activity limitations (regardless of severity) affects 20–23 % of women and 15–19 % of men (Table 13.5). France has the highest prevalence and Italy the lowest.

Country differences are greatest for the oldest age groups. In the 65+ group, 46–57 % of women and 37–53 % of men report activity limitations. France has the highest prevalence and the Netherlands the lowest. Figures 13.6, 13.7, and 13A.1 show prevalence estimates for the TP by age group according to each of the three hypotheses and the 95 % confidence intervals for these values. The above mentioned prevalence, given by the EU-SILC surveys, represents the TP estimates for hypothesis H1.

Table 13.5 Prevalence of “any activity limitations” by age group in the Netherlands, France and Itlay, 2005 EU-SILC survey (weighted prevalences)

	The Netherlands			Italy			France		
Ages	Men %	Women %	Both %	Men %	Women %	Both %	Men %	Women %	Both %
15–19	5	8	7	3	3	3	6	8	7
20–24	7	14	11	3	4	3	6	6	6
25–29	6	12	9	6	5	5	8	7	8
30–34	10	14	12	6	5	6	9	10	9
35–39	11	17	14	8	8	8	11	12	11
40–44	11	22	16	9	9	9	14	14	14
45–49	16	25	20	13	12	13	16	20	18
50–54	19	28	24	13	16	15	18	22	20
55–59	27	31	29	17	22	20	28	26	27
60–64	27	30	28	24	29	27	25	28	26
65–69	30	30	30	30	33	31	37	41	39
70–74	35	40	38	38	47	43	48	42	45
75–79	30	56	46	48	55	53	60	60	60
80–84	55	48	50	56	64	61	62	66	65
85+	49	62	59	70	76	74	77	82	81
15+	16	23	19	15	20	18	19	23	21
65+	37	46	42	45	54	50	53	57	56

For the Netherlands (Fig. 13.5), we see considerable variation between estimates for the oldest age groups, although here the samples are small. Up to the age of 70 the estimates differ little between the hypotheses. Beyond this age, although the differences are greater, they still fall within the confidence intervals. The widest difference, of nearly 10 %, appears in the oldest age group. This difference is due to the fact that at these ages one-quarter of the Dutch population was living in institutions around the year 2000 (though it has reduced since then); the hypothesis that regards 100 % of this population as living with disability automatically increases the estimate.

For Italy, the three hypotheses give very similar prevalence estimates, all within the confidence interval (despite this being narrower due to the large sample size) (Fig. 13.6). The narrow difference is due to the small proportion of the population living outside private households.

For France, the hypotheses affect the estimates differently according to age (Fig. 13.7). Hypothesis 2 overestimates prevalence among the young, owing to a relatively high proportion of young people in the IP$_{\text{N-HR}}$ but with a low prevalence of activity limitations. The assumption that all residents of all institutions have activity limitation thus has a strong impact on the prevalence estimate. At advanced ages, a higher proportion of the population is living in institutions and most of these institutions are health-related. As a result, hypotheses 2 and 3 give similar age-related estimates of prevalence, higher than with the hypothesis 1. The difference is not large, however, since activity limitation prevalence is high at these ages even in private households. Unlike the situation for the young age group: the gap between the estimate based on HP prevalence and those that regard all institutional residents as having activity limitation is narrower.

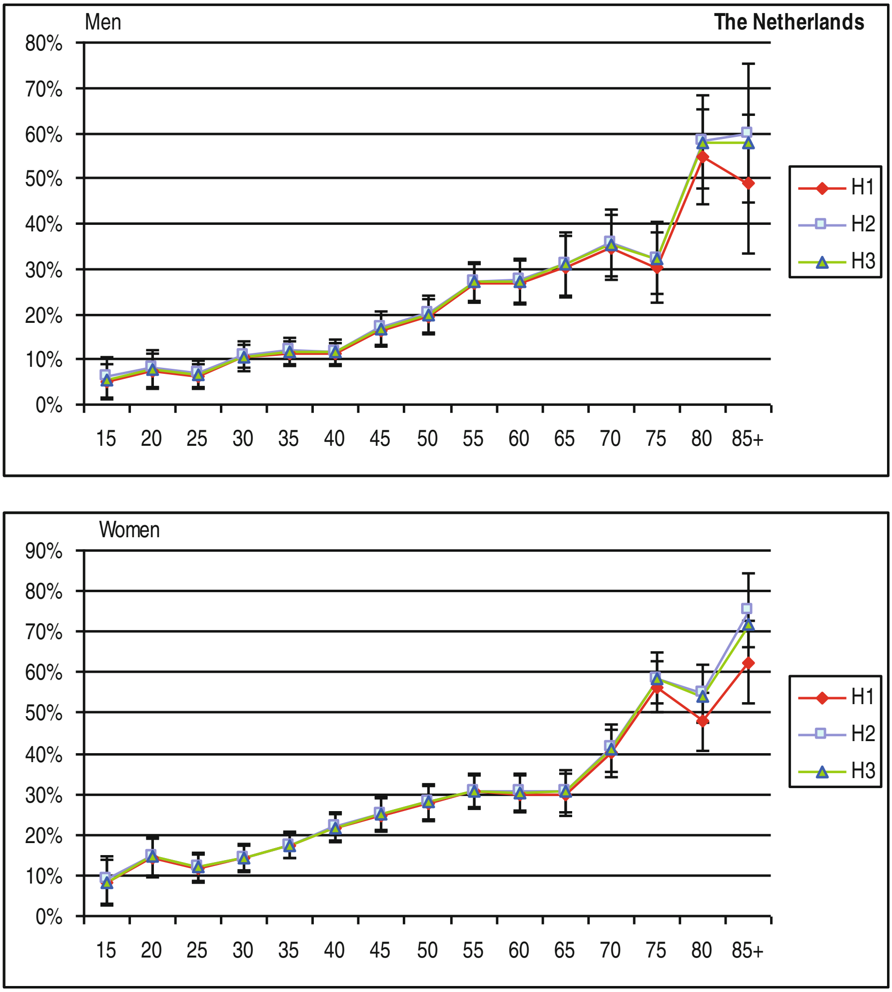

Fig. 13.5 Estimated prevalence of "any activity limitations" from the 2005 EU-SILC survey and the three hypotheses for including the institutionalized population, the Netherlands

Altogether, Table 13.6 shows no significant differences between the estimates. Although it can be large in the 85+ age group, the differences do not exceed the confidence intervals associated with the survey sample sizes and the countries' relative positions do not vary.

Table 13.7 shows the estimates of the number of men and women with activity limitations obtained under the three hypotheses. Italy shows the most stable estimates across the different hypotheses owing to the low proportion of its IP. Taking only the older age groups, hypothesis H1 gives an estimate of 970,000 people aged 65 and over reporting activity limitation in the Netherlands, 5,000,000 in Italy and 5,200,000 in France. The gap between the H1 estimate and the highest estimate

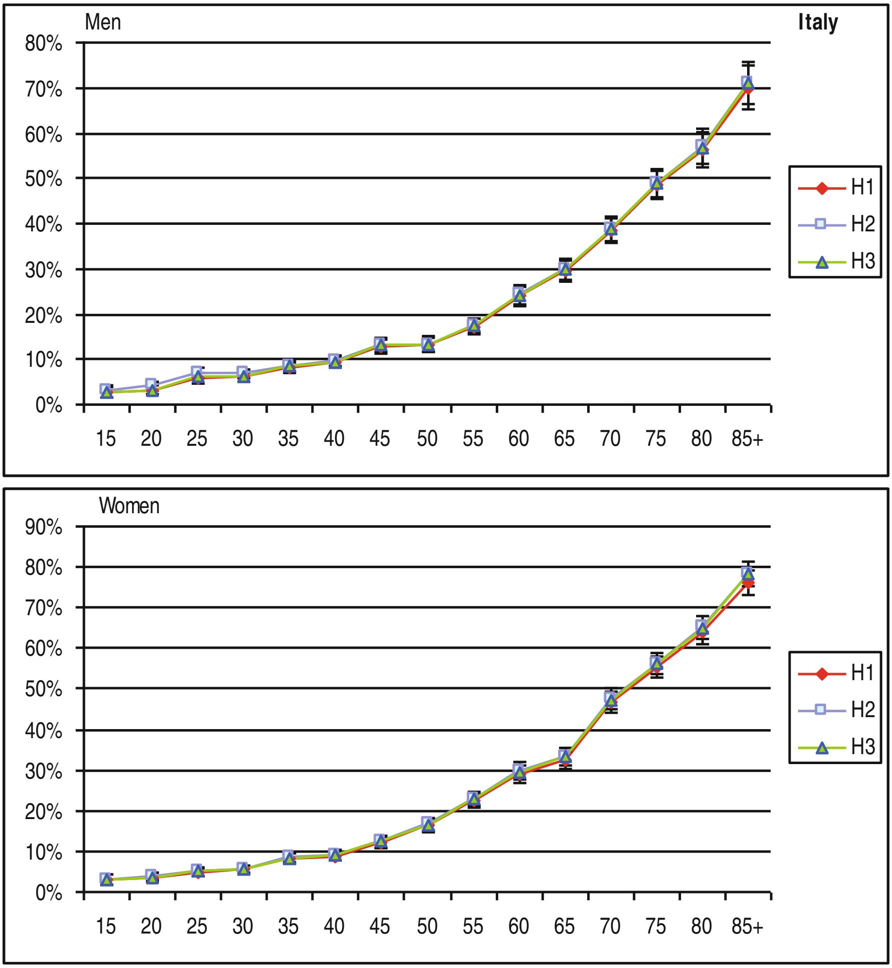

Fig. 13.6 Estimated prevalence of "any activity limitations" from the 2005 EU-SILC survey and the three hypotheses for including the institutionalized population, Italy

(H2) is slightly over 89,000 in Italy (0.8 % of TP). For France, where a higher proportion of people live in institutions, especially at advanced ages, hypothesis H1 underestimates the number of people with activity limitations by 180,000 (slightly under 2 % of TP) compared to the highest estimate (H2). For the Netherlands, as noted above, the error margin is wide at advanced ages due to the combination of a high proportion of people living in institutions and a possible problem for the survey sample's representativeness for very advanced ages. As a result, for the 65+ age group hypothesis H1 probably underestimates the numbers with activity limitation by 38,000, or 3 % of the TP.

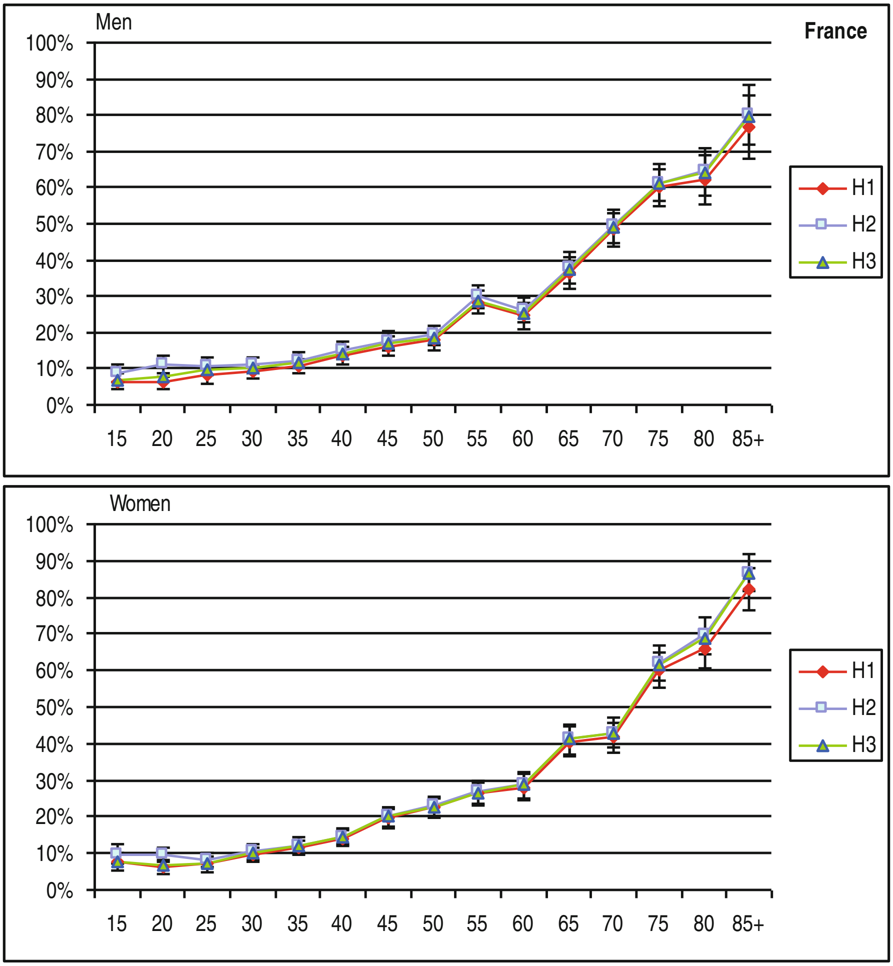

Fig. 13.7 Estimated prevalence of "any activity limitations" from the 2005 EU-SILC survey and the three hypotheses for including the institutionalized population, France

Conclusion

The analyses presented above confirm the difficulty of gathering the data required for accurately calculating the prevalence of disability in the TP, owing to uncertainty over the size and characteristics of the population living outside private households. The analyses also highlight the uncertainty of information gathered on the most advanced age groups by some surveys, where sample sizes are usually small and the risk of selecting an unrepresentative population (one in good health) is greater. This observation and the fact that the age structure of the 85+ varies across countries raises the issue of whether or not to use closed populations to avoid imprecision in

Table 13.6 Estimated prevalence of "any activity limitations" from the 2005 EU-SILC survey and the three hypotheses for including the institutionalized population, the Netherlands, Italy and France

Men		**H1 (%)**	**H2 (%)**	**H3 (%)**
The Netherlands	15+	16 [15–17]	17 [16–18]	16 [15–18]
	65+	37 [33–41]	39 [35–43]	39 [35–43]
	85+	49 [33–64]	60 [45–75]	58 [42–73]
Italy	15+	15 [15–16]	16 [15–16]	15 [15–16]
	65+	45 [43–46]	45 [44–47]	45 [44–47]
	85+	70 [65–75]	71 [66–76]	71 [66–76]
France	15+	19 [18–20]	21 [20–22]	20 [19–21]
	65+	53 [51–56]	55 [53–58]	55 [52–57]
	85+	77 [68–85]	80 [72–88]	80 [72–88]
Women		**H1 (%)**	**H2 (%)**	**H3 (%)**
The Netherlands	15+	23 [22–24]	24 [23–25]	24 [23–25]
	65+	46 [43–49]	50 [47–53]	49 [46–52]
	85+	62 [52–73]	75 [66–84]	72 [63–81]
Italy	15+	20 [19–20]	20 [20–21]	20 [20–21]
	65+	54 [53–55]	55 [54–56]	55 [54–56]
	85+	76 [73–79]	78 [75–81]	78 [75–81]
France	15+	23 [22–24]	25 [24–25]	24 [23–25]
	65+	57 [55–59]	60 [57–62]	59 [57–62]
	85+	82 [76–88]	87 [82–92]	86 [81–92]

Table 13.7 Estimated numbers of people with "any activity limitations" from the 2005 EU-SILC survey and the differences in the three hypotheses for including the institutionalized population

The Netherlands	**H1 (a)**	**H1–H2 (%TP) (b)**	**H1–H3 (%TP) (c)**
15+	2 770 285	+ 138 497 (+ 1,0%)	+ 94 246 (+ 0,7%)
65+	969 596	+ 78 360 (+ 3,4%)	+ 63 760 (+ 2,7%)
85+	177 779	+ 37 770 (+ 12,6%)	+ 28 423 (+ 9,5%)
Italy	**H1**	**H1–H2 (%TP)**	**H1–H3 (%TP)**
15+	9 111 186	+ 243 369 (+ 0,5%)	+ 157 526 (+ 0,3%)
65+	5 045 579	+ 89 353 (+ 0,8%)	+ 86 167 (+ 0,8%)
85+	923 203	+ 21 987 (+ 1,8%)	+ 21 728 (+ 1,8%)
France	**H1**	**H1–H2 (%TP)**	**H1–H3 (%TP)**
15+	10 543 188	+ 781 132 (+ 1,6%)	+ 369 035 (+ 0,8%)
65+	5 217 329	+ 178 706 (+ 1,8%)	+ 152 676 (+ 1,6%)
85+	1 148 008	+ 60 371 (+ 4,2%)	+ 56 224 (+ 3,9%)

Numbers under hypothesis 1 (H1) (*a*), numbers added by using hypotheses H2 (*b*) and H3 (*c*) and corresponding percentages of total population (TP). The Netherlands, Italy and France

the last open age group. Thirdly, they show that the extent of the under- or over-estimation varies with degree of disability and with distribution between HP and IP.

We tested various hypotheses for including the IP in disability prevalence estimates and found that, in the absence of data on institutional residents' health status, the method suggested by Sullivan was most effective, though less so for advanced age groups and for severe disability. For advanced ages, the overestimation resulting from this hypothesis is greater than the underestimation resulting from assuming the prevalence for IP are the same as for HP (hypothesis H1). To refine the results, an alternative solution to the Sullivan hypothesis would be to apply more realistic disability prevalence using data available from other sources. Considering all the residents of health-related institutions as having a disability (H3) is of interest for avoiding underestimation of the population sizes on which estimates of care and support needs are based. The H1 and H3 estimates fall on either side of the observed values and may be used to refine numerical estimates for the population with disability.

In the absence of detailed data on institutions, hypothesis H1 is the closest to observed values. It underestimates the population with disability, but this underestimation falls within the confidence interval computed to assess the uncertainty due to the sample size; it is preferable than assuming that the entire population excluded from the survey have disability (H2); the latter gives estimates which are in some cases significantly different from the observed values. Finally, the estimates obtained under the different hypotheses do not affect the gradient between countries, although they place them at slightly different levels.

These analyses do not provide a basis for choosing between hypotheses H1 and H3: the optimal choice of hypothesis will depend on the information available. However, the analyses do suggest that refinements could be made to bring the estimates closer to the observed values. As suggested in this study, the level of disability of IP_{HR} should be actually higher that the prevalence in HP (as in H1), but not as high as 100 % prevalence (as in H3). One refinement would be therefore to apply to IP_{HR} a prevalence being the average between these two values. Another refinement would be to model the levels of disability in IP as a function of the level of disability in the HP and the risk of living in IP; as shown in Fig. 13.2, it could be interesting to explore a possible link between the excess risk of disability in IP (compared to the HP) and the percentage of IP within the TP. Obtaining data from several countries would make it possible to check this relationship and improve the Sullivan hypothesis.

For international comparisons, hypothesis H1 seems to be preferable in that the data do not allow application of a uniform rule for identifying the IP_{HR}. For these comparisons, the confidence intervals for the estimates leave room for discussing how far H1 is underestimating disability. This discussion is particularly needed when working on the estimates of the numbers of people with activity limitations.

The analysis presented here would indicate that further exploratory work could help to resolve out how to improve the adjustments of the TP disability estimates. Gender specific patterns, regional differences and imprecision in the open-ended age group are important issues which can be further analysed to better understand the links between the distribution IP and HP, the excess disability in IP_{HR} and the way of the observed HP disability prevalence deviates from the TP value.

Further exploration could also help to extend the analysis to contexts outside Europe in order to better assess the extent to which definitions and boundaries between IP and HP might vary worldwide, especially in regions where nursing homes and medical institutions are scarce.

Finally, changes over time may be an issue as social policies around aging and health care can modify the offer of and the access to institutions, as well as their types (more or less health-related). These changes might alter the factors that makes people becoming residents and among them, the health factors.

Nevertheless, these analyses suggest that while it may be necessary for countries to conduct surveys among institutionalized populations for the purpose of assessing their specific characteristics and needs, it is not strictly necessary for the purpose of international comparisons of population disability. In any case the diversity of national situations may make it difficult to analyse such data uniformly and furthermore, the observed and estimated values all fall within the confidence interval associated with the survey data precision. The analyses show that the disability measurement biases due to the use of surveys conducted solely among the HP are manageable, if a margin of error is applied by using either confidence intervals or, if the data allow, hypotheses and scenarios on the situation in institutions.

Acknowledgement This study was conducted within the DG Sanco Programme "*European Health and Life Expectancy Information System*" (EHLEIS – 2007–2010). *EU Grant agreement n° 2006109* [see www.eurohex.eu]

Annex

Table 13.A1 French Handicap and Health (HS) Survey 2008–2009. Sample size of the household based and institution based surveys by 5-year age groups

	HS institutions sample	HS private households sample
15	105	1640
20	437	1025
25	479	992
30	476	1213
35	639	1650
40	657	1920
45	700	2218
50	678	2465
55	530	2922
60	387	1941
65	263	1531
70	296	1807
75	456	1952
80	747	1467
85+	2002	1256
15+	8852	25999

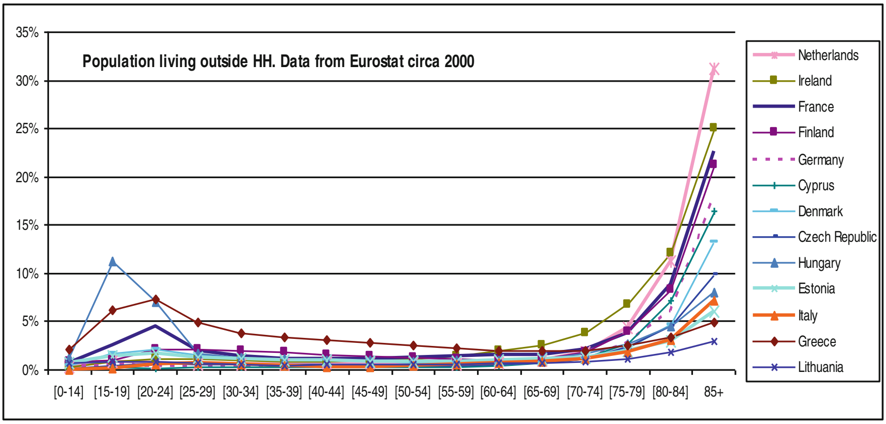

Fig. 13A.1 Percentage population living outside private households in 13 European countries (Source: Eurostat (eurostat.eu))

Table 13.A2 Sample size in EU-SILC 2005 by age group in the Netherlands, Italy and France Source: Euro-Hex database (eurohex.eu)

	The Netherlands		Italy		France	
	Men	Women	Men	Women	Men	Women
[16–19]	116	90	586	616	471	466
[20–24]	170	215	1508	1461	698	765
[25–29]	291	345	1657	1781	579	625
[30–34]	421	481	2079	2076	746	815
[35–39]	492	596	2195	2259	822	903
[40–44]	541	530	2147	2255	875	946
[45–49]	423	429	1978	1979	796	885
[50–54]	387	429	1795	1906	821	850
[55–59]	414	461	1980	2026	804	825
[60–64]	321	400	1547	1658	573	603
[65–69]	174	294	1597	1747	461	557
[70–74]	167	260	1279	1498	457	550
[75–79]	132	241	1012	1366	349	401
[80–84]	89	192	627	1059	208	307
85+	40	87	342	761	92	169
16+	4178	5050	22329	24448	8752	9667

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Part IV

Conclusions: Outcomes and Place of the Washington Group Measures in International Data

Chapter 14
The Washington Group on the Improvement of Disability Statistics Globally: Perspectives from the Philippines

Romulo A. Virola and Jessamyn O. Encarnacion

Introduction

The concern for, the protection, and the care of persons with disability (PWDs) are enshrined in the Philippine Constitution and legislated thru a number of laws aimed at providing equal opportunities for PWDs.

In the Philippines, the promotion of disability concerns is mandated to the National Council on Disability Affairs (NCDA) and is guided by internationally agreed frameworks/commitments (see (Virola 2012)). Specifically, it adheres to the provisions of the United Nations Convention on the Rights of Persons with Disabilities and the ILO Convention on the Vocational Rehabilitation of Persons with Disability.

In addition, the NCDA is guided by local legal/official frameworks such as the following:

1. **The 1987 Constitution**. There are four provisions of the Constitution where PWDs are expressly mentioned to ensure that they have equal participation in the Philippine society.
    a) **Article V. Suffrage. Section 2.**

> *"The Congress shall provide a system for securing the secrecy and sanctity of the ballot as well as a system for absentee voting by qualified Filipinos abroad.*

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*The Congress shall also design a procedure for the **disabled** and the illiterates to vote without the assistance of other persons. Until then, they shall be allowed to vote under existing laws and such rules as the Commission on Elections may promulgate to protect the secrecy of the ballot."*

b) **Article XIII. Social Justice and Human Rights. Section 11.**

*"The State shall adopt an integrated and comprehensive approach to health development which shall endeavor to make essential goods, health and other social services available to all the people at affordable cost. There shall be priority for the needs of the under-privileged, sick, elderly, **disabled**, women, and children. The State shall endeavor to provide free medical care to paupers."*

c) **Article XIII. Social Justice and Human Rights. Section 13.**

"The State shall establish a special agency for disabled person for their rehabilitation, self-development, and self-reliance, and their integration into the mainstream of society." (i.e., the National Commission Concerning Disabled Persons (NCCDP, which was later replaced by National Council for the Welfare of Disabled Persons (NCWDP), and now the NCDA)

d) **Article XIV. Education, Science and Technology, Arts, Culture and Sports. Section 2.**

"The State shall:

(1) *Establish, maintain, and support a complete, adequate, and integrated system of education relevant to the needs of the people and society;*
(2) *Establish and maintain, a system of free public education in the elementary and high school levels. Without limiting the natural rights of parents to rear their children, elementary education is compulsory for all children of school age;*
(3) *Establish and maintain a system of scholarship grants, student loan programs, subsidies, and other incentives which shall be available to deserving students in both public and private schools, especially to the under-privileged;*
(4) *Encourage non-formal, informal, and indigenous learning systems, as well as self-learning, independent, and out-of-school study programs particularly those that respond to community needs; and*
(5) *Provide adult citizens, the **disabled**, and out-of-school youth with training in civics, vocational efficiency, and other skills."*

2. **Accessibility Law (July 26, 1982).** The Law requires that public buildings meet reasonable accessibility requirements in order to promote the mobility of PWDs.
3. **Republic Act. No. 6759 White Cane Act (Sept 18, 1989).** It raises awareness for the benefit of visually impaired persons.
4. **Philippine Republic Act (RA) No. 7277** also known as the "**Magna Carta for Disabled Persons**". It declares that, *"Disabled persons are part of Philippine society, thus the State shall give full support to the improvement of the total well-being of disabled persons and their integration into the mainstream of society. Toward this end, the State shall adopt policies ensuring the rehabilitation, self-development and self-reliance of disabled persons. It shall develop their skills and potentials to enable them to compete favorably for available opportunities."* (see (Republic Act No. 7277 1992)). More specifically, the Magna Carta

- Prohibits acts of discrimination in the area of employment, transportation services and use of public accommodations; and

- Grants 20 % discount privileges in the purchase of medicines and other basic services, among others.

5. **Republic Act. No. 8425 Social Reform and Poverty Alleviation Act (Dec 11, 1997).** RA 8425 declares that it is the policy of the state to "*adopt an area-based, **sectoral** and focused intervention to poverty alleviation wherein every poor Filipino family shall be empowered to meet its minimum basic needs of health, food and nutrition, water and environmental sanitation, income security, shelter and decent housing, peace and order, education and functional literacy, participation in governance, and family care and psycho-social integrity*." Section 6 of said RA defines the composition of the National Anti-Poverty Commission (NAPC), including the 14 basic sectors of Philippine society. One of the basic sectors is PWDs. (see (Republic Act No. 8425 1998))

PWDs and Statistics

The global development agenda has increasingly recognized the importance of statistics and evidence-based decision making.

Clearly, the great concern and enhanced global efforts to address the needs, protect the rights and welfare, and advance the status of PWDs require timely and accurate information on the situation of PWDs. Indeed, the Philippine Statistical System (PSS), particularly the National Statistical Coordination Board (NSCB) acknowledges the need to provide the necessary data support on disability statistics for the formulation of plans and programs for PWDs.

However, in most national statistical systems including the PSS, while economic, social and even environmental statistics have in general, evolved markedly in recent years, the availability, accessibility, and utilization of high quality official and unofficial statistics on PWDs have remained underprioritized in the development agenda.

It was timely therefore that the United Nations International Seminar on Measurement of Disability was held in June 2001. An outcome of that meeting was the recognition that statistical and methodological work was needed at the international level in order to facilitate the comparison of data on disability cross-nationally. As a result, the Washington Group (WG) on Disability Statistics[1] was created under the aegis of the United Nations Statistical Commission (UNSC) in February 2002. The WG is cognizant of the need to promote and coordinate international cooperation in the area of disability statistics and aims to create and promote measures for its generation in censuses and national surveys. (see (National Center of Health Statistics))

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[1] This is a City Group following the format that has been used by the UN in numerous other occasions to address various problems in survey measurement and methodology. The City Group is an informal, temporary organizational format that allows representatives from national statistical agencies to come together to address selected problems in statistical methods. A City Group usually develops a series of three to four working meetings and is named after the location of the first meeting.

Fortunately, the Philippines has been given opportunities to be actively involved in the activities of the WG. Benefiting from the extensive work of the WG on the development and improvement of disability statistics, the Philippines, through the National Statistics Office (NSO), included in the 2010 CPH the core set of questions on functional difficulty, based on the questions formulated and recommended by the WG.[2]

This chapter will present the development and improvement of disability statistics in the Philippines, in the context of the efforts of the WG. This Chapter is organized as follows: the next section will present the efforts of the PSS on the development and improvement of disability statistics in the Philippines prior to the creation of the WG; the third section presents the PSS environment for the development of disability statistics; the fourth section presents the contribution of the WG to the evolution of disability statistics in the Philippines; finally, in the last section, some concluding remarks are made and some ways forward presented.

Efforts of the Philippine Statistical System on the Development and Improvement of Disability Statistics Prior to Its Involvement in the Washington Group

Prior to the establishment of the Washington Group in 2002, the Philippines already attempted to produce official statistics on disability collected through a survey. The NCCDP, which was later replaced by NCWDP, and eventually by NCDA, conducted the National Disability Survey (NDS) in 1980 in collaboration with the Department of Health (DOH) and the University of the Philippines General Hospital (UPGH). Results were intended to serve as important inputs in the development of a National Comprehensive Plan of Action for Filipinos with Disabilities. The 1980 NDS results were released in 1983. Survey results estimated the prevalence rate of disability at 44.17 per 1000 population or 4.4 % for all kinds of disability. There were obvious limitations of the survey including the sampling method used. Unfortunately, the survey documentation is very incomplete. (see (Fermin 2003))

The 1980 NDS asks on the type of handicap/disability, functional limitations, communication, manual dexterity, mobility and endurance, and mental impairment (see (United Nations Statistics Division)). On the other hand, the latest version of the WG Extended Questions for Core Functional Domains asks on the difficulties on vision, hearing, mobility, cognition, communication and self-care (see (National Center of Health Statistics)). The WG Extended Set asks fewer questions than the 1980 NDS and while there are similarities in the questions, the two surveys have different categories/domains. The Questions in the 1980 NDS and WG Extended Questions are provided in the Appendix.

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[2] As of July 29, 2012, the NSO has not published the 2010 CPH results pertaining to disability statistics.

Official statistics on disability were collected through a census for the first time in the 1990 decennial Census of Population and Housing (CPH) conducted by the NSO. This was continued in the 1995 quinquennial Census of Population (PopCen) and the 2000 CPH. According to the 1990 CPH, there were 636,999 PWDs or 1.05 % of the total population. The 1995 PopCen and 2000 CPH reported 919,292 PWDs (or 1.34 %) and 942,098 PWDs (or 1.23 %) in the country, respectively. The census data show that between 1990 and 2000, there had been a slight increase in the proportion of PWDs to total population – indicating that a bigger segment but no more than 1.5 % of the population needs the care and attention of the NCDA and the government to ensure a better quality of life for PWDs.

In 1995, the DOH embarked on a nationwide registration of PWDs, which continued until 1997. The registration form asks for the following information: (a) demographic characteristics; (b) functional assessment such as musculosketal, orthopaedic, mobility, motor disability, visual, hearing, speech, language and communication impairment, mental impairment and deformities; and (c) assistance received/needed. The registration, however, encountered a number of issues/problems such as low turnout and budgetary constraints. No estimate of prevalence rate was generated. (see (Sevilla 2003))

In 2009, the Department of Health (DOH), through its National Center for Disease Prevention and Control, spearheaded the establishment of a web-based Registry of PWDs in the country. The registration process tried to collect the following information on PWDs: type of disability by region, province and municipality; (b) type of disability by sex; (c) type of disability by nationality; (d) type of disability by civil status; (e) type of disability by educational attainment; (f) type of disability by PhilHealth membership; (g) type of disability by nature of employment; (h) type of disability by employment status; (i) statistics based on issuing facility and (j) statistics based on address of the PWD registrant. However, only about 5000 PWDs registered. As of 2010, despite the introduction of web-based registration, only an additional 500 PWDs registered (see (National Center for Disease Prevention and Control n.d.)). The Registry thus captured only approximately 5500 out of the estimated 1.44 million PWDs in the Philippines in 2010. Needless to say, considering the outcome of the efforts of the NSO and the DOH on the measurement of disability, there is a strong need to improve/strengthen the methodological work on this area.

Another initiative also undertaken by the DOH, together with a group of doctors, is a nationwide Disability Prevalence Survey. The survey was conducted from July 2000 to October 2002. Like the 1980 NDS, the documentation of this survey was very incomplete. The survey yielded a crude disability prevalence rate of 2.9 %, way below the 10 % estimate of the United Nations for developing countries. Similar with the experience of the PWD registration systems, the survey encountered problems such as lack of human resources and inadequate medical equipment, among others. (see (Sevilla 2003))

Notwithstanding the constraints, limitations, and weaknesses of these various efforts (i.e., censuses, surveys, administrative-based systems) towards measurement of disability in the country, they provided better understanding and appreciation of the country's disability situation in the 1980s, 1990s, and early 2000s. More importantly, it underscored the critical need for research and development in this area to generate, disseminate and utilize more accurate and reliable statistics on disability towards ensuring equal opportunities for PWDs.

Thus, the establishment of the Washington Group, which aims to address these very same concerns of national statistical systems, is greatly welcomed by the Philippine statistical community, particularly the NSCB and the NSO. In the Philippines, it is well recognized that there is an existing lack of statistical capacity in the NCDA and in other institutions mandated with the formulation of programs for the benefit of PWDs as attested by the failure of past efforts to compile data on PWDs via a Register and the unavailability or inaccessibility of disability statistics from administrative-based systems. On the other hand, official statisticians generally lack conceptual expertise on disability that serves as hindrance in the generation, dissemination, communication, and utilization of high quality disability statistics. Against this backdrop, the importance of the WG and its initiatives cannot be overemphasized.

The Environment for the Development of Disability Statistics in the Philippine Statistical System (PSS)

The PSS is a decentralized statistical system where different agencies of government produce various kinds of statistics. These statistics include those on disability, which has implications on the quality of disability statistics produced in the country. As mentioned earlier and as in most national statistical systems, the generation of high quality disability statistics in the PSS is hindered by the twin problem of lack of statistical expertise in Philippine institutions mandated to protect PWDs and the lack of conceptual expertise on disability among official statisticians. Hence, strong statistical coordination is critical to achieve closer linkages within and among the data producers and data users, which are prerequisites to high quality disability statistics.

In 1987, per Executive Order (EO) 121, the National Statistical Coordination Board (NSCB) was established to serve as the highest policy-making and coordinating body on statistical matters.[3] Specifically, it is tasked to coordinate with concerned agencies/groups/committees on the review and assessment of current

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[3] On 12 September 2013, Republic Act No. 10625 "An Act Reorganizing the Philippine Statistical System, Repealing for the Purpose Executive Order Number One Hundred Twenty-One, Entitled "Reorganizing and Strengthening the Philippine Statistical System and for Other Purposes" was signed. The Act, also known as the Philippine Statistical Act of 2013, created the Philippine Statistics Authority (PSA) constituted from the now abolished major statistical agencies, which were previously engaged in statistical coordination, primary data collection and compilation of secondary data, i.e., the National Statistics Office, the Technical Staff of the National Statistical Coordination Board, the Bureau of Agricultural Statistics, and the Bureau of Labor and Employment Statistics.

issues on sectoral statistics and indicators being produced by the PSS, including disability statistics.

Over the years, the NSCB has issued policies and put in place mechanisms conducive to the development of statistics/sectoral statistics, particularly on disability statistics. These mechanisms have been quite successful in improving statistics in some sectors but not in others. Among them are the following:

Statistical Policies on Disability Statistics

As the policy-making body of the PSS, the NSCB issues statistical policies for the guidance of the PSS member agencies. Among these is

NSCB Resolution No. 8, Series of 1994 – Enjoining Different Agencies to Promote Gender Concerns in the Generation of Statistics. The Resolution covers the sex-disaggregation of disability statistics.

Coordination Mechanisms on Disability Statistics

As the coordinating body of the PSS, the NSCB has successfully introduced coordination mechanisms that have contributed to the development of the PSS.

1. **Philippine Statistical Development Program (PSDP).** The PSDP serves as a guide to the PSS in the formulation and implementation of statistical activities during the period as well as the directions/work plan of the NSCB-coordinated Interagency Committee on Health and Nutrition Statistics (IAC-HNS). One chapter is on Health and Nutrition Statistics, which particularly addresses concerns on the generation, dissemination, and utilization of statistics on health and nutrition, including disability. Any proposal to collect disability statistics including the budgetary requirement will be included in the calendar of activities that forms part of Volume II of the PSDP.

   The PSDP is the country's National Strategies for the Development of Statistics (NSDS). The latest PSDP covers the period 2011–2017 – the eighth edition since 1976.
2. **Statistical Survey Review and Clearance System (SSRCS).** To enhance the quality of statistics generated by the various agencies of the PSS, including the adoption of international statistical standards, classification systems, guidelines, and best practices, all surveys/censuses/administrative systems conducted/maintained by or for the government pass review by the NSCB Technical Staff and/or the NSCB-created Technical Committee on Survey Design (TCSD). The TCSD members are statistical experts coming from different agencies including the research and academic communities. Thus, TCSD-approved data collection systems on disability are required to use classification systems like the International Classification of Functioning, Disability and Health (ICF).

3. **Statistical Budget Review Process.** To minimize if not eliminate duplication of data collection efforts and enhance the efficiency of the PSS, budgets for statistical activities proposed by government agencies have to pass review by the NSCB. This mechanism is being implemented in collaboration, coordination, and cooperation with the Department of Budget and Management. Through this process, any overlap in the data collection systems of the NSO and the program agencies for PWDs can be addressed.
4. **Interagency Committee on Health and Nutrition Statistics (IACHNS).** The Committee aims to resolve statistical issues and to address emerging concerns on health and nutrition statistics, including disability statistics, to be able to provide relevant reliable and timely data for planning and programming purposes. It is being chaired by the DOH with NSCB as Vice-Chairperson. There are 13 member agencies and the representative/s from the National Council on Disability Affairs serve/s as resource person/s. The IACHNS is one of 13 IACs being coordinated by the NSCB.
5. **Hosting of International Conferences/Local Advocacy Interagency Activities.** The statistical collaboration and cooperation among the PSS agencies are strengthened by interagency participation in activities of the PSS. Thru attendance in these activities that include trainings and workshops also builds statistical capacity in the PSS.

   - The Philippines, a member of the Washington Group Steering Committee, hosted the 8th Annual Meeting of the Group. The Meeting was held in the Philippines on 29–31 October 2008.
   - **Annual Celebration of National Statistics Month (NSM).** The NSM serves as a forum for collaboration among PSS agencies towards improvement of sectoral statistics in the Philippines. The DOH co-hosted with the Department of Interior and Local Government (DILG) the 9th celebration of the NSM in 1998, with the theme, "*Statistics in the 100th Year of Independence: Towards a Meaningful Governance, Health and Peace in the Community*."

6. **International cooperation**. The Philippines, mainly through the NSCB and the NSO, has actively participated on various conferences/fora/meetings/regional and global projects such as the following:

   – Meetings of the Washington Group on Disability Statistics, including Annual Reporting on National Activities Related to Disability Statistics
   – Sessions of the UN Statistical Commission, International Statistical Institute, etc.
   – UN ESCAP/Washington Group Project on Disability Statistics
   – Conduct of UNESCAP-WG-NSO Project on the Improvement of Disability Measurement and Statistics in Asia and the Pacific

     - Cognitive and field test of the International Classification of Functioning, Disability and Health (ICF) based disability questions for surveys

- Cognitive and field test project under the Biwako Millennium Framework (BMF) and Regional Census Programme, a project implemented by the UNESCAP from 2007 to 2009
- The Philippines was one of the six countries, which undertook the cognitive and field testing in 2009.

Disability Statistical Products and Services

Following are the statistical products and services on disability in the Philippines, which were earlier discussed in the previous section:

a) 1980 National Disability Survey, released in 1983
b) 1995 and 1997 Philippine Registry for Persons with Disability
c) Conduct of 1990 CPH, 1995 PopCen, and 2000 CPH with one question on disability
d) Conduct of the 2010 CPH with questions on functional difficulty
e) Conduct of some testing for effective data gathering of disability statistics

  - Pretests of Census of Population
  - WHO/UNESCAP Disability Question Set Testing
  - Washington Group General Measure on Disability Cognitive Test

f) Available Administrative Data on PWDs

  - Data/information on the number of PWDs served on a quarterly, semestral and annual basis
  - Data are released through the Compendium of the Department of Social Welfare and Development and Selected Social Welfare and Development Statistics
  - Some Administrative Data on PWDs are also available from the following agencies:

    - Social Security System (SSS) and Government Service Insurance System (GSIS)
      - statistics on members who became disabled and entitled to social security (disability) benefits
    - Department of Social Welfare and Development
      - statistics based on the administrative forms on “Social Services for Distressed and Displaced Population”
    - Department of Education
      - statistics based on enrolment records of public schools and special schools where PWDs are currently enrolled

g) National Registration of PWDs – These registration systems were geared towards the issuance of identification numbers for PWDs to facilitate program intervention and the generation of statistical reports. Unfortunately, they have been unsuccessful so far.

At this point, the authors realize that one of the benefits of this opportunity to contribute to this book is the recognition of the importance of the Philippine involvement in the Accelerated Data Program (ADP) of the International Household Survey Network (IHSN) under the Partnership in Statistics for Development in the twenty-first century (PARIS21).

The attempt made to document the efforts of various concerned agencies in the PSS on the collection of disability statistics in the country has been very challenging. It underscored the need for greater and more comprehensive documentation of the registers/surveys undertaken on PWDs. For example, in tracing the efforts of the National Registry of PWDs undertaken in 1990s and 2000s, the authors faced difficulties in differentiating efforts made in 1995, 1997, 2004, and 2009–2010. Further, forms used and information gathered had to be obtained from various agencies, thru the web (in various sites) or telephone/written requests, among others. The generation of metadata by data producers certainly needs to be improved.

To address such issues/concerns on documentation and dissemination, the international statistical community has put in place various facilities/mechanisms, which countries, specifically developing countries, can benefit from. Particularly noteworthy among these is the ADP of PARIS21. The ADP provides technical and financial support to survey data documentation and dissemination, and to the improvement of survey methods. Key outputs include the establishment of national survey databanks, and the establishment of national data collection standards to foster comparability of data across sources.

The ADP is supporting major Philippine statistical agencies in the establishment of their survey and census data documentation and archive through a comprehensive capacity-building plan. The National Statistics Office (NSO), the Bureau of Agricultural Statistics (BAS) and the Bureau of Labor and Employment Statistics (BLES) have already institutionalized and operationalized their national data archive (NADA) and two more agencies, namely Bangko Sentral ng Pilipinas and Food and Nutrition Research Institute (FNRI), will be putting up their NADA in 2012. A total of 123 survey rounds were already documented and archived in the Philippines using the NADA.

This program benefits from the involvement of the NSCB as the highest policy-making and coordinating body on statistical matters in the Philippines. As the overall statistical coordinating body in the PSS, the NSCB issued NSCB Resolution No. 10, Series of 2010 "Enjoining Agencies in the Philippine Statistical System to Archive and Document Microdata Using International Standards" towards the realization of the Government's vision to provide adequate, relevant, reliable, timely and accessible statistical information and services to the public. As a result of the implementation of said Resolution, ten agencies have undergone orientation and training on NADA conducted by the ADP Office in Manila in coordination with the

NSCB. One of the agencies, which participated in the orientation is the Department of Health and it will be participating in the training component in the latter part of 2012.

Further, the Philippine Statistical Development Program 2011–2017 has identified as one of its statistical programs in the Chapter on Health and Nutrition Statistics, the development and improvement of an integrated health and nutrition statistics web portal under the Philippine Health Information Network (PHIN). This program includes the following: (1) design and establishment of a data warehouse for health and nutrition statistics; and (2) development of data sharing and dissemination protocols. Depending on availability of resources and more importantly, the political will of concerned agencies, it is hoped that significant improvements on the documentation of the efforts to generate disability statistics in the country will be achieved during the plan period and onwards.

Washington Group Contribution to the Improvement of Disability Statistics in the Philippines

Since its establishment in 2002, the Washington Group has done outstanding work towards the generation of comparable disability statistics worldwide. The Philippines gratefully acknowledges the significant contribution of the United States through the National Center for Health Statistics (NCHS), and particularly, Jennifer Madans, who as WG Chair has been the guiding and inspiring force behind the WG. The outstanding contributions of earlier NCHS representatives like Barbara Altman and Elizabeth Rasch are likewise very much appreciated and recognized. Further, the very efficient coordination and strong technical support of the WG Secretariat were clearly instrumental in the success of the 11 WG meetings and two regional workshops undertaken in different Regions.

Cognizant of the Group's objectives and in adherence to existing legal/official frameworks in the Philippines, the PSS has been consistently and actively supporting the Washington Group's agenda, more specifically, on generating accurate, relevant, timely, and comparable statistics on PWDs.

In this regard, the Philippines, through the NSCB and/or the NSO, has benefited significantly by actively participating in the following:

1. **Annual WG meetings**
   The Philippines, through the NSCB, was represented in the first meeting of the WG in 2002, which discussed the objectives of the Group and its work plan, among others. The Philippines submits inputs to the WG Annual Report on National Activities Related to Disability Statistics.

   During the 3rd WG meeting held in Belgium in February 2004, the Philippines, through the principal author, was included in Workgroup 1 of the WG. Workgroup 1 was designated to generate a draft short set of census questions (short form) to be completed by the summer of 2004. The group was charged with developing a list of measurement domains and criteria to rank domains for potential inclusion, determining if inclusion of a severity indicator is necessary and addressing the issue of accommodations. If time allows, the group will pilot the proposed questions.

In the 5th meeting of the WG held in Brazil in 2005, the Philippines through the NSO presented its experience in the pretest of questions and provided several observations and suggestions based on the Philippine experience (e.g., the manual should include several examples and explanations, the need to shorten the questions/questionnaire, the need to structure the format, etc.).

The Philippines also participated in the 6th meeting held in Kampala, Uganda in October 2006 wherein cognitive test results and documentation of the Philippine Experience was presented.

Continuing the Group's objective of a balanced geographic distribution of meeting venues, the Philippines hosted the 8th meeting of the WG on 17–19 October 2007 in Manila, coinciding with the celebration of the 19th National Statistics Month in the Philippines. Discussions on the extended set were undertaken, reaching an agreement that its development would be done in collaboration with the Budapest Initiative, Eurostat, and UNESCAP. The draft of the extended set questions and plans for cognitive and field testing of the questions was presented later in the meeting (see (National Statistical Coordination Board 2008)).

In February 2009, a statistical capacity building activity thru training for the cognitive and field testing of the proposed extended set was conducted, with the Philippines as one of six participants from UNESCAP countries.

During the 9th meeting of the WG held in Dar es Salaam, Tanzania in October 2009, the Philippines, being one of the six countries trained on the cognitive and field testing, presented the results of its preliminary testing. Some observations were presented, i.e., the process was considered long and tedious, required persuasion and good note taking skills, required knowledge of medical conditions especially to validate self-reported ailments or determine health disparities (for functional difficulty), among others.

In November 2010, the Philippines participated in the 10th WG Meeting held in Luxembourg.

2. **Regional workshop organized by the WG**
   The 2nd Regional Workshop of the WG was held in Brazil in September 2005. The Philippines was one of the participating countries in the workshop, which served as a venue for countries in the Latin America and the Caribbean to understand and appreciate the efforts of the WG on the development of the short set of questions, and test protocols, among others.
3. **Membership in the Steering Committee of the Washington Group**
   During the 3rd meeting of the WG in 2004, a governance plan was formulated and adopted by the WG. A Steering Committee was formed, with the Philippines as one of the members. The Committee was tasked to develop a long-range work plan and timeline to facilitate the WG activities. The Philippines, through the

NSCB, actively participated in the regular meetings of the Steering Committee that included teleconferences.

While the Philippines would have wanted to participate in all the WG meetings and regional workshops, this was not possible due to budget constraints. Nonetheless, the Philippines is grateful for the support of the WG, the WG Chair and the NCHS-based WG Secretariat for the support that allowed us to participate in some of the meetings and workshops. Participation in these meetings capacitated official statisticians from the Philippines in the area of disability statistics and enhanced our appreciation for the need to generate official statistics on PWDs in the Philippine Statistical System. It also opened our eyes to the need to strengthen our statistical coordination, collaboration and cooperation with institutions mandated to protect and provide for the needs of PWDs.

Significantly benefiting from the pioneering initiatives and the great help and assistance of the WG, the measurement of disability in the Philippines has definitely evolved and improved. In this regard, we cite a number of specific developmental and statistical capacity building activities related to the development and improvement of disability statistics.

(i) **NSCB Resolution No. 22, Series of 2009 – Approving the Data Items to be Included in the 2010 Census of Population and Housing.** Questions on functional difficulty, based on the recommended questions of the WG, were included in the core data items in the 2010 Census of Population and Housing.

In the 1990 CPH, 1995 PopCen, and 2000 CPH, there was one question on disability:

“Does _______ have any physical or mental disability?”
1 *Yes*
2 *No*

As one of the participating countries in the pilot/pre-test activities of the WG and in the UNESCAP-WG-NSO Project on the Improvement of Disability Measurement and Statistics in Asia and the Pacific, the Philippines had the opportunity to conduct some testing for more effective data gathering of disability statistics. These statistical capacity building activities include the pretests of Census of Population, Washington Group General Measure on Disability Cognitive Test, cognitive and field test of the ICF based disability questions for surveys, among others.

Thus, in the 2010 Census of Population, the Philippines, through the NSO, incorporated the short set of questions developed by the WG that would lead to internationally comparable statistics on disability in the Philippines. Provided below is the short set of questions used in the 2010 CPH.

“Does ____ have any difficulty/problem in…?”
Yes No

a) Seeing, even when wearing eyeglasses
b) Hearing, even when using a hearing aid
c) Walking or climbing steps

d) Remembering or concentrating
e) Self-caring (bathing or dressing)
f) Communicating using his/her usual language

Questions were translated in English, Filipino and five major dialects of the country (Cebuano, Waray, Ilocano, Bicolano, and Hilgaynon).

Incorporation of the short set of questions on disability contributed to the improvement of statistics to be disseminated by the Philippine Statistical System, particularly the NSO. The following tables are planned to be released using the results of the 2010 CPH:

- Table 8. Household population with functional difficulty by sex and age group
- Table 9. Household population 5 years old and over with functional difficulty by type, sex and age group

Likewise, using the results of the short set of questions in the 2010 CPH and as another step to encourage greater utilization of statistics on disability, the NSO plans to make a more detailed study on disability with more special/cross tabulations with other variables in the 2010 CPH.

(ii) Further, the above-mentioned WG-related experiences and activities played a role as the Philippines contributed in the promotion of disability concerns at the global level. Specifically, In the more recent sessions of the United Nations Statistical Commission (UNSC), the Philippine Statistical System, through the NSCB, has been supporting the presentations by the WG Chair – its work plan, activities, etc. The Philippines has also called for the continuing support of the international community on the work of the WG.

In addition, the Philippines has supported/initiated the following resolutions on disability concerns adopted by the UN General Assembly (GA):

A/Res/65/186 – Realizing the Millennium Development Goals for PWDs Towards 2015 and Beyond The Resolution "*calls upon Governments to strengthen the collection and compilation of national data and information about the situation of persons with disabilities following existing guidelines on disability statistics that are disaggregated by sex and age, which could be used by Governments to enable their development policy planning, monitoring, evaluation and implementation to be disability sensitive, in particular in the realization of the Millennium Development Goals for persons with disabilities, and invites Governments to provide, where available, relevant data and statistics to the appropriate mechanisms within the United Nations system, including the Statistical Commission; and requests the United Nations system to facilitate technical assistance, within existing resources, including the provision of assistance for capacity building and for the collection and compilation of national and regional data and statistics on disability, in particular to developing countries, and in this regard requests the Secretary General, in accordance with existing guidelines on disability statistics, to analyse, publish and disseminate disability data and statistics in future periodic reports, as appropriate, on the realization of the Millennium Development Goals for persons with disabilities.*" (see (United Nations 2012))

A/Res/66/124 – High Level Meeting on the Realization of the MDGs and Other Internationally-Agreed Development Goals for PWDs

Indeed, the work of the Washington Group has greatly influenced the availability of more accurate information on disability not only globally but also in the Philippines. This is expected to serve as critical input to policy- and decision-makers working towards the improvement of the welfare of PWDs.

Way Forward

The Philippines recognizes and highly appreciates the efforts and assistance provided by the Washington Group to the Philippine Statistical System towards the development and improvement of disability statistics in the country. However, due to a number of factors, the development of disability statistics in the Philippines has not proceeded as fast as may be wished. Towards mainstreaming disability statistics in the PSS, challenges remain (see (Virola 2012)).

A. **Methodological/Operational.** Despite some progress, there remains a lack of capabilities of official statisticians/data producers on the measurement of disability particularly to address the following concerns: measurement problems associated with functional difficulty, need to ensure use of international standards, and problems being encountered in the establishment of the Philippine Registry for PWDs

B. **Lack of statistical capacity of dutybearers/users of disability statistics.** For greater appreciation of the critical indicators that are urgently needed for actual policymaking and decision-making, there is a need for statistical capacity building, not only of producers but also of users and stakeholders of disability statistics, e.g., the NCDA. The question is, who can provide the training?

C. **Need for better coordination of the agencies of government involved in the generation of disability statistics.** Coordination, even statistical coordination is not easy. Many agencies feel uncomfortable being coordinated, treating the process as turf-building or infringement on their independence. In the past, coordination between the statistical community and the institutions promoting the concerns of PWDs had been minimal, if not nonexistent. As a result of the Philippine involvement in the WG, coordination has improved and its importance recognized, but much more needs to be done.

D. **Lack of resources allocated for disability statistics**. In most countries, while demand for statistics has clearly risen, statistics continue to occupy the bottom priorities in the allocation of budgetary resources. Statistical agencies and the institutions concerned with the welfare of PWDs do not get the resources needed to generate, disseminate, communicate, and use high quality disability statistics.

E. **Absence of clearly demonstrated policy uses of disability statistics.** Users and stakeholders need to demonstrate the relevance/usefulness of data being demanded and generated by data producers. The absence of a demand-driven disability statistics culture is a big challenge that must be addressed to ensure that resources are made available for disability statistics.

F. **High cost of censuses/surveys/registers.** With the advances in information technology, there is a need for data collectors to enhance their efficiency. The high cost of present data collection activities has certainly made it difficult to compile high quality disability statistics.

But while working towards the improvement of disability statistics has been challenging in the Philippines, it also has its rewards/opportunities:

A. The Philippine engagement with the Washington Group under the leadership of NCHS/Jennifer Madans has been an empowering experience towards mainstreaming disability statistics in the PSS. Specifically,

   - Official statisticians now know more about disability.
   - Official statisticians now know better how to measure disability.

B. Efforts of the statistical agencies to improve sectoral statistics like on disability, have opened up avenues to improve statistical coordination within the Philippine Statistical System and enhance appreciation for statistics by stakeholders. Presently, many more agencies of government are now consulting/collaborating with the statistical agencies, such as towards the development of registries of farmers and fisherfolk, among others.

C. Integration of statistics in decision making (on poverty alleviation) in the Philippines has been enhanced.

   - The collaboration of the PSS and the Department of Social Welfare and Development (DSWD) on poverty alleviation (e.g., National Household Targeting System for Poverty Reduction, NHTS-PR) has been an inspiring experience towards the integration of statistics in decision-making.
   - Statistics are now very visibly being used in the primary program of government on poverty alleviation and stakeholders, including politicians know it, even if not all of them like it!

On the way forward, mainstreaming disability statistics in the Philippine Statistical System means:

1. **Availability and accessibility of better statistics on PWDs**. There is a need for timely, regular, relevant and sex-disaggregated disability statistics, with some details on the socio-economic profile of PWDs. Further, there is a need for subnational/local level disability data to be able to locate the PWDs. And these statistics must be accessible to the stakeholders.
2. **Better use of better statistics on PWDs.** The greatest challenge to data users and stakeholders of disability statistics is for them to ensure that these statistics are actually used to craft programs and policies for inclusive development.
3. **Higher investments on disability statistics.** It is hoped that the Philippine Government will give higher budgetary priority to the generation, dissemination/communication, and use of disability statistics.

To mainstream disability statistics in the Philippine Statistical System towards inclusive development, towards better development outcomes for PWDs, some strategies are presented below:

1. **Statistical capacity building** of both data producers and users of statistics.
2. **Greater advocacy.** There is a need for a more convincing articulation of the importance of disability statistics by agencies promoting PWDs. For example, the NCDA should constantly and more aggressively push for better statistics on PWDs. As mentioned earlier, PWDs are one of the 14 basic sectors of Philippine society. But while poverty statistics are generated by the PSS for eight of the basic sectors, there are no poverty statistics for PWDs.
3. **Institutionalization of collection/dissemination of statistics on PWDs in the Philippine Statistical System.** The Philippine Statistical Development Program 2011–2017 has identified statistical programs/activities on disability statistics such as the special tabulations/study on the results of the 2010 CPH, conduct of disability surveys, improvement of the Registry of PWDs, improved sharing of disability data (e.g., development and improvement of an integrated health and nutrition statistics web portal under the Philippine Health Information Network (PHIN), which will include disability statistics)**.** These planned activities for disability statistics need to be implemented.
4. **Better coordination.** To maximize benefits from statistical activities amidst limited resources, statistical coordination is critical – within countries, between the statistical community and the program ministries and among the stakeholders in the international community.
5. **Improved documentation.** As mentioned earlier, the documentation of past Philippine efforts to gather data on PWDS has been very incomplete. This means the use of very limited resources has been wasted, or at least has not been maximized. Continuing engagement with PARIS21 on the ADP initiative should be pursued by the Philippines, and other countries which have not done so should be encouraged and supported to be able to benefit from the ADP.
6. **Continued engagement with/of the international community.** The Philippine Statistical System highly appreciates the efforts by the international community, particularly the WG with regards to the methodological work/capacity building on disability statistics. It is hoped that these are sustained such as on the development of long set of questions by Washington Group, the methodological initiatives of WHO, training programs of SIAP (for both producers and users of statistics), conduct of regional/international workshops (a challenge for the UNESCAP to provide a forum for sharing experiences within the Region), implementation of the Busan Action Plan for Statistics, financial/technical assistance, help in the advocacy for statistics, and advocacy for PWDs.

Finally, it must be stressed that it costs money to generate, disseminate, and utilize high quality statistics. While resources for statistics have increased in the Philippines, these have not been commensurate with the much increased demand for statistics. If better disability statistics are needed, a genuine political will should be cultivated to advocate for statistics. We must invest in statistics, invest in statisticians, and invest in statistical offices.

Acronyms

CPH	Census of Population and Housing
DILG	Department of Interior and Local Government
DOH	Department of Health
DSWD	Department of Social Welfare and Development
EO	Executive Order
IAC-HNS	Interagency Committee on Health and Nutrition Statistics
ICF	International Classification of Functioning, Disability and Health
MDG	Millennium Development Goals
NAPC	National Anti-Poverty Commission
NCCDP	National Commission Concerning Disabled Persons
NCDA	National Council on Disability Affairs
NCDPC	National Center for Disease Prevention and Control
NCHS	National Center for Health Statistics
NCWDP	National Council for the Welfare of Disabled Persons
NDS	National Disability Survey
NGO	Non-Government Organizations
NHTS-PR	National Household Targeting System for Poverty Reduction
NSCB	National Statistical Coordination Board
NSDS	National Strategies for the Development of Statistics
NSO	National Statistics Office
PopCen	Census of Population
PHIN	Philippine Health Information Network
PSDP	Philippine Statistical Development Program
PSS	Philippine Statistical System
PWD	Persons with disability
RA	Republic Act
UNSC	United Nations Statistical Commission
UPGH	University of the Philippines General Hospital

Appendix

Questions in the 1980 Philippines National Disability Survey

1. **Type of handicap/disability**
   a) Missing limbs
   b) Unequal length of limbs
   c) Deformity of limbs
   d) Deformity of spine
   e) Joint/muscle pain
   f) Weakness/paralysis of limbs
   g) Impairment of sensation

   h) Abnormality in limb tone
   i) Abnormal movement of limb
   j) Weakness/paralysis of face
   k) Impairment of bowel/urinary control
   l) Impotence
   m) Hearing disorder
   n) Speech disorders
   o) Visual disorders
   p) Disfigurements
   q) Chronic respiratory disorders

2. **Functional limitations**
   a) Feeding
   b) Dressing
   c) Bathing
   d) Toilet activities
   e) Sexual performance
   f) Fetching water
   g) Looking after children
   h) Going to market/shopping
   i) Washing clothes
   j) Cleaning the house
   k) Moving in and out of the garden/yard
   l) Doing kitchen work
   m) Bed making

3. **Communication**
   a) Talking
   b) Hearing
   c) Writing
   d) Reading
   e) Making gestures/signs

4. **Manual dexterity**
   a) Grasping/holding
   b) Reaching out
   c) Coordination of upper extremities

5. **Mobility and endurance**
   a) Can take public transport without assistance
   b) Ambulant without assistance
   c) Ambulant with aids (canes, crutches, braces etc.)
   d) Ambulant only with artificial limb
   e) Walks, but needs guiding and personal support
   f) Walks but cannot stand/sit unaided

Washington Group Extended Questions for Core Functional Domains

6. **Mental impairment**

Vision:

Do you have difficulty seeing and recognizing a person you know from 7 m (20 ft) away?
Do you have difficulty seeing the print in a map, newspaper, or book?

Hearing:

Mobility:

Cognition:

Do you have difficulty remembering the names of people or places?
Do you have difficulty remembering appointments?
Do you have difficulty remembering how to get to familiar places?
Do you have difficulty remembering important tasks, like taking medications or paying bills?
Do you have difficulty concentrating on doing something for 10 min?
Do you have difficulty learning a new task, for example, learning how to get to a new place?
Do you have difficulty finding solutions to problems in day to day life?

Communication:

Self-Care

Do you have difficulty reaching up over your head?
Do you have difficulty reaching out as if to shake someone's hand?
Do you have difficulty using your fingers to button a shirt or dress?
Do you have difficulty putting on socks or stocking?
Do you have difficulty tying your shoelaces?
Do you have difficulty combing your hair?
Do you have difficulty feeding yourself?

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Chapter 15

International Census/Survey Data and the Short Set of Disability Questions Developed by the Washington Group on Disability Statistics

Mitchell Loeb

Background

Historically, disability data reported internationally have varied greatly [(Mont 2007; Loeb and Eide 2006), and see also: http://unstats.un.org/unsd/demographic/sconcerns/disability/disab2.asp]. Across countries and across years within a country reported prevalence rates have fluctuated depending upon the source of the data, the methodology for collecting the data or the questions used to operationalize disability in a census or survey (Loeb and Eide 2006). The lack of internationally comparable data on disability had been well documented previously [(Altman 2001; WHO-World Health Organization/World Bank 2011) among others] and was the subject of a UN International Seminar on the Measurement of Disability in 2001 (see: http://unstats.un.org/unsd/disability/Seminar%202001.html). There was a broad consensus at that seminar on the need for statistical and methodological initiatives at an international level to facilitate the measurement of disability and the comparison of data on disability cross-nationally. The Washington Group on Disability Statistics (WG), a United Nations City Group created in 2002 under the aegis of the UN Statistical Commission, was tasked with meeting those challenges.

Over the course of the past 10 years, the WG has:

- Developed, tested and adopted a short set of six questions on functioning that are suitable for censuses (Madans et al. 2004; UN Washington Group on Disability Statistics (WG) website; Washington Group on Disability Statistics (WG) 2008, 2009, 2010). The approach endorsed by the WG has been incorporated in the

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2008 UN Principles and Recommendations for Population and Housing Censuses (UNSD – United Nations Statistical Division 2008). (See: Section VI-8: Disability Characteristics pages 178–183, and Tabulations on Disability Characteristics pages 292–294; available online at: http://unstats.un.org/unsd/demographic/sources/census/docs/P&R_Rev2.pdf).

- Developed, tested and adopted an extended set of questions on functioning that expands on the six domains covered by the short set, adding upper body functioning, affect, pain and fatigue; and begins to construct the links between functioning in core domains without accommodation, functioning with accommodation, environment and participation (Washington Group on Disability Statistics (WG) 2012).
- Embarked (in collaboration with UNICEF) upon the development of a set of questions on child functioning and disability. A module of 14 questions has been developed and has been cognitively tested in Belize, USA, and India. Further cognitive and field testing is planned.

Most recently, the World Report on Disability (WHO-World Health Organization/World Bank 2011) addressing similar concerns regarding internationally comparable disability data, makes specific recommendations that would enhance the availability and quality of data on disability internationally and that, in fact, reflect the approaches taken by the WG. These include, among others, the adoption of the International Classification of Functioning, Disability and Health (ICF) (WHO – World Health Organization 2001) as a framework for the development of questions on disability; improved comparability of data; the development of appropriate tools (both quantitative and qualitative methodologies) to improve and expand data collection on disability; and the collection of national population census data according to the recommendations from the UN Statistical Commission (WHO-World Health Organization/World Bank 2011).

Development of an Internationally Comparable Measure for Census

As stated above, the main objective of the WG has been the promotion and coordination of international cooperation in the area of health statistics by focusing on disability measures suitable for censuses and national surveys.

As its first task, the WG developed a short set of questions for use in censuses and sample-based national surveys. The measures identified were to be comparable cross-nationally and cross-culturally and developed according to the Fundamental Principles of Official Statistics (Statistical Commission and Report on the Special Session 1994) and in a manner consistent with the ICF (WHO – World Health Organization 2001). Extensive cognitive and field testing of the question set has shown that they produce internationally comparable data (Miller et al. 2011).

The questions cover six core domains of functioning or basic actions: seeing, hearing, walking, cognition, self-care, and communication (see Box 15.1).

Box 15.1: The Washington Group Short Set of Questions (SS)
The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual language, do you have difficulty communicating, (for example understanding or being understood by others)?

Each question has four response categories: (1) No, no difficulty, (2) Yes, some difficulty, (3) Yes, a lot of difficulty and (4) Cannot do it at all.

Determination of Disability (Washington Group on Disability Statistics (WG) 2010)

The WG chose first to focus on core domains of functioning, or basic actions, since these are considered less likely to be influenced by either specific cultures or the environment, and are thus more suited as international measures capable of providing comparable data cross-nationally. Secondly, basic actions form the building blocks for more complex activities (Altman and Bernstein 2008). For example, a complex activity like *going to the doctor* involves a combination of basic actions and can, in fact, include all six of the WG functional domains: mobility, cognition, communication self-care as well as seeing and hearing. While the ideal would be to collect information on **all** aspects of the disablement process and to identify every person with a disability within every community, this would not be possible given the limited number of questions that can be asked on a National Census. The basic actions represented in the question set are those that are most often found to limit an individual and result in participation restrictions and can be included in a census. Domains were selected using the criteria of simplicity, brevity, universality and comparability (Madans et al. 2004). It is expected that the information that results from the use of these questions will, (a) represent the majority of, **but not all**, persons with limitation in basic actions, (b) represent the most commonly occurring limitations in basic actions, and (c) be able to capture persons with similar problems across countries.

The WG has identified the assessment of equalization of opportunity as the measurement objective that can best be achieved in a Census (Madans et al. 2004). Over the course of time, the Census allows for assessment of equalization of opportunity by monitoring and evaluating outcomes of anti-discrimination laws and policies, and service and rehabilitation programmes designed to improve and equalize the participation of persons at all levels of functioning in all aspects of life.

Using information that can be obtained from a Census, persons with disabilities would be defined as those who are at greater risk than the general population of restricted participation in society due to limitations in performing specific tasks (activities). This group would include persons who experience difficulties in one or more of the six core domains, such as walking or hearing, even if the difficulties they experienced were alleviated by the use of assistive devices, living in a supportive environment or having plentiful resources. Some of these individuals may not experience restrictions in participation such as in shopping, doing household chores, working or going to school, because the necessary adaptations have been made at the level of the person (technical aids, assistive devices or personal assistance) or their environment (physical, social or civic accommodations). They would still, however, be considered to be at greater risk than the general population for participation restrictions because of the presence of difficulties in the six core domains and because, in the absence of their accommodations, their levels of participation would be jeopardized. The WG approach to measuring disability addresses the societal objective, as stated in the U.N. Convention on the Rights of Persons with Disabilities (CRPD) (UN – United Nations Enable 2006), to equalize access through the removal of barriers to participation that are, in turn the result of difficulties in the core domains.

Analytic Approaches

At the sixth annual meeting of the Washington Group held in Kampala, Uganda in 2006 test results from 15 countries were reported and the short set of questions on disability was endorsed by the 23 countries and 5 international agencies in attendance. In 2008 the United Nations Statistical Division (UNSD) presented Principles and Recommendations for Population and Housing Censuses (2nd Revision) (UNSD – United Nations Statistical Division 2008). Among the recommendations outlined in the document are several that pertain specifically to the measurement of disability and that incorporate the approach taken by WG. (See: Section VI-8: Disability Characteristics pages 178–183, and Tabulations on Disability Characteristics pages 292–294; available online at: http://unstats.un.org/unsd/demographic/sources/census/docs/P&R_Rev2.pdf) (UNSD – United Nations Statistical Division 2008).

The response categories used in the six WG questions capture a range of severity of the difficulty experienced. Multiple disability scenarios can be described depending on the domain(s) of interest and the choice of severity cut-off. There is more than one way to capture disability through the application of this set of core questions; resulting in not one but several possible population prevalence estimates that will vary in both size and composition.

The WG recommends (Washington Group on Disability Statistics (WG) 2010) that the following cutoff be used to define the populations with and without disabilities for the purpose of computing disability prevalence rates and reporting to the UNSD for international comparisons:

> The sub-population *disabled* includes everyone with **at least one** domain that is coded as *a lot of difficulty* or *cannot do it at all*.

This recommendation is not meant as a restriction, and, as will be illustrated below, using the WG approach to disability measurement allows for the analysis of the continuity of disability and a full assessment of disability in a population by different levels of severity.

International Comparability

The WG routinely monitors the collection of disability data internationally, and annually requests detailed information from representatives from National Statistical Offices covering survey periodicity, sample size and frame, mode of data collection, language(s) used, question wording with response options and finally prevalence data.

Recently, about 30 countries indicated to the WG that they intended to use the short set of questions on this current (2010) round of censuses. The WG saw this as an opportunity to follow-up on the implementation of the questions in practice and sought to collect information from all countries that were using the WG short set of questions (or not) to catalogue the actual questions and response options used; the year of data collection and the venue (census or survey); and the prevalence of disability derived. Requests explicitly asked for the exact wording of the questions in order to determine whether this may have any impact on the results.

Approximately 120 countries are annually requested to report back to the WG on national activities that relate to disability statistics. Responses are voluntary – and in the last round, responses (including both those that provided data and those that did not) were received from 65 countries. This represents a response rate of about 54 %. These findings were combined with results from other national data collection initiatives that the WG is aware of that also made use of the Washington Group short set of questions (Zambia (Eide and Loeb 2006), South Africa (Statistics South Africa 2010, 2011, 2012), USA (NCHS – National Center for Health Statistics 2011, 2012, 2013, 2014)).

The detailed results of this data collection effort are presented in Appendix 1. The Appendix is populated with the following information (where available) for each submission: the year of the data collection; the data source (census or survey); the preamble to the disability questions if a preamble is used; the question set; the answer categories; and the associated answer cut-off used to define disability. The resulting prevalence rate is also included. Any notes on the specific question set used, observations or other qualifications and/or disclaimers are included in Appendix 2. Country information in the Appendices is first sorted by whether the data collection was a census or a survey and within these two categories in chronological order by year of data collection.

Of the 67 entries in the Appendix, 16 countries provided non-tabular responses to the data request. These are indicated at the end of the Appendix. Five countries reported results from both census and survey (Argentina, Israel, Hungary, Mexico and USA). Peru is represented thrice with one census result and two from surveys. Each of these multiple submissions is included separately in the Appendix.

Forty-four countries are represented in the data table. Geographically, they are distributed as follows:

- Middle East: 8 (Morocco, Oman, Israel, Jordan, Egypt, Palestine, Yemen, Iran)[1]
- North/South America: 11 (Canada, USA, Panama, Aruba, Dominican Republic, Mexico, Argentina, Peru, Bermuda, Costa Rica, Sint Maarten)
- Europe: 7 (Poland, Lithuania, Spain, Netherlands, Norway, Hungary, Turkey)
- Asia/Pacific: 12 (Mongolia, Bangladesh, Australia, New Zealand, Cambodia, Maldives, Thailand, Japan, Togo, Philippines, China-Macao, Republic of Korea)
- Africa: 6 (Lesotho, Malawi, Mauritius, South Africa, Zambia, Ghana)

Twenty-six countries reported census results and 25 countries reported survey results. Some countries reported census or survey data that pre-date the 2006 adoption of the WG short set of questions (4 census and 3 survey); and there was a clear distinction between countries that took a more medical-model approach to identifying disability on their census or survey (i.e. by listing impairments or types of disability) and those that operationalized a social-model approach (by addressing activity limitations). All data received are included to provide a breadth of internationally collected disability data and prevalence rates.

Table 15.1 summarizes the information in the Appendices for Censuses. For each data collection information is provided on the number of disability questions, the response options and cutoffs to define disability, the data collection year and the prevalence rate. Data collections are sorted by the approach to data collection used: Impairment; Activity limitation but not using the WG questions; and Washington Group. The group label Activity Limitation is heterogeneous and variations in how the questions are framed can have a large effect on prevalence rates. Deviations from the recommended Washington Group Questions are also indicated. Unless otherwise indicated, estimates are for the total population (all ages).

Census Data Results

For census data, prevalence rates ranged from below 1 % (0.4 and 0.6 recoded for the Dominican Republic [2002] and Egypt [2006] respectively) to over 10 % (10.9 %, 12.2 % and 12.9 % recorded for Peru [2007], USA [2010] and Argentina [2010]

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[1] Data supplemented with information provided by countries (Morocco, Oman, Jordan, Egypt, Palestine, and Yemen) attending an Arab Institute for Training and Research in Statistics (AITRS) sponsored a disability seminar in held in Damascus, Syria, December, 2010.

Table 15.1 Results from censuses

Type of questions: (See Appendix 1 for actual questions)	# of questions	Response options: cut-off in bold	Country	Year	Prevalence[b]	Reference Appendix 1
Type of disibility/impairment						
	4	**Yes**/no	Morocco	2004	2.3	4
	5	**Yes**/no	Cambodia	2008	1.4	8
	6	**Yes**/no	Mongolia	2010	4.1	13
	8	**Yes**/no	Dominican Republic	2002	0.4	2
	11	**Yes**/no	Egypt	2006	0.6	5
	2	**Yes**/no	Jordan	2004	1.2	3
	1	**Yes**/no	Iran	2011	1.4	23
	2	**Yes**/no	Hungary	2011	6.2	22
Activity limitation						
	3	**Yes**/no	Macao (China)	2011	2.0	21
	5	**Yes**/no	Malawi	2008	4.0	9
	5	**Yes**/no	Peru	2007	10.9[a]	7
	5	**Yes**/no	Argentina	2010	12.9	19
	6	**Yes**/no	Panama	2010	8.4	15
	7	**Yes**/no	Republic of Korea	2010	7.6[c]	18
	9	**Yes**/no	Mauritius	2000	3.5	1
	34	**Yes**/no	Bermuda	2010	4.9	17
	6	**Yes**/no	USA	2012	12.2	26
	7	**Yes**/no	Ghana	2010	3.0	20
	1	No difficulty	Palestine	2007	2.0	6
		Some difficulty				
		Major difficulty				
		Completely unable				

(continued)

Table 15.1 (continued)

Type of questions: (See Appendix 1 for actual questions)	# of questions	Response options: cut-off in bold	Country	Year	Prevalence[b]	Reference Appendix 1
Washington Group						
	7	**Yes**/no (screener)	Oman	2010	3.2	11
		Some/**enormous**/cannot do at all			1.5	
	6	No problems	Sint Maarten	2011	1.8	25
		Yes, some problems				
		Many problems cannot do at all				
	6	**Yes**/no	Philippines	2010	3.1[c]	16
	7	**Yes**/no	Mexico	2010	4.1	14
	6	No, no difficulty	Turkey	2011	6.9	24
		Yes, some difficulty				
		Yes, a lot of				
		Cannot do it at all				
	4	No, no difficulty	Israel	2008	**6.4**	10
		Yes, some difficulty				
		Yes, severe				
		Yes, can't do it at all				
	6	No, no difficulty	Aruba	2010	**6.9**	12
		Yes, some difficulty				
		Yes, a lot of				
		Cannot do it at all				

[a] Refers to households, not persons

[b] Population includes all ages except where noted with[c]

[c] Population 5 years of age and older

respectively). Lower rates (most below 3 %) predominated among (though were not restricted to) censuses that pre-dated the Washington Group, and relied on lists of impairments or types of disability in their questionnaires (see: Appendix 1 and Table 15.1). Censuses that took place post 2006 more often operationalized the social model of disability and used an activity limitation approach to measurement. Most of these reported disability prevalence rates in the range of 4–12 %.

Only Aruba (using 6 questions) and Israel (using 4 questions) used the Washington Group questions as intended; with the recommended cut-off (Aruba 6.9 %/Israel 6.4 %). Turkey used 6 questions on their 2011 census that were similar to, but not identical with the WG questions. They replaced the self-care domain with an upper body question; and using the recommended response categories, reported a prevalence rate of 6.9 %. (It should be mentioned that the self-care domain was intended to also capture difficulty in upper body functioning.)

Several other countries employed modifications of the WG questions with varying results: Mexico, Panama, Philippines and USA all used the WG approach but used a dichotomous Yes/No response option and reported prevalence rates of 4.1, 8.4, 3.1 % and 12.2 % respectively.

Sint Maarten used the six Washington Group questions and reported a prevalence rate of 1.8 % when those who reported *many problems* or *cannot do at all* were included. The questions operationalized by Sint Maarten used slightly different language than intended – referring to problems rather than difficulties – and more importantly the questions followed a list of "physical and mental disabilities" and were prefaced with the statement: *Some people experience difficulties due to physical or mental disabilities when performing certain activities. Do you have any difficulties when performing certain activities in the following situations?* Question wording and placement are known to influence the way people respond, and the placement of the WG questions, in this case, may have been influenced by both the preceding list of impairments and the lead-in statement referring to physical or mental disabilities.

Oman's 2010 census included questions very similar to the WG questions but used a yes/no response option. Furthermore, the 6 questions were preceded by a filter question: *Is the person suffering from any difficulty/disability in the exercise of everyday life?* Only those who responded *Yes* to this filter question were asked the WG questions. The reported prevalence rate in this case was 3.2 %

Survey Data Results

Prevalence rates derived from surveys (Appendix 1/Table 15.2) were generally higher than those from censuses but also varied widely from less than 5 % (1.4 % in Togo [2010], 2.0 % in Yemen [2005/6], 2.9 % in Thailand [2007], and 2.6 % in Lesotho [2011]) to greater than 10 % (10.5 % in Costa Rica [2011], 11.1 % in Hungary [2011], 12.5 % in Netherlands [2009], 13.8 % in Poland [2009], 14.3 % in Canada [2006], 14.8 % in Israel [2012] and 16.6 % in New Zealand [2006]).

Table 15.2 Results from surveys

Type of questions: (See Appendix 1 for actual questions)	# of questions	Response options: cut-off in bold	Country	Year	Prevalence	Age	Reference Appendix 1
Impairments							
	1	**Yes**/No	Togo	2010	1.4	All ages	43
	9	**Yes**/No	Yemen	2005/6	2.0	All ages	29
	13	**Yes**/No	Lesotho	2011	2.6	All ages	46
	Uncertain	Not indicated	Japan	2005/6/8	5.4	All ages	30
Impairments & activity limitations							
	17/6	No, no difficulty	Thailand	2007	2.9	All ages	35
		Some difficulty			1.6[c]	7 years +	
		A lot/cannot do					
Activity limitation							
	12	**Yes**/No	Lithuania	2005	N/A	15+	28
	24	**Yes**/No	Argentina	2002/3	7.1	All ages	27
	27 of 136[a]	**Yes**/No	Australia	2009	7.4	All ages	40
	44	**Yes**/No	Spain	2008	8.5	All ages	37
	7	**Yes**/No	Costa Rica	2011	10.5	All ages	47
	7	**Yes**/No	Mexico	2012	6.6	All ages	49
	5	**Yes**/No	Peru II	2012	1.0	All ages	50
	7	No	Canada	2006	14.3	All ages	31
		Yes, sometimes					
		Yes, often					
	23	easily	New Zealand	2006	16.6	All ages	32
		With difficulty not at all					
		Yes/No					

Type of questions: (See Appendix 1 for actual questions)	# of questions	Response options: cut-off in bold	Country	Year	Prevalence	Age	Reference Appendix 1
	8 of 17[b]	**Yes**/no – If Yes:	Norway	2008	7.0	16+	36
		Do you have…					
		-Some difficulty					
		-A lot of difficulty					
		-Cannot do					
	9	Yes, with no difficulty	Poland	2009	13.8	15+	39
		With some difficulty					
		With a lot of difficulty					
		Not at all					
	7/10[e]	Easily	Netherlands	2009	12.8	12+	41
		With a bit of effort			12.5	55+	
		With a lot of effort					
		Impossible/Only with the help of others					
	9 of 16[d]	Multiple response patterns used	Hungary	2011	11.1	15+	44
	7	**Yes**/No	Peru I	2006	8.4	All ages	33
Washington Group	6	No, no difficulty	Bangladesh	2010	9.1	5+	42
		Yes, some difficulty					
		Yes, severe difficulty					
		Yes, can't do at all					
	5	No, no difficulty	Israel	2012	14.8	20+	48
		Yes, some difficulty					
		Yes, a lot of					
		Do not do at all					

(continued)

Table 15.2 (continued)

Type of questions: (See Appendix 1 for actual questions)	# of questions	Response options: cut-off in bold	Country	Year	Prevalence	Age	Reference Appendix 1
	6	No, no difficulty	Zambia	2006	**8.5**	all ages	34
		Yes, some difficulty					
		Yes, severe difficulty					
		Yes, can't do at all					
	6	No problem	Maldives	2009	**9.6**	5+	38
		Some difficulty					
		Lot of Difficulty					
		Cannot do it at all					
	6	No, no difficulty	South Africa	2009	4.0	5+	45
		Yes, some difficulty		2010	4.6		
		Yes, a lot of difficulty		2011	3.7		
		Do not do at all					
	6	No, no difficulty	USA	2010	8.9	18+	51
		Yes, some difficulty		2011	8.5		
		Yes, a lot of difficulty		2012	7.9		
		Do not do at all		2013	9.5		

[a] Based on 27 of 136 questions – that fall into 5 of the 6 WG domains: seeing, hearig, mobility, self-care and communcation

[b] Based on 8 of 17 questions – that fall into domains similar to the WG domains: seeing, hearig, mobility, self-care and remebering/concentrating

[c] Based on 6 of the domains that are similar to the WG domains

[d] Based on 9 of 16 that cover four WG domains: seeing, hearing mobility and self-care (bathing/dressing)

[e] Two estimates provided

Only four countries used an impairment-based approach to the measurement of disability on their surveys and all reported relatively low disability prevalence rates (Togo 1.4 %; Yemen 2.0 %; Lesotho 2.6 %; and Japan 5.4 %).

Twenty-one countries used various means of collecting disability data using an activity limitation approach. Four countries Argentina [2002/3], New Zealand [2006], Spain [2008] and Australia [2009] included long lists of activities that generated prevalence rates that were higher than most: 7.1 %, 16.6 % 8.5 %, and 7.4 % respectively.

Lithuania also presented a rather long list of 12 activities – but they conducted a case/control study that did not permit the calculation of a prevalence rate.

In addition to the number of questions asked, the age range specified for the survey sample also affects the prevalence rate. Unlike censuses that cover the entire population, surveys can be age specific; and the surveys included in this overview demonstrate that quality of survey design. Countries reporting some of the highest prevalence rates of disability also included samples that were selective: Poland [15 years and over], Netherlands [12/55 years and over], Hungary [15 years and over] and Israel [20 years and over]. Disability prevalence increases with an age – and this may be reflected in the results presented here.

Canada's 2006 Participation and Activity Limitation Survey (PALS) used a single question incorporating eight domains (hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities) as a filter to a lengthy survey of activity limitations and participation restrictions.

Peru I in 2006 operationalized activity limitations over eight domains of functioning (seeing, hearing, speaking, using hands/arms, walking/climbing stairs, understanding/learning (concentrate or remember), communicating, and other) and asking about difficulty or limitation that has lasted 6 months or more. Responses were dichotomous Yes/No. The resultant prevalence rate was 8.4 %. In 2012 Peru II used a slightly different approach, operationalizing activity limitations over six domains of functioning (seeing, hearing, speaking/understanding, using arms or legs, learning (concentrate or remember), relating to others (thoughts, feelings, emotions or conduct) and asking about permanent difficulty that prevents them from participating in society on an equal basis with others. Responses were dichotomous Yes/No. The resultant prevalence rate was 5.2 %.

Thailand, Norway, Poland, Netherlands and Hungary all used approaches to measuring disability that approximated the WG approach – but did not use the questions as written. Each country could identify a sub-set of domains from within a longer battery of questions that approximated the WG questions. With the exception of Thailand (prevalence rate 1.6 %) the other countries (Norway, Poland, Netherlands and Hungary) generated prevalence rates that were more in line with what might be expected (7.0 %, 13.8 %, 12.8 % and 11.1 % respectively).

Israel's 2012 Social Survey, targeted to adults 20 years and above, used five WG domains (seeing, hearing, walking/climbing, getting dressed/washing, remembering/concentrating); with the four recommended response categories. The prevalence rate was 14.8 % for those who responded *a lot of difficulty* or *cannot do at all* on any of the five domains of functioning. Bangladesh conducted a Household Income and

Expenditure Survey (HIES) in 2010 and included a module on disability for the first time. While the disability questions were operationalized as intended, and included the four recommended response options, the Bangladeshi HIES operationalized a lower threshold for the determination of disability. They included those who responded *some difficulty* to any of the six domains of functioning and the resulting prevalence rate was 9.1 %. Furthermore, after each functioning question, two follow-up questions were added requesting the age at onset and the cause of the difficulty. It is well documented that question order and placement in a survey may influence how people respond. The addition of these follow-up questions may have had some impact on the responses to the six questions, though the measure of that impact on the quality of data derived remains undetermined.

Six countries used the WG short set of questions in recent surveys: Maldives [2009], Bangladesh [2010], Israel [2010], Zambia [2006], South Africa [2009/10/11] and USA [2010/11/12/13]. Maldives, Zambia, South Africa and USA each used the WG short set as written and the response options as recommended.

- Maldives directed their questions to all household members aged 5 years and above (prevalence 9.6 %).
- Zambia conducted a survey of living conditions among people with disabilities in 2006 (Eide and Loeb 2006) and in a representative sample of almost 6000 households (28,000 individuals of all ages) determined a prevalence rate of 8.5 %
- In South Africa, lower prevalence rates (among those 5 years of age or older) were obtained than in other surveys: 4.0 %, 4.6 %, and 3.7 % in 2009, 2010 and 2011 respectively (Statistics South Africa 2010, 2011, 2012).[2]
- In USA the National Center for Health Statistics (NCHS) has included the WG short set of questions on the sample adult file for the years 2010 through 2013 (NCHS – National Center for Health Statistics 2011, 2012, 2013, 2014). Weighted prevalence estimates (among those 18 years of age or older) reveal that disability measured using the WG questions as intended, with the recommended cut-off, was 8.9 %, 8.5 %, 7.9 % and 9.5 % for 2010 through 2013 respectively.

Discussion and Conclusions

At its inception, certain goals were identified for the WG. Among them, to foster international cooperation in the area of health and disability statistics, to develop a short set of general disability measures suitable for censuses and to untangle the web of confusing and conflicting disability estimates and to produce internationally

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[2] Data presented here differs from published data in: http://www.statssa.gov.za/publications/P0318/P0318April2012.pdf (see page 19) due to use of different thresholds for determination of disability. Statistics South Africa published data states that those who “had some difficulty with two or more of the activities or had a lot of difficulty/were unable to perform any one activity, are then ranked as disabled.” For this paper, disability is defined as those who report a lot of difficulty or cannot do any activity.

tested measures for use to monitor status of disabled populations. By developing a standardized set of questions it was believed to be possible to provide comparable data cross-nationally for populations living in a variety of cultures with varying economic resources.

The data presented here illustrate, as has been shown previously (Mont 2007; Loeb and Eide 2006), that historically and geographically disability prevalence rates vary greatly. Data are presented from across the globe and spanning several years: from 2000 to 2011. Prevalence rates range from 0.4 % in the Dominican Republic [2002/census] to 16.6 % in New Zealand [2006/survey]. As mentioned earlier, reasons for the disparity observed in disability prevalence rates are attributed to both the methods used to define and identify disability and data collection methodologies. Questions that focus on activity limitations were found to produce higher rates than impairment-based questions; and surveys were found to produce higher rates than censuses.

The objective of the WG in proposing its approach to disability definition and measurement is not to achieve the highest disability prevalence rate possible, but rather to report the rate that best reflects the situation of persons with disability in the country; according to the WG, those at risk of being restricted in their ability to fully participate in society. And secondly to propose a methodology that could be used internationally to produce disability prevalence rates that could be compared cross-nationally.

Although countries have reported disparate disability prevalence rates; with few exceptions, those that use the WG *as intended* (Israel [census/2008]; Aruba [census/2010]; Zambia [survey/2006]; Maldives [survey/2009] and USA [survey/2010–2013] have reported disability prevalence rates that are comparable: 6.4 %, 6.9 %, 8.5 %, 9.6 % and for the USA 8.9 %, 8.5 %, 7.9 % and 9.5 % respectively. Israel, Aruba and Zambia included all ages in their census/survey, while Maldives included only those 5 years of age and older and the USA included those 18 years of age or older. This may have resulted in a slightly higher reported prevalence rates for Maldives and USA. (For Israel and Aruba, the prevalence rates for those 5 years of age and over are 7.0 % and 7.3 % respectively.) Results from Turkey's 2011 census can also be viewed favorably in light of these findings. Having replaced the self-care question with a specific upper body functioning question they reported disability prevalence (6.9 %) on their census in line with the census results from Israel and Aruba. The Bangladeshi HIES used the WG questions as intended but included those who had reported *some difficulty, a lot of difficulty* or *unable to do* in their prevalence estimate (9.1 %). Had they used the suggested cut point of *a lot of difficulty* or *unable to do*, the resultant prevalence rate would have been correspondingly lower. Again it can be noted that prevalence results generated from surveys generally produce higher rates than those generated from a census. This is in part due to the fact that surveys provide a different context for the questions than does a Census and are unrestricted in the number of questions that can be included.

Israel [survey/2012] and South Africa [survey/2009/2010/2011] represent outliers in this regard. Israel, operationalizing 5 of the functional domains and restricting the survey to the population 20 years and over produced a prevalence rate that might be considered an outlier at 14.8 %; and South Africa, surveying the population of 5 years and older, achieved prevalence rates over the 3 years surveyed of between

3.7 and 4.6 %. These disparate results were obtained using the same set of questions. However, beyond the questions used to measure disability – and the age cohorts included in the surveys, there are several other factors that may influence the prevalence rate obtained in a survey. Among these is questionnaire design: the length of the questionnaire and the placement of questions in the questionnaire. For example, do the functioning/disability questions come towards the end of a lengthy questionnaire? Are the disability questions ‘embedded’ within an array of other health-related questions? The purpose of the survey itself, coupled with the socio-cultural determinants of disability in a society, may influence the observed prevalence rate. Some of these are discussed in section on “How Does Question Content Inform Response?” below. More analyses of these surveys are needed to better understand the results obtained.

In addition a few countries modified the WG questions which affected results. For example, WG questions were preceded by a qualifying statement or filter question (1.8 % in Sint Maarten and 3.2 % prevalence in Oman) or response categories were dichotomized (yes/no) with an associated change in the wording of the question [*permanent difficulty* – 8.4 % in Panama/census or *serious difficulty* – 11.9 % USA/survey]. In some cases domains were modified, deleted or added. It has also been shown that question order and placement may influence the way individuals respond to questions. All of these deviations affect the resultant prevalence rate and subsequently reduce the overall comparability of the results.

Furthermore, some uncertainty must be apportioned to the translation of the questions – from the English to the local/national language(s) for the census or survey; and back again when reporting results internationally. It becomes incumbent upon the WG – and others interested in the international comparability of disability data – to ensure not only that translations are accurate but also that they most suitably (for both the local language and the socio-cultural context) correctly capture the *concepts* that are being measured.

How Does Question Content Inform Response?

The question/response process requires that a respondent go through several stages once a question is ‘delivered’: comprehension, retrieval, judgement and response. In reverse, the answer that is finally mapped onto the available response options is rooted in the actual wording of the question asked and how that question interfaces with the language and socio-cultural context of the respondent. According to Mont (Mont 2007) and Groce (2006), the word “disability” in a question often carries a negative connotation and some people in certain cultures may feel stigma or shame at self-identifying as disabled. For that reason, a question similar to that asked in Mongolia [2010]: *“Do you have any disability?”* may be considered inadequate at identifying, for example, intellectual/mental or psychological impairments which tend to be particularly stigmatizing. Individuals may, when questioned, deny their disability or hide the fact that they have a disabled family member. Moreover, to some respondents the term "disability" often implies a more severe or very significant condition. Persons who can walk around their homes but are incapable of walking to the market may perceive their situation as not severe enough to be considered a disability even though their daily activities are limited. Questions that either use the term *disability* or focus on impairments (*blind, deaf, dumb, mentally retarded*, etc.) as in Dominican Republic, Morocco, Egypt (census) or Yemen, Lesotho, Japan (survey) had lower prevalence rates reinforcing the above argument.

The choice of words can be very important in question formulation. In a few cases reported here (Palestine, Oman and Jordan) individuals are asked whether they *suffer* from difficulty or disability. The resultant prevalence rates reported were low: 2.0, 3.2 and 1.2 % respectively. *Suffering* may be associated with disease or illness and not necessarily with the life experiences of a person with disability and may negatively influence the self-reporting of functional difficulties (Schneider 2009).

Disability has also, in some surveys, been linked to *diagnosable* conditions. For instance, in Japan [2008] a survey of persons with "mental disabilities" included a list of the following disorders: epilepsy, Alzheimer's, neurotic/stress-related, mood disorders, schizophrenia, psychotic disorder, personality disorder, or other mental disorders – and resulted in a reported prevalence rate for "mental disabilities" of 2.3 %. Classifying disability this way may also result in under-reporting since many people may not know their diagnosis, particularly with respect to intellectual/mental and psycho-social conditions. Furthermore, knowledge about one's diagnosis is often correlated with education, socio-economic status, and access to health services, all of which may bias collected data.

Questions that employ a more neutral language (WHO –World Health Organization 2001) and focus on difficulties performing certain basic actions/activities like those proposed by the WG, serve as a better basis for identifying disability. Without mentioning disability, impairment or chronic conditions (diagnosed or not) the question *Do you have difficulty walking or climbing steps?* is able to identify mobility limitations resulting not only from paralysis or amputation, but also serious heart problems or other medical conditions that may be associated with vision or balance for example. Similarly, the question *Do you have difficulty communicating?* can identify limitations associated with stuttering, loss of speech due to stroke, autism, or a number of other conditions. For purposes of social participation and the equalization of opportunities, the functional status – and how that impacts someone's life – is of interest and not necessarily the cause (medical or otherwise). The WG proposed questions do not yield the highest prevalence rates – nor was that intended. They have begun, however, to produce rates of disability that are comparable across countries.

Conclusions

In order to develop and evaluate policies and programs with the objective of improving the lives of their constituents, governments rely on the availability of data in the form of statistics that are relevant, valid and reliable. Much of the information that is collected, normally through censuses and surveys, is intended for domestic purposes. Within the international community there is however a long standing interest in making comparisons among countries not only to monitor how one's own country ranks against others, but to benefit from the experiences of others (Madans and Loeb 2013). In order for these cross-national comparisons to be meaningful, the information itself must be comparable across countries; the indicators used must address the same constructs and the data collection process must not introduce differences that would affect the relevance and validity of the comparisons. Many countries collect information on disability – and have been doing so for decades. Disability statistics however have long been plagued as examples of indicators where international comparisons are most difficult (Mont 2007; Loeb and Eide 2006; NCHS – National Center for Health Statistics 2011; Me and Mbogoni 2006). With respect to disability statistics that have been reported internationally, the fact that there are differences among countries does not mean that the data are not comparable but when these differences exhibit unexpected patterns, questions are raised. Observed differences illustrating the highest disability rates among the most developed countries and the lowest rates among the least developed countries are counterintuitive (Madans and Loeb 2013). A closer examination of how the data have been collected illustrates that there are major differences in approach, definition and methods (Loeb and Eide 2006; WHO-World Health Organization/World Bank 2011). This lack of comparability has hampered not only international uses of the data but also draws into question the usefulness of the information for domestic purposes.

The United Nations Convention on the Rights of Persons with Disabilities (UN – United Nations Enable 2006) provides, for the first time within a human rights framework, specific articles that call for the international collection (Article 31) and reporting (Article 36) of statistical data on disability. In the absence of valid and reliable population-based data on disability it is not possible to monitor, over time, the effects of policies instigated that would promote the lives of persons with disabilities and ensure their participation in all aspects of life on an basis equal to those without disability. These data would provide the evidence that can be used to address whether countries have been successful, or the degree of their success, in meeting the general principles outlined in the Convention (Article 3) including the achievement of equalization of opportunity and accessibility, among others. Monitoring the U.N. Convention and other international initiatives such as the Millennium Development Goals (UN – United Nations 2002) (see: http://www.un.org/millenniumgoals/) depend on the production of quality and internationally comparable data – and these have been sorely lacking.

The information and data that are presented here would indicate that WG efforts in fostering international cooperation in the area of health and disability statistics has begun to bear fruit through the development and implementation of a short set of general disability measures suitable for censuses. The operationalization of the WG short set of six questions is an important step forward in untangling the web of confusing and conflicting disability estimates and producing internationally tested measures for use to monitor status of disabled populations. These questions, when adopted as intended, were able to provide comparable data cross-nationally for populations living in a variety of cultures with varying economic resources.

Appendices

Appendix 1: Detailed Results from Census and Survey

(Information sorted by source [census followed by survey] and is then presented in chronological order by year of data collection.)

Results from Censuses

	Country	Year	Questions asked	Answer categories – cut-off in bold	Pre-valence[a]
1	**Mauritius**	2000	Does the person experience any disability (i.e. any limitation to perform a daily-life activity in a manner considered normal for a person of his/her age), because of a long term physical/mental condition or health problem?	**Yes**/No	3.5
			If Yes, insert as many disabilities as applicable as follows: speaking and talking; hearing and listening even with hearing aid; seeing disabilities even with glasses; walking, running and other ambulation disabilities; manual activity disabilities such as fingering, gripping and holding; disturbance of ability to learn and acquire education; disturbances of behavior, including antisocial behavior, maladjustment and liability to self-injury; inability to look after oneself with regard to personal care and hygiene, feeding etc.; other disabilities (specify)		
2	**Dominican Republic**	2002	Blind in one eye	**Yes**/No	0.4
			Blind in both eyes		
			Deaf		
			Mute		
			Any loss or limitation in the movement of the arm(s)		
			Any loss or limitation in the movement of the leg(s)		
			Mentally retarded		
			Any other limitation(s)		

(continued)

3	**Jordan**	2004	Does he/she suffer from disability?	**Yes**/No	1.2
			What kind of disability does (…) have? Deaf/dumb, physical, cerebral palsy, mental, visual, multiple handicaps, other		
4	**Morocco**	2004	For all family members, select the type of disability:	**Yes**/No	2.3
			Nothing	Mark all that apply	
			Mobility		
			Sensory		
			Mentality		
			Chronic disease		
5	**Egypt**	2006	1. Blind	**Yes**/No	0.6
			2. One-eyed		
			3. Deaf		
			4. Dumb		
			5. Deaf-Dumb		
			6. Mentally retarded		
			7. One-handed or handless		
			8. One-legged or lost both legs		
			9. Infantile paralysis		
			10. Quadriplegia or paralysis		
			11. Other (mention)		
6	**Palestine**	2007	A single question covering five domains of functioning:	No difficulty	2.0
			Does the individual suffer difficulty in: Visual; Hearing; Moving; Comprehension; Communication?	Some difficulty	
				Major difficulty	
				Completely unable	

7	**Peru**	2007	If a person is disabled, it means that they have a permanent difficulty, physical or mental, that limits one or more of their daily activities; so tell me: Does someone in this home have a difficulty of permanent limitation:	**Yes**/No	10.9 (households)
			(read each alternative and circle one or more numbers)		
			1. To see, even when using glasses?		
			2. To hear, even when using hearing aids?		
			3. To speak (to intonate/to vocalize)?		
			4. To use arms and hands/legs and feet?		
			5. Some other difficulty or limitation?		
			6. Nobody has a disability		
8	**Cambodia**	2008	Physical/mental disability, if any:	**Yes**/No	1.4
			If the person is physically/mentally disabled, give the appropriate code number from the list below (Otherwise enter 0):	Mark all that apply	
			1. In seeing		
			2. In speech		
			3. In hearing		
			4. In movement		
			5. mental		
9	**Malawi**	2008	Does NAME have difficulty or problems in the following?	**Yes**/No	3.97
			1. None		
			2. Seeing		
			3. Hearing		
			4. Speaking		
			5. Walking/climbing		
			6. Other		

(continued)

10	**Israel**	2008	1. Do you have difficulty hearing, even if using a hearing aid? (All ages)	No, no difficulty	6.4
			2. Do you have difficulty walking around the house or walking up and down stairs? (Age 5+)	Yes, some difficulty	
			3. Do you have difficulty remembering or concentrating? (Age 5+)	**Yes, severe difficulty**	
			4. Do you have difficulty dressing or bathing? (Age 5+)	Yes, can't do it at all	
11	**Oman**	2010	Is the person suffering from any difficulty/disability in the exercise of everyday life?	**Yes**/No	3.19
			What is the main type of difficulty/disability the person is suffering from?		
			1. Seeing, even if wearing glasses		
			2. Hearing, even if wearing earphone		
			3. Walking or climbing up steps		
			4. Remembering or concentrating		
			5. Taking care of him/herself		
			6. Communicating in normal language		
			7. Movement of the upper part of the body		
			What is the **level of** this difficulty/disability?	Some/**enormous**/cannot do at all	1.48
12	**Aruba**	2010	The following questions concern difficulties you may have when doing certain activities – due to a health problem	No, no difficulty	6.85
			1. Do you have difficulty seeing, even if wearing glasses/contact lenses?	Yes, some difficulty	
			2. Do you have difficulty hearing, even if using a hearing aid?	**Yes, a lot of difficulty**	
			3. Do you have difficulty walking or climbing steps?	Cannot do it at all	
			4. Do you have difficulty remembering or concentrating?		
			5. Do you have difficulty (with self-care such as) washing all over or dressing?		
			6. Because of a physical, mental of emotional health condition, do you have difficulty communicating? (e.g. understanding others or others understanding you)		

13	**Mongolia**	2010	Do you have any disability?	No	4.08
			If you have any disability please specify the type:	**Yes:** Congenital	
			1. Seeing	**Yes:** Acquired	
			2. Speaking		
			3. Hearing		
			4. Mobility		
			5. Cognitive		
			6. Other		
14	**Mexico**	2010	In his/her daily life, (NAME) has any difficulty to perform the next activities:	**Yes**/No	4.07
			Read all the options and circle affirmative answers		
			Walking, moving or climbing steps?		
			Seeing, even if wearing glasses?		
			Speak, communicate or chat?		
			Hearing, even if using a hearing aid?		
			Dressing, bathing or eating?		
			Paying attention or learning simple things?		
			Has any mental limitation?		
			So, he/she doesn't have physical or mental limitations?		
15	**Panama**	2010	Health Limitation	**Yes**/No	8.4
			a) Even with hearing aids for deafness, do you have trouble hearing?		
			b) Even wearing glasses, do you have difficulty seeing?		
			c) Do you have any permanent difficulty walking or moving?		
			d) Do you have any permanent difficulty using arms and/or hands?		
			e) Do you have any permanent difficulty speaking or communicating?		
			f) Do you have any permanent difficulty learning?		

(continued)

16	**Philippines**	2010	Does [name] have any difficulty in:	**Yes**/No	3.1 (5 years and older)
			Seeing, even when wearing eyeglasses?		
			Hearing, even when using a hearing aid?		
			Walking or climbing steps?		
			Remembering or concentrating?		
			Self-care (bathing or dressing)?		
			Communicating using his/her usual language?		
17	**Bermuda**	2010	Please look at the card and tell me which of the following health conditions, if any, lasted more than 6 months	**Yes**/No	4.9
			No conditions present (list of 34 health conditions, plus *other*, including: learning disabled, learning difficulties, and difficulties hearing, seeing, speaking, gripping/holding, behavioral, moving/mobility, body movement and limited use of arms or legs)	Mark all that apply	
18	**Republic of Korea**	2010	Does this person have mental or physical limitations that have existed for 6 months or have been diagnosed to last longer?	**Yes**/No	7.6 (5 years and older)
			Visual/hearing/language disabilities	Mark all that apply	
			Difficulties in walking, taking stairs		
			Mental deficiencies or disorders		
			Learning, remembering, concentrating		
			Dressing, bathing, eating		
			Shopping, going to hospital		
			(16 years old or over) Job activities		
			None		

19	**Argentina**	2010	Do you have difficulty or permanent limitation …	**Yes**/No	12.9
			Seeing, even with glasses or glasses on?		
			Hearing, even when using hearing aid?		
			Walking or climbing stairs?		
			Grasping objects and/or containers with open hands?		
			Understanding and/or learning?		
20	**Ghana**	2010	Does [NAME] have any serious disability that limits his/her full participation in life activities (such as mobility, work, social life, etc.)?	**Yes**/No	3.0
			1. Sight		
			2. Hearing		
			3. Speech		
			4. Physical		
			5. Intellect		
			6. Emotional		
			7. Other		

(continued)

21	**Macao (China)**	2011	1. Do you have difficulties carrying out daily activities due to your physical, mental or emotional conditions (daily activities include: self-care, mobility, communicating with others, and other activities, e.g. bad hearing, weak eye-sight, sprain, diabetes, depression, high blood pressure, nervousness, seeking job, doing housework, studying, participating in community life etc.)?	**Yes**/No **Yes**/No **Yes**, difficulties still persist after using… YES, Difficulties disappear after using…	2.0
			2. Have these difficulties been lasting, or will expect to last, for 6 months or more?	**No**	
			3. Do you use any auxiliary equipment?		
			Supplement:		
			a) What are the activities you have difficulties in carrying out?	a) self-care, mobility, communicating with others, *other*	
			b) What are the physical, mental or emotional conditions that cause such difficulties when carrying out the above-mentioned activities?	b) vision disorder, blindness, speech disorder, speech impairment, hearing disorder, deafness, impaired limbs or trunk, mental retardation, psychiatric conditions, autism, chronic illness, emotionally disturbed, *other*	
			c) When did you start having such difficulties		

22	**Hungary**	2011	1. Do you have any long lasting disease or deficiency?	**Yes**/No	6.2 (excluding 20.7 % of sample that chose not to respond to this question)
			2. What deficiency do you have?	Mark all that apply	
			Movement deficiency		
			Autism		
			Mental deficiency/Mental injury (psychic injury)		
			Speech handicap/Speech deficiency		
			Hard of seeing/Blind		
			Hard of hearing/Deaf		
			Deaf and blind		
			Serious deficiency of internal organs		
			Other		
23	**Iran**	2011	Is there anybody in the household with at least one of the following disabilities?	**Yes**/No	1.4
			Blind		
			Deaf		
			Voice and speech disorder		
			Hand amputation		
			Hand impairment		
			Leg amputation		
			Leg impairment		
			Torso impairment		
			Mental disorder		

(continued)

24	**Turkey**	2011	1. Do you have difficulty in seeing? (even if you use glasses or contact lenses)	Not at all	6.9
			2. Do you have difficulty in hearing? (even if you use hearing aid)	Some difficulty	
			For those 3 years and older:		
			3. Do you have difficulty in speaking such as speech impairment, lalopathy, stammering, etc.?	**A lot of difficulty**	
			4. Do you have difficulty walking or climbing stairs?	Cannot do it at all	
			5. Do you have difficulty holding or lifting something?		
			6. Do you have difficulty learning, doing simple calculations, remembering and concentrating when compared to your peers?		
25	**Sint Maarten**	2011	1. Do you have problems with sight even with glasses/contact lenses?	No problems	1.8
			2. Do you have problems with your hearing even with a hearing aid?	Yes, some problems	
			3. Do you have problems walking or going up the stairs?	**Many problems**	
			4. Do you have problems remembering things or concentrating?	Cannot do it at all	
			5. Do you have taking care of yourself like bathing and or dressing?		
			6. Do you have difficulties communicating due to a physical, mental or emotional problem? (for example, understanding others or making yourself understood?)		
26	**USA**	2012	1. Is this person deaf or do they have serious difficulty hearing?	**Yes**/No	12.2
			2. Is this person blind or do they have serious difficulty seeing, even when wearing glasses?		
			3. Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?		
			4. Does this person have serious difficulty walking or climbing stairs?		
			5. Does this person have difficulty dressing or bathing?		
			6. Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping?		

Results from surveys

	Country	Year/source	Questions asked	Answer categories – cut-off in bold	Pre-valence[a]
27	**Argentina**	2002–2003:	Is/Does the person mentioned on the list:	**Yes**/No	7.1
		National Survey for Persons with Disabilities	Blind?		
			Have permanent difficulty to see, even with glasses or lenses?		
			Close?		
			From afar?		
			Or have other difficulties to see?		
			Read and write in Braille or uses other forms of aid?		
			Deaf? (you can hear no sound)		
			Have permanent difficulty to hear what is said?		
			Require and/or use hearing aids or implant to hear what is said?		
			Read lips to understand what is being said?		
			Mute?		
			Have permanent difficulty speaking?		
			Use sign language?		
			Lack or have paralyzed or atrophied one or both		
			Feet or legs?		
			Lack or have paralyzed or atrophied one or both		
			Arms or hands?		
			Have permanent difficulty to get up, lie down,		
			Keep standing or sitting?		
			Have permanent difficulty to grasp objects with		
			One or two hands?		
			Have permanent difficulty walking or climbing stairs?		

(continued)

			Need or use (permanently) a wheelchair?		
			Require or use (permanently) Walker, crutches, Canadian sticks, splints, prostheses, etc.?		
			Have some delay or mental retardation that hinders learning, work, and/or ability to relate?		
			Have permanently some other mental problem that will hinder their ability to relate and/or work? (e.g.: child psychosis, autism, etc.)		
			Per retardation or mental problems concurs or attended a hospital day or therapeutic educational center?		
			Have any other permanent mental or physical difficulty not asked?		
28	**Lithuania**	2005: Health Interview Survey	Based on absence/presence of functional difficulties (without aids):	**Have difficulty**	N/A presented as case/control study (15 years and older)
			Clearly see newspaper print	Do not have difficulty	
			Clearly see the face of someone 4 m away		
			Hear what is said in a conversation with one other person		
			Walk 500 m		
			Walk up and down a flight of stairs		
			Use fingers to grasp or handle a small object		
			Turn on tap or unscrew the lid of a jar of coffee		
			Bite and chew on hard food		
			Reach out (stretch out an arm) to shake someone's hand		
			Bend and kneel down		
			Lift and carry a full shopping bag weighing 5 kilos		
			Make him/herself clearly understood by others		

29	**Yemen**	2005/2006: Multi-Purpose Household Budget Survey	Does the family have an individual with a disability or chronic illness?	**Yes**/No	2.0
			The response categories were as follows:		
			Blindness (blind)		
			Difficulty hearing sounds		
			Slurred speech		
			Deaf/Persians		
			Difficulty walking from one place to another/hemiplegia		
			Difficulty of the movement of the body holistically		
			Difficulty constipation and move things		
			Mental difficulty prevented him from learning or behavior control or self-care		
			Multiple disability		
			Other		
30	**Japan**	2005/2006/ 2008/2011	Impairment-based definition of disability, divided into three independent groups*:	Not indicated	Physical: 2.8 (updated 2011: 3.7)
			Physical/2006/2011 (visual; hearing/speech; internal; orthopedic);		Intellectual: 0.3
			Intellectual/2005 (…manifested during the developmental period [birth-18 years] and displays functional deficits in skills for daily life which require supportive services);		Mental: 2.3
			Mental/2008 (epilepsy; Alzheimer’s; neurotic/stress-related; mood disorders; schizophrenia; psychotic disorder, personality disorder; other mental disorder).		TOTAL: 5.4 (Persons living at home)
			*No reference made to those with multiple impairments		5.8 with those in facilities

(continued)

31	**Canada**	2006: Participation and Activity Limitation Survey (PALS)	Filter questions:	**(1) Yes, sometimes**	14.3
			Do you (Does …) have any DIFFICULTY hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities?	(2) Yes, often	
			Does a physical condition OR mental condition OR health problem REDUCE THE AMOUNT OR THE KIND OF ACTIVITY you (…)	(3) No	
			Can do at home?		
			Can do at work or at school?		
			Can do in other activities, for example, transportation or leisure?		
32	**New Zealand**	2006: New Zealand Disability Survey	Preamble: I am going to ask you some questions about long-term difficulties that some people have doing things. By long-term, I mean difficulties that have lasted 6 months or more, or are expected to last for 6 months or more	Easily	16.6
			The questions cover a range of difficulties that some people will have	**With difficulty**	
			Hearing a conversation with one person	**Not at all**	
			Hearing what is said in a group	or/	
			Speaking and being understood	**Yes/**No	
			Seeing ordinary newspaper print		
			Seeing across a room		
			Walking the distance around a rugby field		
			Walking up and down stairs		
			Carrying 5 kilos while _walking		
			Moving between rooms		
			Standing for 20 min		
			Bending down and picking up something off the floor		
			Getting dressed and undressed		
			Cutting toenails		
			Grasping or handling things like scissors or pliers		
			Reaching in any direction		

			Cutting food		
			Getting in and out of bed without help		
			Learning		
			Remembering		
			An intellectual disability		
			An intellectual disability and you go to a special school or receive special education		
			Everyday activities because of a long-term emotional, psychological or psychiatric condition		
			Communicating, mixing with others or socializing		
33	**Peru I**	2006	Do you have difficulty or limitation that has lasted 6 months or more?	**Yes**/No	8.4
			1. To see, even using glasses or contacts		
			2. To hear, even using hearing aids		
			3. To speak		
			4. To use your arms or hands/hold things		
			5. To use your legs or feet/walk or use stairs		
			6. Understand/learn (concentrate or remember)		
			7. Communicate, understand others or that others understand you		
			8. Some other difficulty or limitation (specify)		
34	**Zambia**[1]	2006	The next questions ask about difficulties you may have doing certain activities because of a health problem:	No, no difficulty,	8.5
			1. Do you have difficulty seeing, even if wearing glasses?	Yes, some difficulty,	
			2. Do you have difficulty hearing, even if wearing a hearing aid?	**Yes, severe difficulty**	
			3. Do you have difficulty walking or climbing steps?		
			4. Do you have difficulty remembering or concentrating?		
			5. Do you have difficulty (with self-care such as) washing all over or dressing?	Yes, can't do it at all	
			6. Because of a physical, mental or emotional health condition, do you have difficulty communicating, e.g. understanding or being understood by others?		

(continued)

35	**Thailand**	2007/2012: Disability survey	Persons with disabilities identified by activity limitations and impairments as follows:	No difficulty	2.2
			Activity limitation (asked person aged 7 years and over) such as; seeing, hearing, speech, learning, understanding, remembering, gripping or holding things, raising hand, sitting up from lying down, squatting, walking on even surface for 50 m, climbing steps, mental or emotional condition, recurrent pain or discomfort, breathing, blackouts or fits or loss of consciousness, and self-care	**Some difficulty**	
			Impairments such as; blindness, deafness, loss of hand, paralysis, paresis, psychosis, autistic, etc.	A lot of difficulty	
			Selecting the 6 WG domains	Cannot do it at all	
				A lot/cannot do	1.6 (7 years and older)
36	**Norway**	2008: Living Conditions Survey	1. Do you have difficulty seeing newspaper print? Please answer with normal use of glasses or contact lenses	YES/NO	7.0 (16 years and older)
			2. Do you have difficulty recognizing someone 4 m away?	If Yes: Do you have…	
			3. Do you have difficulty hearing what is said in a conversation between two people, with normal use of a hearing aid?	Some difficulty	
			4. Do you have problems concentrating or remembering things?	A **lot of difficulty**	
			5. Do you have difficulty walking up or down a flight of stairs one floor without resting?	**Cannot do**	
			6. Do you have difficulty walking for 5 min at a reasonably fast pace?	Without difficulty	
			7. Are you able to dress and undress yourself?	With some difficulty	
			8. Are you able to bathe or shower yourself?	**only with help from others**	

37	**Spain**	2008: Survey on Disability, Personal Autonomy and Dependency Situations	Preamble in Appendix 2	**Yes**/no (**Significant difficulty**)	8.5
			44 activities listed under 8 domains:		
			Sight (4)		
			Hearing (3)		
			Communication (6)		
			Learning & application of knowledge and development of tasks (4)		
			Mobility (9)		
			Self-care (9)		
			Home-life (3)		
			Interactions & interpersonal relations (6)		
38	**Maldives**	2009: Demographic and Health Survey	1. Does (name) have difficulty seeing, (even when (he/she) is wearing glasses or contact lenses?	No problem	
			2. Does (name) have difficulty hearing, (even when (he/she) is using a hearing aid?	Some difficulty	22.0
			3. Does (name) have difficulty communicating (for example understanding others or other understanding him/her)) because of a physical, mental or emotional condition?	**Lot of Difficulty**	**9.6**
			4. Does (name) have any difficulty with remembering or concentrating?	Cannot do it at all	1.3 (5 years and older)
			5. Does (name) have any physical condition that makes it difficult for (him/her) to walk or climbing steps?		
			6. Does (name) have any physical condition that makes it difficult for (him/her) (with self-care such as) washing all over or dressing?		

(continued)

39	**Poland**	2009: European Health Interview Survey (EHIS)	Do you wear glasses or contact lenses?	Yes, with no difficulty	13.8 (15 years and older)
			Can you see newspaper print?	With some difficulty	
			Can you see the face of someone 4 m away (across a road)?	**With a lot of difficulty**	
			Do you wear a hearing aid?	Not at all	
			Can you hear what is said in a conversation with several people?		
			Can you walk 500 m on a flat terrain – without any aid or assistance?		
			Can you walk up and down a flight of stairs – without any aid or assistance?		
			Do you usually have difficulty doing any of these activities by yourself?		
			Dressing and undressing		
			Bathing or showering?		
40	**Australia**	2009: Survey of Disability, Aging and Carers	I now have some questions about health conditions that have lasted, or are likely to last, for 6 months or more	**Yes**/No	7.4
			Does anyone in this household have any loss of sight		
			Can … see normally wearing glasses or contact lenses?		
			Does … have total loss of sight?		
			Does anyone in this household have any loss of hearing?		
			Does … have total loss of hearing?		
			Does … ever need help or supervision when going to, or getting around, a place away from home?		
			Does … ever need help or supervision when moving about the house?		
			Does … ever need help or supervision to get in or out of bed or a chair?		
			Is … in a wheelchair?		
			Does … ever need help or supervision to shower or bathe?		
			Does … ever need help or supervision to dress themselves, for example doing up shoelaces, buttons or zips?		

			Does … ever need help or supervision when eating a meal, for example cutting up food?		
			Does … ever need help or supervision using the toilet?		
			Does … have any difficulty controlling their bladder or bowel?		
			Does … have any difficulty understanding someone they don't know?		
			Can … understand them at all?		
			Does … ever need help with this?		
			Does … have any difficulty understanding family or friends?		
			Can … understand them at all?		
			Does … ever need help with this?		
			Does … have any difficulty being understood by someone they don't know?		
			Can … understand them at all?		
			Does … ever need help with this?		
			Does … have any difficulty being understood by family or friends?		
			Can … understand them at all?		
			Does … ever need help with this?		
			Is … able to communicate more easily with others using any of these non-spoken forms of communication?		

(continued)

41	**Netherlands**	2009: Netherlands Health Interview Survey (NethHIS)	Functional limitations are observed in the module ‘Health and Labor Conditions’ of the Integrated System of Social Surveys in two groups of questions:		A. 12.8 (12 years and older)
			A. The OECD indicator		B. 12.5 (55 years and older)
			1. Be able to follow a conversation in a group of three or more persons (with or without a hearing aid)	Easily	
			2. Have a conversation with one person (with or without a hearing aid)	With a bit of effort	
			3. Read the small print in the newspaper (with or without glasses or contact lenses)	**With a lot of effort**	
			4. Recognise somebody’s face at a distance of 4 m (with or without glasses or contact lenses)	Impossible	
			5. Carry an object of 5 kg, for instance a shopping bag over a distance of 10 m		
			6. Pick up something from the floor from an upright position		
			7. Walk 400 m without stopping (with or without a stick).		
			B. The GDA (General Daily Activities) indicator		
			1. Eating and drinking	Easily	
			2. Sit down in a chair and rise from a chair	With a bit of effort	
			3. Get into and out of bed	**With a lot of effort**	
			4. Dress and undress	Only with the help of others	
			5. Go to another room on the same floor		
			6. Walk up and down the stairs		
			7. Leave and enter the house		
			8. Move outdoors		
			9. Wash one’s face and hands		
			10. Wash one’s whole body		

42	**Bangladesh**	2010: Household Income and Expenditure Survey (HIES)	1. Does (name) have difficulty seeing, even if wearing glasses?	No, no difficulty	9.1 (5 years and older)
			2. Does (name) have difficulty hearing, even if wearing a hearing aid?	**Yes, some difficulty**	
			3. Does (name) have difficulty walking or climbing steps?	Yes, severe difficulty	
			4. Does (name) have difficulty remembering or concentrating?		
			5. Does (name) have difficulty (with self-care such as) washing all over, dressing, feeding, toileting etc.?	Yes, can't do it at all.	
			6. Does (name) have difficulty communicating, e.g. understanding or being understood?		
43	**Togo**	2010: Demographic and Health Survey	Does [Name] have a handicap? Please specify.	**Yes**/No	1.4
44	**Hungary**	2011: European Health Interview Survey (EHIS)	Now I would like you to think about situations you may face in everyday life. Please ignore any temporary problems.	Questions 2/3/5–7:	11.1 (15 years and older)
			1. Do you wear glasses or contact lenses?	Yes, with no difficulty	
			Yes/No/**I'm blind or cannot see at all**		
			2. Can you see newspaper print?	With some difficulty	
			3. Can you see the face of someone 4 m away (across a road)?	**With a lot of difficulty**	
			4. Do you wear a hearing aid?	Not at all	
			Yes/No/**I am profoundly deaf**		
			5. Can you hear what is said in a conversation with several people?	Question 8/9:	
			6. Can you walk 500 m on a flat terrain without a stick or other walking aid or assistance?	No difficulty	
			7. Can you walk up and down a flight of stairs without a stick, other walking aid, assistance or using the banister?	Yes, some difficulty	
			8. Do you usually have difficulty doing any of these activities by yourself? (Dressing and undressing)	**Yes, a lot of difficulty**	
			9. Do you usually have difficulty doing any of these activities by yourself? (Bathing or showering)	I can't achieve it by myself	

(continued)

45	**South Africa**[2]	2009/2010/2011:	Does… have difficulty in doing any of the following?	No, no difficulty	2009: 4.0
		General Household Survey	1. Seeing (even with glasses if he/she wears them)		2010: 4.6
			2. Hearing (even with a hearing aid, if he/she wears one)	Yes, some difficulty	2011: 3.7 (5 years and older)
			3. Walking a kilometer or climbing a flight of steps	**Yes, a lot of difficulty**	
			4. Remembering and concentrating		
			5. With self-care, such as washing or dressing		
			6. In communicating in his/her usual language including sign language (understanding others and being understood by others)	Do not see at all	
46	**Lesotho**	2011: Demographic Survey	Is (name) disabled? Note: state the main disability	**Yes**/No	2.6
			Amputation of fingers		
			Amputation of arms		
			Amputation of hands		
			Amputation of toes		
			Amputation of foot/leg		
			Lame/Paralyzed limb		
			Blind (total/partial)		
			Deaf (total/partial)		
			Speech problem		
			Mental illness		
			Mental retardation		
			Not disabled		
			Other (specify)		

47	**Costa Rica**	2011: National Disability Survey	Does [Name] have some permanent limitation:	**Yes**/No	10.5
			To see even when wearing glasses?		
			To hear even with headphones?		
			To speak?		
			Walking or climbing stairs?		
			Using arms or hands?		
			Intellectual: (mental retardation, Downs syndrome, etc.)		
			Mental: (bipolar, schizophrenia, etc.)		
48	**Israel**	2012: Social Survey	1. Do you have difficulty seeing, even if wearing glasses?	No, no difficulty	14.8 (20 years and older)
			2. Do you have difficulty hearing, even if using hearing aid?	Yes, some difficulty	
			3. Do you have difficulty walking or climbing stairs?	**Yes, a lot of difficulty**	
			4. Do you have difficulty in getting dressed or washing?	Do not do at all	
			5. Do you have difficulty remembering or concentrating?		
49	**Mexico**	2012: National Household Survey of Income and Expenditure	In his/her daily life, (NAME) has any difficulty to perform the next activities:	**Yes**/No	6.6
			Read all the options and circle affirmative answers		
			Walking, moving or climbing steps?		
			Seeing, even if wearing glasses?		
			Speak, communicate or chat?		
			Hearing, even if using a hearing aid?		
			Dressing, bathing or eating?		
			Paying attention or learning simple things?		
			Has any mental limitation?		
			So, he/she doesn't have physical or mental limitations?		

(continued)

50	**Peru II**	2012: First National Specialized Survey on Disability	DISABLED refers to people who have some limitation or physical, mental, intellectual or sensory (sight, hearing, touch, smell, taste) difficulty that PERMANENTLY prevents them from participating in society as anyone else. In their daily activities:	**Yes**/No	5.2
			1. Does [name] have permanent limitations in their ability to move or walk/ to use their arms or legs?		
			2. Does [name] have permanent limitations in their ability to see even using glasses?		
			3. Does [name] have permanent limitations in their ability to speak or understand, even if using sign language or other means of communication?		
			4. Does [name] have permanent limitations in their ability to hear, even using headphones?		
			5. Does [name] have permanent limitations in their ability to understand or learn (concentrate or remember)?		
			6. Does [name] have permanent limitations in their ability to relate to others (thoughts, feelings, emotions or conduct)?		
51	**USA**	2010/2011/ 2012/2013: National Health Interview Survey (NHIS)	7. Do you have difficulty seeing, even when wearing glasses?	No, no difficulty	2010: 8.9
			8. Do you have difficulty hearing, even when using your hearing aid(s)?	Yes, some difficulty	2011: 8.5
			9. Do you have difficulty walking or climbing steps?	**Yes, a lot of difficulty**	2012: 7.9
			10. Do you have difficulty remembering or concentrating?	Yes, can't do it at all	2013: 9.5 (18 years and older)
			11. Do you have difficulty with self-care such as washing all over or dressing?		
			12. Using you usual language, do you have difficulty communicating, for example, understanding or being understood?		

[1] Source: (Eide and Loeb 2006)

[2] Source: Statistics South Africa, 2010/2011/2012. Data presented here differs from published data in: http://www.statssa.gov.za/publications/P0318/P0318April2012.pdf (see page 19) due to use of different thresholds for determination of disability

[a] Prevalence rates are not age-adjusted. Unless otherwise indicated all ages considered

Data from other sources

Armenia: Register data (prevalence 6.2 %)
Croatia: Register data (prevalence 11.7 %)
Czech Republic: Register data (prevalence estimated at 10 %)
UAE: Register data
No data supplied
Denmark: will conduct the EHIS in 2012
Singapore: disability data not collected on census
Lebanon: currently conducting the Household Budget Survey that includes the WG questions
Kazakhstan: due to census form constraints, recommended questions on four domains of disability (vision, hearing, walking, and speech) were combined into one question, which was: “Do you have difficulty with walking, hearing, vision and speech?” The response options were: “Yes”, “Yes, often” and “No”
Slovak Republic: No current plans to collect disability data
China: China National Monitoring Survey on Disability – 2012: data not yet available
Sweden: do not use the WG Short Set of Questions
Kenya: currently completing disability monograph following the 2009 Kenya Population and Housing Census; other statistical survey on people with disabilities will be realized next year and results will be available in mid-2014
Paraguay: census 2012 – WG questions included “with adjustments according to our reality”
England: Life Opportunity Survey (2009–2011) includes participation restriction questions (learning, work/economic life, transport, community/leisure/civic life), questions on accessibility in and outside the home, services and policies, domestic life, caring for others and discrimination. There is a suite of questions intended to capture Disability Discrimination Act (DDA) disability which would enable analysis of the number of individuals that are likely to have rights under the act. Finally, a series of 55 questions are included that cover impairments and health conditions. These include the following domains: seeing, hearing, speaking, mobility, dexterity, pain, learning, intellectual difficulty, behavior, memory, and emotional/psychological/mental difficulties. Questions similar to the WG short set are included among these
France: WG questions tested in third wave of the Etudes des relations familiales et intergénérationnelles/Studies of family and intergenerational relations (2011)
Botswana: 2011 Population and Housing Census uses an impairment approach listing 13 possible impairments including vision, hearing, speech, lower/upper body, intellectual impairment and mental health disorder

Appendix 2: Additional Notes, Observations or Other Qualifications and/or Disclaimers Provided by the Country

Censuses		
	Country	Notes
2	**Dominican Republic**	Questions used in the 2010 Census
		Does (Name) have permanent difficulty…
		To see, even if you use glasses or lenses?
		To hear, even if you use headphones?
		For walking or climbing steps?
		To move one or two arms?
		To move one or both legs?
		To remember or focus?
		To grab objects or open containers with your hands?
		To speak?
		Is he/she mute?
		Does he/she have mental problems?
		Does he/she lack one or two legs?
		Does he/she lack one or two arms?
3	**Jordan**	Population and Household Census/Disability Survey scheduled for 2014
4	**Morocco**	Population and Housing Census planned for 2014
5	**Egypt**	Cause of disability included in 2006 Census
		1. Congenital
		2. During delivery
		3. Epidemic diseases
		4. Other diseases
		5. Abuse (Physically, Psychologically)
		6. Injuries/Accidents
		7. Aging
		8. Others (mention)
		2013/WG questions to be used in pre-test population census
6	**Palestine**	Reasons coded:
		1. Congenital
		2. During pregnancy
		3. Illness
		4. Psychological/physical abuse
		5. Aging
		6. Work injury
		7. Traffic accident
		8. Other accident
		9. Israeli measurements
		10. War
		11. Other

(continued)

7	**Peru**	735,334 households had at least one disabled person
8	**Cambodia**	Coded for since birth/after birth
9	**Malawi**	Includes cause:
		Congenital
		Disease/illness
		Injury/accident
		Not known
		Other
10	**Israel**	Vision question not asked – Israel has an available administrative source of people who have heavy vision impairment and who are eligible to receive special benefits.
11	**Oman**	Additional question:
		What is the main reason for this difficulty/disability?
		1. Since birth
		2. Disease
		3. Car accident
		4. Work injury
		5. Old age
		6. other
12	**Aruba**	Also includes question on handicaps and type of handicap: motor dysfunction, visual, auditory, organ, light mental, severe mental other
13	**Mongolia**	Includes WG domains as type of difficulty following a disability screener
14	**Mexico**	It is important to point out that, even that it is true that international recommendations for the design of questions about the topic of disability, the ones from the Washington Group and United Nations specifically, adaptations that, according to the pilot test for such an statistical exercise responded adequately to Mexico characteristics and INEGI's possibilities, were performed. For example, a question about the cause of the difficulty was included, and the request of the Mexican civil society to explicitly asking about mental limitation was attended; however, the grade of difficulty that an individual may present in each one of the activities included in the questionnaire couldn't be collected due the effect such intent had in the interview's time and cost
26	**USA**	The 2010 American Community Survey (ACS) operationalizes questions that elicit serious difficulty in six domains and have yes/no response options. Five of the six are similar to the WG questions (seeing, hearing, walking/climbing steps, remembering/concentrating, and dressing/bathing) while the communication question is dropped in favor of a participation question: difficulty doing errands alone such as visiting a doctor's office or shopping

(continued)

Surveys		
	Country	Notes
27	**Argentina**	Planned 2010/National Survey for Persons with Disabilities
		She/he has difficulty or permanent limitation:
		Seeing, even with glasses or lenses?
		Hearing, even when using a hearing aid?
		Walking or climbing steps?
		Grabbing objects or opening containers with your hands?
		Understanding and/or learning?
		Response options: Yes/no
28	**Lithuania**	European Survey on Health and Social Integration planned for 2012
29	**Yemen**	Other questions were as follows:
		What type of disability/chronic illness suffered by the individual patient?
		What the cause of this disability/chronic disease?
		When the individual became disabled or chronically infected with the disease?
		Did the individual require aid as a result of disability/chronic illness?
30	**Japan**	The number of Persons with mental disabilities corresponds to the number of patients of ICD-10 "Chapter V: Mental and behavioral disorders," excluding the number for intellectual disabilities and adding the number for epilepsy and Alzheimer's
		Outpatients in the "patient survey" are considered to be persons living at home, and inpatients are considered to be persons staying at facilities
31	**Canada**	We have only used the short set for one survey as a test to replace our current disability identification questions. We inserted the WG short set along with selected questions from the extended set on our national health survey as a test from January to April this year. During that period, the survey was administered to about 27,000 cases but I'm not sure what to expect in terms of a disability rate
32	**New Zealand**	Plans for a New Zealand Disability Survey in 2013
		CENSUS: Mark as many spaces as you need to answer this question.
		Does a health problem or a condition you have (lasting 6 months or more) cause you difficulty with, or stop you doing:
		Everday activities that people your age can usually do
		Communicating, mixing with others or socialising
		Any other activity that people your age can usually do, or
		No difficult with any of these
		Do you have any disability or handicap that is long-term (lasting 6 months or more)?
		Response options: Yes/no
33	**Peru I**	Continuous National Survey (ENCO)
		382,000 private dwellings at the national level
34	**Zambia**[a]	Data derived from additional analyses of an independent source: Eide AH, Loeb ME (eds.) (2006); Living Conditions among people with activity limitations in Zambia: A national representative study. Report No. A262, SINTEF Health Research, Oslo. Available online at: http://www.sintef.no/lc

(continued)

36	**Norway**	The Survey of Living Conditions is a national survey, covering the population 16 years and older and living in private households. It includes 10 questions on activity limitations in 6 functional domains and 7 questions on participation restrictions. Eight questions were selected that reflect 5 WG domains (seeing, hearing walking/climbing, remembering/concentrating, dressing/washing)
		The domain on communication is not covered in the survey and is thus not a part of the definition
		Preamble to questions 1–3: The following questions are about more permanent problems, do not consider passing problems or temporary problems that you may have at the moment. With permanent or long lasting problems we mean problems that have lasted, or are expected to last for 6 months or longer
		Preamble to question 4: I will read out some everyday activities to you, and I would like to know if you have difficulty performing any of these activities. Think about what you manage when you have your normal aids (assistive devices) available or when you are receiving the assistance you normally get
		Questions 5/6 to only those who have a health problem that affects their everyday activities to a great extent
37	**Spain**	**Preamble:**
		I shall ask you a few questions regarding possible difficulties or limitation with carrying out everyday activities. It is intended to detect persons in the household 6 years old and over currently facing them. These questions refer to difficulties or limitations fulfilling two requirements:
		They have lasted or are expected to last more than 1 year (for example, minor accidents such as slight injuries which are overcome in a matter of months are not considered)
		The cause of the limitation or difficulty is a health-related problem or disability
		In order to respond, one should keep in mind persons when they are not using aids or supervision. If someone overcomes their limitation through use of an aid or receiving supervision, they must still be considered to be facing the corresponding difficulty. For example, if someone can only eat when assisted by another person, then he or she does have a limitation. However, an exception is made in the case of visual impairment (myopia, astigmatism …): If the person has these difficulties and overcomes them with spectacles or contact lenses, he or she is regarded as not having the limitation
		By assistance we mean two types thereof: technical aids and personal aids
		[a]Any technical product or instrument used or aimed at use by a disabled persons, which compensates or lessens the limitation. For example: earpieces, illuminated lenses, external prostheses, sticks, wheelchairs, hoists, oxygen, cutlery with adapted handles, access ramps, guide dogs, …
		[a]Personal assistance in regarded as all collaboration by another person, necessary for carrying out an activity
		Supervision is regarded as the need for another person to be overseeing what someone else does, in the event that problems arise in an everyday activity
		Plans: European Survey on Health and Social Integration/2012

(continued)

39	**Poland**	June 2011: Module on the employment of disabled people – will not use the WG questions
40	**Australia**	The survey includes 136 questions covering impairments, activities of daily living and the need for help or supervision in performing the activity. The reported prevalence rate of 7.4 % is based on a subset of questions that reflect the WG domains
		2012/Survey of Disability, Aging and Carers underway
41	**Netherlands**	The OECD indicator (Organization for Economic Cooperation and Development) is based on 7 questions as listed in Appendix 1
		The respondents are persons in the age category 12 years and older. As from 2001, a question has been added concerning speech impediment: can you speak audibly? This question does not affect the indicator
		The GDA (General Daily Activities) indicator is based on the following 10 questions (Appendix 1)
		The questions were asked to persons in the age category 55 and older in the oral part of the module 'Health and Labor Conditions'. From 2001, questions 2, 3 and 6 have also been asked to persons in the age category 12–54
42	**Bangladesh**	Each question is followed by:
		How old were you when the difficulty began?
		What was the cause?

[a] Data collected independently

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Chapter 16
Swift and Systematic? Identifying and Recording Disability in Forced Migration

Mary Crock and Laura Smith-Khan

Persons with disabilities who find themselves displaced by human conflict have been described as "too often invisible, too often forgotten and too often overlooked" (António Guterres, cited in WRC 2008, p. 1). As an agency of the United Nations – and therefore bound by international law, the United Nations High Commission for Refugees (UNHCR) has embraced the paradigm shift in approach demanded by the Convention on the Rights of Persons with Disabilities (CRPD) (2008). In this chapter we explain how the work of the Washington Group has been used in multi-country fieldwork to explore the adequacy of the systems used by UNHCR and other agencies to identify disabilities in populations of displaced persons. The overall aim of the research was to encourage these humanitarian actors to improve the accessibility of their operations (Crock et al. 2013, p. 737). The project provides an interesting illustration of how the "functionality" approach pioneered by the Washington Group can be used in diverse field situations.

The importance of identifying and recording accurate and comprehensive information about disability is widely acknowledged. Article 31 of the CRPD creates an explicit duty in states parties to collect statistics and data "to enable them to formulate and implement policies" to promote Convention rights. In 2010, UNHCR's Executive Committee recommended that states and UNHCR undertake:

> a swift and systematic identification and registration of refugees and other persons with disabilities, with particular attention to those who cannot communicate their own needs, in

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This chapter draws on an article prepared during an early stage of the "Protection of Refugees with Disabilities" Project. See: Smith-Khan et al. 2015a.

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> order to identify their protection and assistance needs, including as part of a global needs assessment (ExCom 2010).

While data collection is a global challenge, displacement situations throw up particular problems. There are a range of reasons why people living in fear of persecution or in situations of extreme deprivation may be reluctant to present themselves to local host authorities or to agencies like UNHCR. Refugees and displaced persons may be unaware of the benefits of registering with these agencies. They may have lost critical identity documents in the course of their flight. Services may be inaccessible to those with disabilities (Hart et al. 2014, p. 149). In the result some may be overlooked (HelpAge International and Handicap International 2014, p. 16). Even for those who register with UNHCR and its implementing and operational partners (different government agencies, NGOs and IGOs in the various countries), our experience suggests that disability can be overlooked or not accurately recorded (Smith-Khan et al. 2015a, b; HelpAge International and Handicap International 2014, p. 16).

The chapter begins with a brief overview of our research and the methodologies used in collecting data in the various countries in which fieldwork was undertaken. Thereafter we use a discussion of the disability data collected by the support organisations studied to outline apparent shortcomings in the systems being used. We then critique in greater detail the practices and tools used for identifying and recording disability in displacement situations, drawing out examples of good and bad practice. The chapter concludes with some reflections on the benefits of using the Washington Group question sets, as well as other important factors in facilitating identification and information sharing.

Outline of Project

This chapter shares findings from a project conducted by a team based at the University of Sydney's Faculty of Law. The work involved predominantly qualitative research, combining a critical review of existing studies, tools and standards, with multi-site fieldwork in six host countries: Malaysia and Indonesia in 2012, Pakistan and Uganda in 2013 and Jordan and Turkey in 2014.

These countries were selected to allow for the study of disabilities in a variety of displacement situations. In Malaysia and Indonesia, the research was focused on refugees and asylum seekers living in urban settings. Critically, the presence of these people was tolerated but not supported by government. In Uganda, refugees living in the capital city of Kampala were compared with persons living in government-sponsored refugee settlements who receive subsistence support and services. In Pakistan, UNHCR provided us with survey data that provided an overview of the diverse refugee population living in urban, rural and camp-like settings. Finally, research in Jordan and Turkey involved a case study of raw and fresh displacement scenarios: refugees fleeing ongoing conflict in Syria living in both camp and urban refugee settings. Unlike the other research countries where refugees came from a variety of countries, the refugees studied in Jordan and Turkey generally shared similar cultural and linguistic backgrounds. While Uganda is the only one of these countries to have unconditionally ratified the Refugee Convention (1951) and its Protocol (1967), all are parties to the CRPD.[1]

In each country, we met and interviewed representatives from UNHCR; UNHCR's partners and local Disabled Persons Organisations (DPOs). In Uganda, Pakistan, Jordan and Turkey we also met with government officials. In every country but Pakistan we conducted individual and focus group interviews with refugees and asylum seekers. Critically, for present purposes, our research tools used drew heavily on the *International Classification of Functioning, Disability and Health* (ICF) developed by the World Health Organization (WHO). As many in this volume attest, the ICF reflects and operationalizes the CRPD approach to disability. It seeks to capture not only a person's impairment or health condition, but also the environmental barriers that create disability (WHO 2011, p. 4). The ICF conceptualises disability as difficulty in any one of three interconnected areas: *impairments* ('problems in body function or alternations in body structure'); *difficulties in executing* activities – for example, walking or eating; and *participation* ('problems with involvement in any area of life') (p. 5).

The ICF forms the basis for a number of national and international identification tools (WHO 2011, p. 25), including question sets developed by the Washington Group on Disability Statistics. These include a basic set of questions:

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even when using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remember or concentrating?
5. Do you have difficult with self-care, such as washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating (for example, understanding or being understood by others)? (WHO 2011, p. 26)

For each of these questions, responses range on a scale from "No difficulty" to "Cannot do at all" (WHO 2011, p. 26). Questions about anxiety and depression, fatigue and pain are also included (Washington Group 2011, pp. 9–11).

Having tested ICF-based surveys extensively, WHO (2011) recommends the adoption of the ICF as an international standard. Further, it advocates a "difficulties in functioning" approach in place of an "impairment" approach, recommending that disability questions be added to existing surveys as a "cost-effective and efficient" implementation strategy (p. 45).

The individual questionnaire included a disability identification tool based on the ICF and Washington Group questions. As WHO recommends (2011, pp. 40–1), we asked questions about assistance with functional difficulties, fatigue, pain and

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[1] Turkey is a party to the Refugee Convention, but limits its application to refugees from Europe. Malaysia ratified the CRPD on 19 July 2010; Indonesia on 30 November 2011; Pakistan on 5 July 2011; Turkey on 28 September 2009; Jordan on 31 March 2008. Uganda acceded to the Refugee Convention and its Protocol on 27 September 1976. Turkey ratified the Refugee Convention on 30 March 1962 and acceded to its Protocol on 31 July 1968.

affect, as well as access to income, food, water, education, health care and experiences of discrimination. After asking basic demographic questions, the tool asked whether the interviewee had a disability and, if so, to describe it. Responses to this open ended question could then be compared with the data collected using the functionality questions.

In total, the following individual interviews were conducted with refugees: in Malaysia – 151; in Indonesia – 58; and in Uganda – approximately 80. In Uganda, we also collected over 900 questionnaires that were either self-completed, or completed in French or English with the assistance of an interpreter. This occurred because so many people approached us expressing a desire to participate in the research that we finally distributed the remaining paper surveys we were carrying with us. The refugees located photocopiers in the settlement and reproduced the documents for further distribution over a 3 day period. This response, in itself, indicated the extent to which the interviewees regarded themselves as forgotten refugees.[2]

The disability identification questionnaire was used with a further 11 individual participants in Jordan. We also conducted four focus groups, each of approximately 40 people, in Uganda and Indonesia; and of around 20 people in Malaysia, Jordan and Turkey. In each instance we asked questions about functional difficulty and accommodation for persons with disabilities.

In Pakistan, constraints of time and personnel did not permit research within the refugee communities. However, interviews were conducted with UNHCR and with government officials. Most importantly, UNHCR provided us with data from its 2011 *Population Profiling Verification and Response* (PPVR) exercise where a tool was used that included questions similar to those in the Washington Group's basic set (see CCAR and UNHCR 2011). In Malaysia, Indonesia and Uganda, we were given data extracted from UNHCR's Profile Global Registration System '*ProGres*' (UNHCR 2004), listing persons identified as having a disability, and data from UNHCR's partners. Finally, in anticipation of our arrival in 2012, UNHCR in Malaysia commissioned an internal report on disability (Sario 2012). This provided background into the existing data and identification procedures there.

The fieldwork across the six countries visited threw up many challenges. Limitations of time and a modest budget lead us to use purposive sampling techniques to locate most of our participants: we were not in a position to implement our questionnaire randomly over a large sample. Accordingly we make no claim that the questionnaire data is statistically valid (Bloch 2007, p. 233). Relying on gatekeepers, like UNHCR and other staff and community leaders, may have also excluded some persons (Harrell-Bond and Voutira 2007, pp. 288–9; Bloch 2007, p. 235). In some instances, the information gathered was self-reported by participants, meaning its accuracy cannot always be verified: see also note 2 above.

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[2] See further below. The behaviours exhibited may also reflect the aspiration of the participants that involvement in the survey could deliver a benefit, for example in terms of resettlement to a third country. This was despite every effort on our part to explain the nature of the research and what participation in the survey would (and would not) mean for them.

Ensuring voluntary informed consent was another challenge: our status as Western researchers created a power imbalance (Abdel-Messih et al. 2008, p. 36). We stressed that there was no obligation to participate and that our research could not produce improved protection outcomes for individuals interviewed. Ensuring participants' privacy during interviews was also challenging as we often had limited options in terms of venue and accommodation. The problems were particularly acute in Uganda where our presence attracted considerable curiosity. We endeavoured to hold our interviews in private areas or at some distance from gatherings. Even so, the environment for the research was less than ideal.

In Uganda, the pressure of numbers meant that we resorted to distributing 300 questionnaires for self-completion. Returning some days later we were astonished to find that the refugees had made more copies, returning close to 900 completed questionnaires. As we processed these, we observed some comprehension issues which led us to revise the wording of the questionnaire for subsequent use. The experience also reinforced the importance of providing ample training for community leaders and interpreters or anyone else responsible for implementing such tools. Providing questionnaires in refugee languages would also help overcome comprehension issues and facilitate inclusion (Bloch 2007, p. 239). Again, we were unable to address all of these issues because of funding and time restraints.

Current Data on Refugees with Disabilities

As noted earlier, UNHCR in Malaysia, Indonesia and Uganda shared with us statistics extracted from the *ProGres* database on "persons of concern" recorded as having a disability. These are the people registered with the agency for whom UNHCR has some level of responsibility. As of June 2012, UNHCR in Malaysia reported caring for 202 refugees with a disability (Sario 2012). This amounted to 0.21 % of the 94,000 registered persons of concern at the date in question. In September 2012, UNHCR in Indonesia reported caring for 51 such persons, or 0.64 % of approximately 8000 persons of concern (UNHCR 2012). The situation in Uganda was broadly similar. Of 66,589 refugees and persons of concern living in Nakivale Settlement in September 2013, only 309, or 0.46 %, were recorded as having a disability (UNHCR 2013b, p. 1). In neighbouring Oruchinga Settlement, 99 persons with disabilities were recorded out of a population of 5799, equating to 1.71 % of the resident refugees. As percentages, these figures fall well below the WHO global estimate of 15.6 %, and even the 2.2 % estimate for severe disability. The estimates are removed even further from WHO's estimates for developing countries, even though a number of our research locations were in such countries (WHO 2011, p. 27). In spite of early suggestions from some UNHCR staff interviewed in 2012 that persons with disabilities do not travel, it was clear to us from the outset that the data collected in UNHCR's initial registration processes was not capturing the disabilities of the persons in their care.

Happily, our research coincided with major initiatives by UNHCR to revise its methodologies for collecting data on disabilities. The *ProGres* data from Malaysia, Indonesia and Uganda contrasts sharply with the results of the PPVR in Pakistan.[3] In that exercise, UNHCR and its government partners conducted home visits that covered 974,961 Afghans living throughout Pakistan. The total survey resembled a census, asking a range of questions of a principal informant about the members of their household. The disability section drew on the ICF and used questions resembling the Washington Group set. This was the first location in which we saw this approach used, and the results reflected the change in approach. Of the 974,961 persons reviewed, 79,954 were identified as having functional difficulties. This equates to 8.2 % of the population surveyed.

The WHO estimate of 15.6 % as the global average for the incidence of disability is based on adults (aged 18 years and older). Impairments were found to be significantly higher amongst adults and the elderly than amongst the young (WHO 2011, p. 27). When data covers a complete population, the percentage would be expected to fall. When limited to adults, disability prevalence in the PPVR rises from 8.2 % to 14.97 %, close to the WHO estimate. Given that the *ProGres* data includes refugees of all ages, this could account for *slightly* lower percentages. However, the significantly low percentages suggest that even if the data for children were removed, the percentages would still remain incongruously low.

Although the PPVR was an exceptional verification exercise, it demonstrates the value of adopting an approach embracing internationally-recognised standards. The contrast between the *ProGres* and PPVR data suggests strongly that UNHCR's standard procedures may not be capturing all those with disabilities, even at the crudest of levels. We say this, acknowledging that disability is an inherently difficult concept to capture: it is occurs on a continuum and so cannot be accurately dichotomised. The Washington Group questions at least allow for a range of responses, encouraging responses where labelling serves to deter those who do not perceive their impairment as serious.

Procedures and Tools

UNHCR's *Registration Handbook* (2003) states that registration is "crucial for identifying those at risk and those who have special needs" (p. 7) and that persons with disabilities should be given priority for registration and interviews (p. 145). However, it provides no further guidance on how persons with disabilities or their assistance needs are to be identified during registration.

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[3] We have not obtained *ProGres* data from UNHCR Pakistan, so it was not possible to compare the data collected during the PPVR with standard *ProGres* data on disabilities in Pakistan. However, even if this were available to us, the majority of refugees in Pakistan are not registered with UNHCR, but rather in the Government of Pakistan's database (interview with UNHCR Islamabad, 9 April 2013) meaning that comparative value would be limited.

UNHCR's *Guidance* (published after the making of the CRPD) acknowledges that persons with disabilities may be overlooked, stating that it is "vital to introduce explicit procedures for identifying persons with disabilities" (2011b, p. 9). Later in this document the identification of children with disabilities not attending school is highlighted as essential to ensuring inclusive education (p. 13).

The rollout of UNHCR's *ProGres* has been a particularly valuable step in ensuring uniform and systematic identification and information sharing. At time of writing, the cloud-based program was being used in over 75 countries at registration and thereafter to record details about persons of concern (Microsoft 2015). The information can be shared between multiple UNHCR offices and between units within each office. UNHCR staff are provided with training and guidelines to help standardise the information recorded (UNHCR 2004).

Although *ProGres* provides the framework for data collection, the next challenge is in how the data is categorised by UNHCR. The database includes a section to record "special protection or assistance needs" for persons of concern. The way this operates is explained in the Registration Handbook. The "Disability" category within the area of special protection and assistance needs (coded as "DS") includes "physical, mental, intellectual or sensory impairments" (UNHCR 2009, p. 4).[4] There are further subcategories for different types of disabilities, set out in the table below (Table 16.1).

These subcategories were being used in both Malaysia and Uganda. Our concern is that they operate as labels for impairments that do not align directly with functionality and needs. There are no linked questions about the environment in which the person is living and the assistance available. Without this information the interviewer is not capturing a clear picture of the person's disability or needs. Moreover, the questions do not ensure that like cases are treated alike. When determining whether someone has a severe or moderate physical disability, some guidance is provided. However, the definitions do not capture the role that barriers and accommodation play in creating disability. In practice, similar or identical impairments can have very different effects depending on the accessibility of environment, so like impairments can be very dissimilar in actuality. For example, a person who is paraplegic but who has an appropriate wheelchair and who lives in an area with accessible buildings may be able to function independently. A person with similar impairments who does not have such assistance or who faces barriers in the built environment may be severely restricted. The impairments of the two people may be identical but their situations are different and result in different disabilities (Sario 2012, p. 22). UNHCR's guidance recommends "specialist/qualified personnel" to determine severity (UNHCR 2009, p. 5) which may create an evidentiary (and financial) burden on individuals that is difficult to meet.

UNHCR's guidance recommends that "staff should code each specific need separately, seeking the most appropriate category but avoid multiple vulnerability

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[4] It should be noted that earlier guidance in UNHCR's Registration Handbook mentions only a "Disabled" category for persons of concern who are "physically or mentally disabled" (UNHCR 2003: 169).

Table 16.1 UNHCR disability subcategories (UNHCR 2009: 5–6)

Subcategory	Description	Code
Visual impairment (including blindness)	Person who has a visual limitation from birth or resulting from illness, infection, injury or old age, which impacts daily life, may restrict independent movement, or require on-going treatment, special education or regular monitoring	DS-BD
Hearing impairment (including deafness)	Person who has a hearing limitation from birth or resulting from illness, infection, injury or old age, which impacts daily life, and may require regular treatment, special education, monitoring or maintenance of artificial hearing device. The person may be able to communicate through sign language	DS-DF
Physical disability – moderate	Person who has a physical impairment from birth or resulting from illness, injury, trauma or old age, which does not significantly limit the ability to function independently. This category may include mine victims and persons who lost fingers or limbs, which may be corrected with a prosthetic device	DS-PM
Physical disability – severe	Person who has a physical impairment from birth or resulting from illness, injury, trauma or old age, which severely restricts movement, significantly limits the ability to function independently or pursue an occupation, and/or requires assistance from a caregiver	DS-PS
Mental disability – moderate	Person who has a mental or intellectual impairment from birth or resulting from illness, injury, trauma or old age, which does not significantly limit the ability to function independently and interact, but may require special education, some monitoring and modest medication	DS-MM
Mental disability – severe	Person who has a mental or intellectual impairment from birth or resulting from illness, injury, trauma or old age, which significantly limits the ability to function independently or to pursue an occupation. It requires assistance from a caregiver, and may require medication and/or medical treatment	DS-MS
Speech impairment/disability	Person who is unable to speak clearly from birth or resulting from illness, injury, trauma or old age, which restricts or limits the ability to function independently, and may require speech therapy or medical intervention. The person may be able to communicate through sign language	DS-SD
Mental Illness	NB: Falls within the ‘Serious medical condition’ category (rather than the Disability category) and captures persons with a ‘mental or psychological condition which impacts on daily functioning’	SM-MI

codes for the same characteristic" (UNHCR 2009, p. 1). The response of officials in different countries suggested to us that it was unclear to staff whether this means that disability should be coded once only or whether there is scope for recording different types of disabilities, with multiple sub-categories for a single individual. In Uganda, an officer working at the PSN desk during a verification exercise told us that she believed she was expected to record only one disability code for each person. She recognised that in some cases persons do have multiple difficulties. She acknowledged that failing to note each disability undermines the supporting organisations' ability to provide appropriate assistance (interview, September 2013). We observed a similar tendency to record only one disability against persons of concern in Malaysia and Indonesia. In Malaysia, UNHCR's list included cases in which persons with cerebral palsy were identified simply as having a "mental disability", a categorisation that may or may not have been accurate. The list also included individuals recorded as having one impairment (paraplegia) who also had difficulty seeing and hearing. The less obvious impairments were not recorded.[5]

In Indonesia, disability was categorised as either mental or physical by UNHCR and its implementing partner CWS in the documents provided to us. A separate list was constructed for "medical" cases (interviews, UNHCR and CWS September 2012). Where disability or any other vulnerability was identified by UNHCR staff, these persons were referred to CWS for assessment and support.

In practice, UNHCR staff reported that questions asked during initial registration were often truncated because of time and resource constraints. In Indonesia staff reported collecting basic bio-data and asking only one open question about the person's protection claim during initial interviews. Questions regarding physical and mental wellbeing are only asked at Refugee Status Determination (RSD), potentially more than 12 months after initial contact (interview, UNHCR, September 2012). In Malaysia, disability may be identified through basic vulnerability assessments that are carried out during registration. However Sario (2012) writes that "there are no tools specifically designed for registration staff to detect disabilities… They rely primarily on both visual perceptions as well as the information provided by the individuals themselves" (p. 16).

In Malaysia, Indonesia and Uganda, some measures were in place to identify disability beyond registration. UNHCR's *Heightened Risk Identification Tool* (HRIT) was being used as a basis for needs assessments in Malaysia. The HRIT includes one question about whether the person has any "health problems, conditions or disabilities" (UNHCR 2010, p. 9). This provides a basic starting point for identifying impairments.

In Uganda, UNHCR was using the more recently developed *Resettlement Assessment Tool: Refugees with Disabilities* (UNHCR 2013a) as sensitisation for staff, encouraging them to include refugees with disabilities as potential candidates for resettlement. UNHCR and its partners were also undertaking participatory assessments in the refugee settlements, guided by UNHCR's *Age, Gender and Diversity Policy* (UNHCR 2011a).

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[5] Cognitive functioning of persons with cerebral palsy is a complex area, with varied ability reported: see Fennell and Dikel (2001) for a description.

In contrast, we noted significant developments in Jordan. There, UNHCR and its partners were developing and implementing the *Refugee Assistance Information System* (RAIS) and the *Vulnerability Assessment Framework* (VAF). These tools deliver a more comprehensive picture of the lived experience of refugees in Jordan, identifying particular needs and considering impairment or illness contextually. Individuals and families are assessed holistically, with home; family and social networks; income; and personal attributes all taken into account. The RAIS is implemented through systematic and repeated house-to-house visits. This means that there is less chance of someone falling through the cracks, and assessments can record changing circumstances. Special attention was also being paid to information-sharing between organisations. At the time of our research the several organisations assisting refugees were negotiating which information to share and how to synchronise their records. While presenting significant challenges, these measures demonstrated a more sophisticated approach to disability identification and assistance.

Relying on Self-Identification

Without detailed and systematic procedures for identifying disability it becomes important for individuals to step forward and offer information about themselves. This is especially the case for those with disabilities that are not easy to identify visually (Davis 2005, p. 153). However, as the UNHCR Registration Handbook (2003) observes, those with special needs are "often the least likely to come forward and make their needs known" (p. 7).

We found a number of factors that can impede self-identification. First, understandings of disability can vary across groups or cultures (see discussion in WHO 2011, chapter 1). This may mean that individuals may not believe that they have a disability, even though they may meet organisational definitions. This is borne out in the results of our questionnaire, as we discuss below (see box story). The discrepancy between responses to open-ended questions about disability and responses to questions about functionality were sometimes very marked.

Social stigma can operate to deter disclosure. This is especially so with many psychosocial conditions (Garand et al. 2009, p. 114), and may vary between groups. For example, we observed a particular stigma around epilepsy in Uganda. Sexual violence and the effects thereof was also something that elicited shame and a reluctance to disclose. Bureaucratic requirements for proving disability can also act as a barrier. This is a particular concern in development contexts where refugees may lack the financial or logistical means to access specialist services required to document or attest impairments. Those with disabilities are often the poorest members of a community. In a tragic "Catch-22", this can make them less likely to have the resources necessary to obtain the evidence they need to access services (including financial assistance). The final obstacle concerns access to information. We encountered individuals who expressed the view that disclosing their disability to refugee support organisations would be of little benefit to them. Indeed some seemed to believe that disclosure would have negative outcomes such as being rendered ineligible for consideration for resettlement.

It Matters What You Ask

By including an open-ended question in our survey tool, we were able to compare the variation in data gathered by different types of questioning. We observed that richer information could be obtained by asking functionality-based questions. In some cases, this included identifying issues not mentioned at all in response to the open-ended question. For example, the very first participant we interviewed in Malaysia was a man who was paraplegic and used a wheelchair. We could observe visually that he had functional difficulties that affected his mobility. However, it was not until we explicitly asked about his ability to see and hear that we discovered that he had trouble seeing and was completely deaf in one ear. He commented: “no one has ever asked me about that before” (participant interview, Malaysia, 2012).

An analysis of the data from 151 people interviewed in Malaysia showed a clear divergence in the amount of information collected using the initial open-ended question and that gained from asking the same participants the follow-up functionality questions. In total, 36 % of participants failed to mention in their initial description of their disability functional difficulties that were identified subsequently. Most commonly underreported were cognitive difficulties (difficulties remembering or concentrating), which were only reported initially about a third of the time. Nearly half of all reports of difficulties with seeing were only elicited through direct functionality questioning. This may be explained by other data collected during the research. In particular, refugee community leaders in Malaysia explained that sight tests had been carried out amongst some groups. Individual participants also reported these. However, even where participants were told that they had vision problems that warranted glasses, no glasses were provided. This may have contributed to a belief that there was little utility in reporting difficulties with sight.

It is clear that questioning style can play a significant role in determining the type and amount of information collected. The findings suggest that where disability is understood narrowly or where there is little expectation of assistance for certain difficulties, these are likely to go unidentified. This means that only those difficulties perceived as most urgent or most likely to garner assistance will be reported without specific prompting. In some locations, service providers argued that asking these specific questions could raise unrealistic expectations amongst beneficiaries about the types of assistance realistically available. This highlights the need for awareness-raising and training both for staff and refugee communities. Even if assistance cannot be provided at a specific point in time, knowledge of the difficulties faced by a particular group is important. First, in terms of the design of procedures, communication and facilities: if there are a large number of people who have difficulty seeing, design may need adjusting. Second, with competing demands on tight humanitarian budgets, data revealing these types of trends could lend valuable support to targeted funding campaigns.

Making Strides Towards Inclusive Identification

There are clear and significant challenges to identifying disability amongst displaced populations. However, UNHCR and its government and non-government partners are demonstrating their willingness to overcome the difficulties and to make their policies and practices more inclusive. This is demonstrated in a variety of measures we observed across the fieldwork locations.

First, we acknowledge again and stress the value of integrating the Washington Group questions into the PPVR in Pakistan. If a similar approach were to be adopted in registration and verification procedures in UNHCR's operations across the world, we are confident that the agency would be able to generate comprehensive data that aligns more closely with global standards. Such data would be particularly valuable for targeted funding appeals.

However, reforming registration and data collection is by no means sufficient on its own. Throughout our fieldwork, we observed examples of valuable initiatives that help to overcome barriers to identification. As mentioned above, even when asked specific questions, refugees can be reluctant to disclose some difficulties. The nature of displacement lends itself to many unusual if not unique challenges. These reinforce the importance of awareness raising and training, and the dissemination of information in suitable languages and formats. Empowering refugee communities and groups of refugees with disabilities may also create a valuable conduit for referrals.

Much is being done to improve the situation for refugees with disabilities. However, there is still a long way to go. Identifying impairments is not sufficient of itself, although it is a crucial first step. Only through understanding the lived experiences and context of persons with disabilities living in displacement can we can begin to design suitable responses, facilities and procedures. The identification of disability is thus essential to ensuring all refugees have equal access to protection and humanitarian assistance.

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Chapter 17
The Washington Group's Contribution to Disability Statistics and a Look to the Future

Jennifer H. Madans

When the National Center for Health Statistics was asked to organize the first meeting of what would be called the Washington Group on Disability Statistics we were happy to accept. Judging from what we knew about other City Groups, we expected that a modest number of countries would accept the invitation to attend and that the work plan would be targeted and specific. Our expectations were not borne out. At the first meeting of the Washington Group in February 2002 there were over 60 attendees representing National Statistical Offices from 35 countries, as well as Eurostat (coordinating the European Statistical System), the World Health Organization (WHO), the United Nations Children's Fund (UNICEF), the United Nations Statistical Division (UNSD), and International Organizations of people with disabilities. Membership in the Washington Group has continued to be much higher and more diverse than for any other City Group. Attendance at the first and subsequent meetings is a vivid illustration of the interest among national statistical organizations and their partners in improving the quality and availability of disability statistics. Throughout the existence of the Washington Group members have maintained an extremely high degree of interest in the topic and their dedication to the work has not faltered in the group's 13 year history.

The attendees at the first meeting were well aware that they had a difficult task ahead of them. Disability statistics that were available at the time of the meeting were based on different conceptualizations and definitions of disability resulting in disparate estimates of disability worldwide. However, the group was able to benefit from the extensive conceptual work that had been done which provided a framework that could guide the development of high quality statistics. The most recent was the publication of the WHO International Classification of Functioning, Disability and Health (ICF) which the group adopted as an organizing framework.

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The fact that a concerted effort would be needed to improve disability statistics should not be too surprising. While there are numerous concepts that present challenges from a measurement point of view, disability may be one of the most challenging. Disability is most often considered as part of the health sector but the concept encompasses almost all aspects of life, including education, employment, income, civic engagement and all aspects of social participation. While there are many definitions of disability, there are some key components including the multiple aspects of body structure and function, functioning[1] in a range of core domains both with and without accommodation and the potentially negative outcome of the interaction of functional abilities with the built, social and legal environments. Developing statistics on any of these components of disability would be a challenge. Addressing them all, given the complex relationships among them and the varying social and cultural contexts that can affect how questions are interpreted, is a daunting task. The Washington Group took on this challenge with the full knowledge that the group would need to prioritize its work and that a long term commitment would be needed. Washington Group members are still committed to these tasks.

Washington Group Products

As noted in other chapters in this volume, the Washington Group's first task was to determine which piece of the disability puzzle to address. The decision was to develop a short set of questions that would produce statistics to evaluate equalization of opportunity – the purpose identified by members as being the most critical and most amenable for achieving international comparability. Building on this work, an extended set of questions was developed that covered more domains and produced more information on each domain. The development of a question set for children in collaboration with UNICEF was the next product developed. This question set is similar in design and structure to that developed for adults but addresses domains of importance to children. This was particularly challenging since children's development happens quickly and the trajectory of change varies considerably across individuals. All these questions sets focus on basic functioning for the most part without taking into account accommodations particularly at the individual level. The Washington Group acknowledged that while the question sets developed would provide the most critical information on disability; they could only provide information on a part of the mosaic of disability information that was needed. It would be necessary to build on the core information provided by the short, extended and children's question sets to determine how an individual's functional status interacts with the environment in which he or she lives to either hinder to enhance

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[1] Throughout this chapter the term functioning will be used to refer to the level of difficulty (if any) an individual has in core functional domains. These domains are included in the Washington Group short, extended and children's question sets.

participation in society. This information is necessary to develop policies and programs that increase social participation thereby breaking any link between functional difficulties and full participation in society.

Given the importance that the Washington Group placed on international comparability, there was an early and consistent commitment to assure that questions would be interpreted the same way across the globe. In order to meet this requirement, the Washington Group had to work with question evaluation experts to develop a testing method that would produce comparable testing data across countries and cultures (see Chap. 7). The methods developed can be used for all national and international data collections and represent an unplanned contribution to survey methodology in general.

Much of the work of the Washington Group has been focused on the development and testing of internationally comparable question sets that address various aspects of disability. Guidelines for how to use the question sets have also been developed as have analytic guidelines. These documents are available on the Washington Group website: http://www.cdc.gov/nchs/data/washington_group/meeting8/interpreting_disability.pdf and http://www.cdc.gov/nchs/data/washington_group/recommendations_for_disability_measurement.pdf. However, more work in this area is needed and the Washington Group will devote considerable time to analysis and dissemination activities in the future to meet the need for comparable data to monitor major international efforts.

The primary aim of the work of the Washington Group was to institutionalize the collection of high quality disability statistics as collected by National Statistical Offices. It is an added benefit that the products can be used by other governmental agencies, NGOs, international organizations and researchers.

Implementation of Washington Group Data Collection Tools

As a United Nations City Group, the primary constituencies of the Washington Group are National Statistics Offices (NSO). The Washington Group approach to data collection has been adopted by the U.N. and the UNECE Conference of European Statisticians recommendations for the 2010 and 2020 round of censuses. However, the use of the questions has expanded beyond NSOs. The questions are being used in surveys and research projects throughout the world; for example in the United States – National Health Interview Survey (NHIS); Maldives – Demographic and Health Survey (DHS); Bangladesh – Household Income and Expenditure Survey (HIES); South Africa – General Household Survey (GHS); and surveys of living conditions among people with disabilities in southern Africa (see: http://www.sintef.no/globalassets/upload/helse/levekar-og-tjenester/zambialcweb.pdf). In addition, the questions are being adopted for use in development programs. For example, US AID has announced that it will prepare a disability module for their Demographic and Health Surveys (DHS) that will include the Washington Group short set of questions.

The need for good statistical information on disability has been made more critical by the ratification of the U.N. Convention on the Rights of Persons with Disabilities (UNCRPD) which includes data and reporting requirements as well as by the process currently underway to create the post-2015 Sustainable Development Goals (Open Working Group Proposal Sustainable Development Goals, 2014; https://sustainabledevelopment.un.org/content/documents/1579SDGs%20Proposal.pdf). The data that would result from universal implementation of the Washington Group short set of questions would meet the monitoring needs for both these initiatives. There has been much discussion about how best to address the data needs of post-2015 goals. The Secretariat to the UNCRPD in the Division for Social Policy and Development, Department of Economic and Social Affairs hosted an Expert Meeting in collaboration with United Nations Educational, Scientific, and Cultural Organization (UNESCO) to address this issue. The report, 'The United Nations Expert Group Meeting on Disability Data and Statistics, Monitoring and Evaluation: The Way Forward – a Disability-Inclusive Agenda Towards 2015 and Beyond', identified a set of overarching recommendations to achieve international comparability of disability data, analysis and reporting, the first of which is to:

> Include the Washington Group short question set (six questions) in censuses and ongoing periodic surveys conducted or financed by national statistical offices, government ministries and United Nations agencies and encourage its inclusion in data collections sponsored by NGO funding agencies. In this regard, the context and scope of their application needs to be well-understood by implementers. Attaining this goal will provide a strategy for the data needed to monitor the UNCRPD and to disaggregate and monitor progress in the post-2015 development goals by disability status.

A follow-up meeting, the 'London Disability Data Conference: Leave No One Behind. Making Disability Count' was held in October 2014 was hosted by the Department for International Development in the United Kingdom (DFID) and co-chaired by UNDESA, DFID and Leonard Cheshire Disability. The London conference was held to further discuss the recommendations of the UN Expert Meeting with a wider group of stakeholders and practitioners to further common understanding and support action in order to advance the inclusion of disability data in the development agenda. A key outcome of the conference was strong support for the short set of Washington Group questions. The discussion during the conference demonstrated that the Washington Group questions can be used effectively in a broad range of contexts, from population surveys to disaggregating programme data by disability. Their strength comes from their ability to be inserted into mainstream data collection efforts, and the relative ease in with which they can be deployed.

Other recommendations from the London meeting addressed the need to develop capacity so that the question sets can be incorporated into a range of data collections. Toward this end, the Australian Department of Foreign Affairs and Trade (DFAT) is working with the Washington Group to carry out regional workshops focused on capacity building and to develop tools that will facilitate the adoption of the questions sets.

Future Activities

The early work of the Washington Group has focused on addressing the conceptual complexity of disability and developing internationally comparable questions sets that address specific aspects of disability. The material that has been developed by the Washington Group on how to implement the data collection tools and how to analyze and present the resulting data will need to be greatly expanded given the recent recommendations that the Washington Group short set be added to Censuses and ongoing surveys to assure that data will be available to monitor progress towards the goals of the UNCRPD and the post-2015 Sustainable Development Goals. These activities are key components of the Washington Group's work plan for the next several years. An increase in the number of countries using Washington Group tools and a sustained effort to analyze and disseminate the data could culminate in a data base of comparable disability statistics that can be used for monitoring the success of programs and policies in all countries.

The Washington Group short set of questions was designed to address the need for information to determine whether persons with disabilities are fully included in society. The format was selected in order to minimize the time and space needed to obtain the necessary information and great attention was made to craft and test questions that would be universally applicable and understandable. While a key first step, the short set of questions could not, and were not intended to, address the multiple aspects of disability. The extended set on functioning for adults was developed to expand the information available on functioning across multiple domains; and to include, where relevant, functioning with and without assistive devices. The question set on children was designed to address functional domains of specific relevance for children.

The question set on school participation, now under development in collaboration with UNICEF, will be the Washington Group's first major attempt to directly investigate the interaction of functional status as measured by the child functioning question set and aspects of the educational environment (including the physical environment but also attitudes of the public, parents, and teachers along with appropriate curricula and teacher skills) on school participation. The information generated will specifically and directly address the interaction of functional status and environmental characteristics in determining participation. The Washington Group hopes to develop and test question sets that will address multiple environmental effects more directly and to evaluate how the environment affects full participation across a wider range of sectors. This will be the most difficult task that the Washington Group has taken on. The short set and extended question sets address aspects of disability that are universal. Even though cultural context can affect all human endeavors, the topics covered by the short and extended sets (difficulty functioning in basic activities) are the most 'culture free'. This is not the case with respect to the environment or in more complex activities and social roles. These vary considerably across cultures; and because of that, designing comparable questions in a standard way may not be successful for this aspect of the Washington

Group's work. Due to the variability and complexity of measuring the environment and participation across countries, it may be necessary to craft questions that differ depending on context but which obtain information on the same basic concepts (employment for example) (see Chap. 13). In that way, comparisons can be made across countries in how persons with disabilities are included in the employment sector even though the characteristics of that sector vary greatly. This will be a complex task.

Workgroups have also recently been established to address mental health and its relationship to disability and the use of administrative data bases including registries as additional sources of disability data.

In addition to continuing to develop new question sets, the Washington Group will provide assistance in the implementation of the questions sets. This will involve creating implementation guidelines and supporting capacity building activities. The goal is to have a strong set of regional 'Washington Groups' that can facilitate the adoption of the questions and address region specific implementation challenges. As more countries adopt the questions, the Washington Group will be able to focus on the dissemination of the resulting information in a standard format to inform international comparisons. As early as 2003, only two years after the Washington Group began their work, the United Nations Statistical Commission emphasized the need to ensure the collection of internationally comparable statistics and approved the collection of disability statistics from member states on a regular basis through the United Nations Demographic Yearbook system. In 2005, as requested by the Statistical Commission, the Statistical Division of the United Nations initiated the compilation of national statistics provided by member states. While the lack of comparable data has hampered these effects, the wide adoption of the Washington Group standard question sets that are capable of producing comparable data will, in the future, provide the information requested by the Statistical Commission.

The Australian Department of Foreign Affairs and Trade is working closely with the UN's Washington Group on Disability Statistics to establish a new 4 year partnership that will greatly improve the availability and quality of disability data throughout the world. The partnership will support the implementation of the questions developed by the Washington Group in national statistical systems, the analysis of the data that are produced and the dissemination of the information to inform policies and programs to improve the lives of persons with disabilities and to monitor compliance with the U.N. Convention on the Rights of Persons with Disabilities and attainment of the Post 2015 Sustainable Development Goals.

Impact on Policy

The Washington Group short set of questions was designed to provide policy makers with a way to determine if policies and programs result in the full inclusion of persons with disabilities. The questions provide the data needed to classify the population according to disability status, whether as a dichotomy (yes/no) or on a continuum with larger number of response categories (no difficulty, some difficulty, a lot of difficulty, cannot do at all). The classification is based on measuring an individual's difficulty functioning in core domains for the most part without assistance.[2] Information on participation, such as education or employment, is gathered using other questions routinely asked about the same individuals as part of a census or survey. If participation levels (e.g., the percent employed) are the same across all categories of disability, the policies and programs have reached their desired goal. If they are not, additional interventions are needed at the individual, community and societal levels to achieve the goal. The extended set of questions provides information on more functional domains and the data generated can be used to develop a more complete classification of disability status. Comparisons can be made using a composite measure of disability which takes all domains of functioning into account or focusing on one or a group of related domains; for example, sensory difficulties, combining vision and hearing. The comparisons, whether based on the short set of questions or the extended set, provide a powerful documentation of whether persons with disabilities, in this case difficulties in functional domains, are afforded the same opportunities as those without these difficulties and have achieved the same levels of inclusion in society.

Achieving equalization of opportunity has been the purpose of the Washington Group measures of disability since the onset of the group. Too often and in too many countries are those identified as having disability excluded from society – with respect to education, employment or participation in social, cultural and leisure activities. A goal of the Washington Group is to use the information from the extended set and future modules focusing on participation to explore why the link between functional difficulties and participation restrictions has been broken for some but not for others. Policy and program initiatives exist that can be implemented to break this link; and the information produced by the module on school participation among children and future modules on other aspects of participation can be used to identify where interventions are needed so that appropriate policies and programs can be developed and targeted to those who need them most. If the data are collected in a consistent way over time, it will be possible to monitor and evaluate, on a population level, the impact of those policies. The approaches that will be most successful in breaking the link may be situational dependent. Questions that will capture the information needed to disentangle the interdependencies among functional difficulties, the environment and participation in a specific socio-cultural context can be added to customize the standard set of survey questions. When taken as a whole, the standard sets of disability questions along with country specific questions will provide the information needed to develop and target policies and programs to improve the lives of persons with disabilities. When this is done, the Washington Group can come to an end.

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[2] The inclusion of assistive devices was considered for two domains only, seeing and hearing, as limitations in these domains can often be overcome with the use of glasses or hearing aids.

1. Washington Group on Disability Statistics (WG) website, http://www.cdc.gov/nchs/data/washington_group/meeting8/interpreting_disability.pdf
2. Washington Group on Disability Statistics (WG) website, http://www.cdc.gov/nchs/data/washington_group/recommendations_for_disability_measurement.pdf.
3. SINTEF website, http://www.sintef.no/globalassets/upload/helse/levekar-og-tjenester/zambialcweb.pdf
4. Open Working Group Proposal Sustainable Development Goals, 2014; https://sustainabledevelopment.un.org/content/documents/1579SDGs%20Proposal.pdf.

Chapter 18
What If Here Were No Washington City Group?

Mary Chamie and Judy Heumann

When the United Nations Statistical Commission (hereafter referred to as the Commission) recognized the need to improve disability statistics in 2001, it formed a city group to complete the work. The group's name was decided by the location of its first meeting, which in this case was Washington D.C. The Commission laid out goals for the Group and asked that it report back regularly on progress in achieving them.

The Commission asked the Washington City Group to set directions for statistical data collection and analysis in the area of functioning and disability. The Commission invited a group of national statistical offices to convene and work together to achieve these goals. National statistical offices invited consultant experts, non-governmental organizations and representatives of interested scientific and community groups to join them in this effort.

Under the auspices of the Commission the Washington Group establishes programs of work, seeks funding for research development and implementation of trials and pilot testing, scientifically reviews the consequent results and eventually seeks to propose a set of useful guidelines or standards for use by national statistical offices (United Nations Statistics Division 2014a). City groups report progress to the Commission on a regular basis indicating their achievements in setting new directions (United Nations Statistics Division 2014b).

When a city group reaches a point where its members have successfully tested numerous ideas and are ready to propose new methodologies or standards of data collection and analysis, they take their proposals back to the Statistical Commission for a broader review by national statistical offices, through the United Nations system, world-wide. The Statistical Commission then decides on internationally agreed

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guidelines and recommendations for data collection and analysis. Once the recommendations are decided they are usually published in the six official languages of the United Nations and sometimes are published by many national statistical offices in additional languages. The Washington Group integrated disability statistics into this process and these official guidelines and recommendations are now successfully incorporated into United Nations *Principles and Recommendations for Population and Housing Censuses* (United Nations 2008).

Ultimately, a city group's success is reflected by the fact that its activities are taken over by regular official statistics mechanisms under the coordination of the Commission. After guidelines and standards are agreed upon, national statistical offices then take up the work of implementing the newly agreed standards and methods, using agreed international coordination mechanisms provided by the Statistical Commission for further monitoring of the results over time. The Statistical Commission reviews this work on a regular basis and considers the need for coordination of the statistics being collected and disseminated at the national level, for its standardized and harmonized use at the regional and international level.

Why Did the Statistical Commission Request That Standards Be Set for the Topic of Disability?

The collection of disability data by national statistical offices is not a new practice. For at least one hundred years, since the mid 1800s, national statistical offices counted people with disabilities in censuses and surveys and the data were then tabulated and often, unfortunately, shelved (United Nations 1986).

In many respects, the shelved disability statistics reflected how people with disabilities were treated. The way in which data were collected and shelved appropriately reflected the lower status of persons with disabilities and the lack of their inclusion in national policy and program debates. Although there was sufficient pressure from war veterans, concerned and often prominent families of persons with disabilities, and others that sought improved services and requested that disability questions be included in population censuses and surveys, there was often a serious lack of follow-through that presented the disability results at the data analysis and report-writing stage. Survey researchers were not trained in the field of disability, nor were economists, labor statisticians, demographers and others who were most likely to prepare the reports. By the time the reports were prepared, the data on disability was forgotten.

Survey questions that asked about disability were often included without proper vetting and testing. Surveys that asked questions about persons with disabilities often asked questions to a third person and made reference to types of disability that were harsh and often offensive, referring to people as crippled, dumb, mute, beggars and the like (United Nations 1986).

Resultant disability data collected in these censuses and national surveys were either not published at all, or were published in one general statistical table in the back of a huge book of statistical tables. Disability data were often not tabulated into even the most basic tables or classified by age and sex. Consequently, the data were ignored in major national policy reports and were not referred to in the major statistical descriptions used for policy and planning purposes. Instead, the underutilized data were stashed in bureau files or in some cases never even tabulated (United Nations 1986).

At the time these data were collected, there were no internationally agreed guidelines or standards for disability data collection. When governments tried to compare their national disability data sets, the data were not sufficiently comparable. There were significant differences in definitions, concepts and methods of data collection, as well as no agreed sets of tabulations for reporting purposes (United Nations 1990).

Frustrated with the lack of comparable data, some researchers worked to produce comparable data sets based on disease rates, rather than through direct measurement of disability (Murray and Lopez 1996). It was not a new idea to use disease to assume disability. Programs had done this for decades, often with sad results. The diagnosis of a disease or condition, such as cerebral palsy or Down's Syndrome, or spinal bifida, for example, was used even in the 1960s and 1970s and into the 1980s as a reason to place even small infants in institutions, permanently, and to assume that people having a specific medical diagnoses could never participate in normal family or community life. The process of institutionalizing and exclusion was done based on the medical diagnosis rather than through seeking valid and reliable observation of a person's potential for functioning, activity and community participation, or rehabilitation (Chamie 1995, 2011; Groce et al. 1999; Mont and Loeb 2008).

The idea of producing disability data by making assumptions about the likely rates of disability associated with a specific disease simply continued this old way of thinking. The results, although smooth and comparable, were not necessarily valid measures. Broad-based concerns emerged among teams of disability researchers about the validity of disability data being produced using these disease assumptions. These comparable, but not necessarily valid estimates of disability were not even expected to be valid disability estimates by the researchers who produced them. They were instead parts of a larger model used to estimate the burden of disease through a weighting procedure and were erroneously being thought of as disability rates (Grosse et al. 2009).

Frustrated with the limitations of their data sets, governments continued to seek a more satisfactory way to produce disability statistics that could improve the comparability, validity and reliability of the results and improve their usefulness for policy formulation and program planning. They also saw the need for identifying persons with disabilities in such a way that they could be more readily compared with other subpopulations for levels of employment, poverty, economic activity, educational attainment, marital status, household characteristics and the like.

Meanwhile, progress was occurring in the World Health Organization on the development of internationally agreed disability classifications, especially with respect to improved definitions and concepts. Also, the knowledge base of the newly emerging rehabilitation field was significantly growing and at the same time, communities were paying greater attention to disability civil rights. Since the 1950s, concepts and definitions of disability significantly shifted and are now focused more upon the functional levels of people based upon improved knowledge of the interaction between personal characteristics and the characteristics of environments (World Health Organization 2001). Greater attention is being paid to the human rights of persons with disabilities, and to civil rights protecting their participation in activities of everyday life, without exclusion from the community. This trend toward increased participation is expected to continue into the future.

Since the beginning of the new millennium and officially starting in 2001, international agreement was reached by the World Health organization on the definitions, concepts and classification of human functioning and disability (ICF). Human functioning became front and center to the description of disability concerns. New terminology emerged describing differences of functioning across varied population groups, according to variation in micro-environments and according to a range of personal characteristics such as age, sex, and also according to personal experience with specific impairments as well as through experiences with specific disease patterns or accidents or injuries. These experiences result in populations that report differing rates of difficulty seeing, hearing, moving about or coping with stress, and so forth. These rates potentially vary over time.

Disability is now increasingly viewed as a population characteristic, a result of interactions of people with socioeconomic conditions and culture and not solely as a personal and permanent attribute caused by a single disease or injury. Human functioning is studied according to important socioeconomic and demographic conditions such as age, sex, residence, as well as through personal experience with war and trauma and according to shifts in socioeconomic and structural conditions such as availability of public transport and according to widths of doors, among other things. The challenge for statistical offices to address all these new concerns is enormous.

Shifts in knowledge, attitude, and practices regarding definitions, concepts and classifications of functioning and disability have far reaching consequences, socially and economically and politically. In order to be useful, statistical methodology and statistics must keep up with these sweeping changes. Hence, the Washington City Group was formed by the Statistical Commission to tackle these challenging issues.

It is not only disability that has experienced such major shifts in definitions, concepts as well as knowledge, attitudes and practices. Over the last 100 years, significant shifts took place in definitions of seemingly simple concepts such as marriage, family, race, poverty and gender. Even such straightforward and widely used concepts as rural and urban or definitions of rich, middle-class and poor, have changed over time and across geographic areas. These shifts in definitions and concepts must be accurately reflected in statistical measurement if official statistics are to assess the actual conditions and concerns of people and be useful for policy and planning purposes.

What Are Some of the Key Issues That Drew the Commission to Be Concerned with the Need for Improved Disability Statistics?

In its review, the Commission noted that for many people with disabilities, that they were being identified then isolated, institutionalized or hidden from public places or abandoned thus making statistics of such "rare events" difficult (United Nations 1986). More recently, as attitudes, opinions and scientific knowledge about disability changed, levels of participation of persons with disabilities in public life have also changed, no longer keeping the experience of disability as a rare and isolated event. In order to find persons with disabilities, one needs to look not only in institutions with locked doors, but also in households and in school systems and places of work. Such shifts in thinking must be reflected in survey research measurement and in the definitions of the universe in which people with disabilities will be found and environments in which they participate.

Some of these changes came about through activism, some through improved scientific activity, and some from shifts in philosophy, knowledge and practice. The major contributing factors are briefly summarized below.

1. "***Nothing about us without us***" – refers to the cry of the disability movement; Controversial and radical shifts in the civil status and right of participation of persons with disabilities in the mainstream, ultimately led to major changes in their civil rights and participation levels of persons with disabilities at home, at school and at work. This also resulted in new ways of approaching survey reporting about disability. In the past, people were not directly asked about disability, but their disability was reported by others, and the terms used to describe them were likely to be disparaging. Under the new international agreements, surveys now seek to assess disability through direct reporting mechanisms, asking each person about their functioning, activity and participation at home, at school, and at work. Rates and levels of functioning and disability are shared characteristics of all people.
2. "***By that I mean***" – refers to the many revisions taking place to disability definitions and concepts brought about by improved knowledge, attitudes and practice. This was most notably seen through the transition that took place in the use by surveys of classifications of disease through the International Classification of Diseases (World Health Organization 1992), to early trial disability classifications (World Health Organization 1980) and ultimately to an internationally agreed classification of functioning (ICF) for assessment of disability (World Health Organization 2001). Similar to the controversies that took place concerning changes in definitions and classifications of race, gender and sexual orientation, family and marriage, employment and poverty, statistical offices now confront the need for improved descriptions of human functioning and disability. Improved survey questions are needed for reporting of difficulties in completing

socially required tasks such as seeing, hearing, reading, computing, and moving about, or participating in key activities at home, school or at work.

3. ***For whom the bell tolls*** – refers to shifting characteristics of whole populations owing to large demographic and socioeconomic shifts brought about through reduced fertility and mortality rates and increased longevity that has resulted in entire populations aging and calls for subsequent revisions to pension planning, official retirement ages, social security programs and greater concern to the broader issue of public sector planning of populations and how they function (mobility, activity, employment). Statistics must now consider disability attributes of an entire population using general statistical tabulations rather than viewing disability characteristics solely as personal attributes to be reported on an individual basis or as a simple head count or listing of disabled persons primarily for the identification of persons requiring special services in institutions or for the serving of homeless populations and street beggars. This shift in approach is reflected in John Donne's famous quote that states, "because I am involved in mankind, and therefore never send to know for whom the bells tolls; it tolls for thee." In other words, disability is a concern of all of us.

How Did the Washington Group Approach the Setting of Standards and Methods Under These Difficult and Challenging Conditions?

Disability is but one area of work with such challenges. Definitions and standards that are set for development of statistics on employment, family, poverty, national identity, ethnicity and race and disability, among others, are also subject to change over time. Nations do not, for example, define race or poverty the same way today as they did 100 or even 50 years ago. National definitions of poverty vary, for example, even today.

Working committees are formed to stay on top of the differences and to accurately reflect them in national statistics through proper description and footnoting, while remaining comparable, valid and reliable, to the extent possible. It is often a challenging and most interesting aspect of official statistics that the offices must remain adaptable and sensitive to local conditions while remaining as comparable as possible at higher levels. Like measures of poverty or race, measurement of disability succeeds when it reflects the current state of affairs accurately, both in the present and to the extent possible, over time.

This is an enormous challenge for statisticians. Will the Washington City Group succeed in setting international standards for data collection and analysis of disability under these constantly shifting conditions and at times controversial situations?

Official statistics do try to reflect reality. It is worth noting that the way in which the Washington City Group conducts its work, is itself, an indication of how the field of disability is faring. When statistical definitions are difficult, if questions don't quite hit the mark, it is probably because programs and planners and communities and families still struggle with ways to describe disability in a way that is useful for policy and planning purposes through the reporting of actual personal experience with disability.

If the arguments and debates on the floor of the Washington City Group are a bit confused owing to contradictory proposals from government officials, statisticians and other scientists, representatives of non-governmental organizations and representatives of organizations of persons with disabilities, then it is probably because the relationships across these groups is still a little confused as well, regarding the matter of disability.

Why Should the Disability Debate Be Required to Be Any Different than Other Debates of Social Issues Such as Those of Poverty, Race, Unemployment, Socioeconomic Status and the Like?

They are by their very nature, social concerns, subject to shifts in attitudes, knowledge and practices over time. It is both the challenge and the privilege to try to stay on top of these events and to provide valid and reliable data for their policy and program assessment.

The Washington Group inevitably must struggle with the following issues:

1. contradictions in terminology;
2. changing definitions and concepts;
3. the need to test survey questions for their ability to validly reflect newly agreed definitions and concepts in a way that populations can understand and report on, while still maintaining an ability to measure change across time;
4. the need for ways to collect relevant and accurate statistics for policy review and planning purpose while correctly incorporating newly acquired scientific knowledge and applications;
5. the need to prepare comparable disability statistics across age groups, according to sex, region, status in the household, community, according to national identity, and across time, using agreed statistical tabulations.

To address these important concerns, the Washington Group has addressed terminology problems; coordinated statistical definitions and concepts and integrated them with internationally agreed standards and classifications, conducted pilot tests of survey questions, world-wide, included a wide group of persons with disabilities into their working committees, analyzed the data and identified the policy relevance of the results. Last but certainly not least, the Washington Group conducted its work while staying open to the relevant shifts that occur in social concerns over time, a requirement of all official statistics prepared for socioeconomic policy and planning purposes.

How Is the Washington Group Doing?

The Washington City Group is by definition destined to cease to exist when its work is successfully completed. Yet, it cannot set its work in stone because the study of disability, like our economies, continues to change and evolve. Similar to definitions of employment, marriage, families, ethnicity and race and the like, disability changes over time and according to types of interventions and interactions that occur. One can view statistical work in this area as a cross-cutting photograph of a particular time, or one may also consider its potential for comparisons longitudinally, over time. In either view, it is a constantly shifting and changing phenomenon.

The Washington Group is in a position to propose standards and guidelines for monitoring these major shifts in functioning and disability. It succeeds when it carries its proposals back to the United Nations Statistical Commission for review and implementation.

New understandings of the disability field will emerge as people acquire increased opportunities for integration and participation. As this happens, further adaptation of knowledge, attitudes and practices will occur in daily life, in policy formulation, in program planning and in data collection and analysis. When discussions of definitions are again difficult, if questions don't quite hit the mark, it is probably because we are all still struggling with ways to describe disability that are useful for policy and planning purposes and accurately reflect personal experiences with disability. If the arguments and debates on the floor are a bit messy owing to contradictory proposals from government officials, statisticians and other scientists, representatives of non-governmental organizations and representatives of organizations of persons with disabilities, then it is probably because the relationships across these groups remain a little messy also. Success is defined by incorporating these major shifts into the scientific study of disability through the use of official statistics using ongoing and internationally agreed mechanisms.

The Washington City Group Is Progressing in Achieving Its Goals Because It has;

1. addressed contradictions in terminology;
2. acknowledged and incorporated shifts in definitions and concepts;
3. tested survey questions for their validity and reliability and for their ability to accurately reflect current definitions and concepts;
4. focused on relevant concerns of policy and planning and of persons with disabilities and their families;
5. participated in the first set of internationally agreed guidelines and recommendations for implementation of disability statistics into population and housing censuses and related surveys;
6. included representatives of persons with disability and their families and communities in the project; and
7. recognized how survey measurement changed over time, a necessary requirement of all official statistics prepared for socioeconomic policy and planning purposes.

The work of the Washington City Group now needs the force of international review and agreement to move it forward as part of the official work program of the United Nations Statistical Commission and related international agencies and organizations regarding population and housing censuses and household surveys. The next opportunity to do so is through participation of the Washington Group in the United Nations collection and review of the disability results of the 2010 round of Population and Housing Censuses and Surveys and in the planning of the upcoming 2020 round.

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