DISABLING DOMESTICITY

EDITED BY
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Editor

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For Carlos

FOREWORD

It is a distinct pleasure to write this foreword to *Disabling Domesticity*. As anthropologists researching kinship, family, and disability, we are delighted to welcome such a groundbreaking volume. This book deploys the insights of disability studies to examine how domestic life in North America is "cripped" by the experiences of living life with a difference. We also write as parents of children with disabilities; our households have been shaped by their needs, along with those of increasingly frail elderly family members whose bodies and minds are declining. We thus read this book with the double vision that our own caregiving and scholarship provide; these identities deepen our appreciation for the attention each author brings to what it means to disable domesticity.

This wide-ranging collection offers exciting contributions by a vigorous group of outstanding "hybridized intersectional" writers, as the editor notes. They are historians of social life and its material culture, sociologists, as well as scholars of literature, architecture and design, gender studies, American studies, science studies, health sciences, and (of course) disability studies. All have important interventions to make in using disability perspectives to critically rethink home, care, and family, the three sections into which the chapters in this book are divided. The work of these authors underscores the originality and importance of the editorial vision that the distinguished historian/disability studies scholar Michael Rembis brings to this book. As his introduction highlights, domesticity as a potentially productive topic has been relatively neglected in disability studies until recently. This is largely because the field of disability studies came of age in the 1980s through the work of activists and scholars (often with overlapping identities) who were

> …focused on moving themselves, as well as other disabled people, out of their homes (or other institutionalized settings) into the wider world of work, school, and various forms of public accommodation and recreation… family and home became sites of ableist oppression that had to be avoided or actively dismantled. (Rembis, 2016, Introduction, p. 7)

This necessary concern with advancing "civil disabilities" (Hirschmann and Linker, 2015) has been and continues to be crucial to ongoing struggles for political, social, and cultural inclusion. Indeed, "for many disabled people, the home and other domestic spaces remain dreaded sites of oppression" (Rembis 2016, p. 7). Nonetheless, *Disabling Domesticity* makes clear that the time has come to rethink the complexity of western domestic life as a crucial realm for those with disabilities and their allies, providing "critically important spaces within which they not only empower themselves, but also form meaningful, life sustaining, and often transformative relationships" (ibid., p. 7) In short, the analyses offered here are long overdue and promise to launch a much-needed consequential wave of scholarship.

In examining the normative underpinnings of home, care, and family, the authors in this book also offer alternative inclusive perspectives that speak to the idea of "accessible futures," a utopian-political term introduced by disability scholar Alison Kafer (2013). Their chapters do the rigorous and creative work of using a disability framework to critique our social order, suggesting how it might be otherwise. Collectively, the chapters destabilize domesticity as a taken-for-granted foundation of social life, interrogate independence as an ideological construct, underscoring the lively interdependence necessary to sustain lives of dignity and possibility for people with disabilities and their caregivers throughout the life course. Too often, the authors remind us, networks of domestic support and caregiving that might make accessible futures possible have remained invisible, unexamined, and undercompensated. Moreover, oppressive domestic arrangements are sustained by entrenched hierarchies: gendered and racialized labor, heteronormativity, the inequalities of class, and (in the Global North) extreme bureaucratization of education, health care, and other social services.

The book's project resonates deeply with our own research on how American families incorporate disability across the life course. The stresses on households can be considerable when faced with the distinctive needs of the sometimes-unrelenting quotidian work involved in managing life with disability. These include the struggle to obtain truly accessible housing and services, the often-futile search for sites of cultural and social inclusion, and the daily grind of managing transportation, education, and medical appointments. These seemingly mundane if overwhelming activities are fundamental to stabilizing home, care, and family for people with disabilities and their supporters; they are also crucial to the project of embracing humanity in all its diversity. Our subjects address this persistent juggling act by reconfiguring kinship relations, sometimes beyond "flesh and blood," creating supportive relationships wherever they can be established. Their "new kinship imaginaries" chart an emergent terrain that encompasses a broader range of experience than is usually acknowledged in mainstream culture. This is often accomplished against the grain of hegemonic normalizing discourse that has for so long diminished and stigmatized people with disabilities and their allies as full participants in social life. Our observations and interviews are filled with frequent paradigm shifts that occurred as "disabled families" realized their experiences did not map easily onto pre-existing models of domestic life. In nearly every encounter, our respondents offered narratives about how they were reimagining everything—from rebuilding domestic space, to revising household budgets, to reconsidering school and work, to reimagining models of humanity—in ways that helped them take into account life with a difference.

In circumstances that do not conform to the temporalities and expectations of normative kinship, families often feel pressure to reinvent themselves, reframing conventional rhythms of daily life, what disability scholars and activists often call "crip time." This includes accommodating alterations in the life cycle. Ritual transitions marking typical life cycle events, for example, can serve as harsh reminders of the different temporalities that often accompany disability. Ceremonies such as family or school reunions, graduations, and weddings can be fraught and inadvertently exclusionary. While some families initially experience "crip time" as a problem unique to their own household, eventually, encounters with others like them—for example in schools or religious settings—contribute to the expansion of a new kinship imaginary into wider public recognition.

Like many of the book's authors, we have seen time and again how an embrace of a family member with a disability reverberates into both daily life and the claim on future possibilities, pushing against the pervasive symbolic and actual violence produced by the taken-for-granted ableism that persists despite legislative victories. Notably, children with all types of disabilities experience maltreatment at greater rates than their non-disabled counterparts, in particular those with emotional or behavioral disorders and/or intellectual or developmental disabilities and those who are in special education (Lightfoot, Hill, and LaLiberte, 2011). Moreover, the costs of care for those whose situation requires ongoing paid assistance—from the Neonatal Intensive Care Unit (NICU) to the nursing home—mean that families are called to shoulder these additional expenses, and/or the complex bureaucratic work, as well as the advocacy required, to secure (always inadequate) government aid for their foreseeable future. As parents face their own debility and mortality through illness, accident, or aging, they may experience a crisis as they reach the limits of their capacity to support their adult children with significant disabilities. When familial caregiving arrangements that have been stable for decades begin to collapse, desperate parents may turn to extended family members, friends, religious institutions, and social service supports in search of alternative solutions. Abandonment is the dark shadow haunting all of this.

The lives of parents with disabilities are particularly complex. As many as 6.1 million children have disabled parents in the USA; these parents are at substantial risk for losing custody of their children, with removal rates as high as 80 percent for parents with psychiatric or intellectual disabilities, often violating the intent of the Americans with Disabilities Act (ADA) (National Council on Disability 2012). In addition to the legal issues at stake, parents with disabilities are continually challenged by the stigma that historically has eroded the recognition of their parental capacity.

The diverse chapters in this volume illuminate such troubling, if under-recognized, circumstances—along with many others—from a variety of perspectives, expanding the range of experiences that disability studies needs to consider. Read together, these chapters show the often-unrecognized oppression that has too long shaped the most intimate aspects of disability worlds, serving as both cautionary tales and catalysts. As such, *Disabling Domesticity* provides welcome and innovative scholarship, contributing to a much-needed social fund of knowledge on which resistance and social transformations are sometimes built. From domestic architecture to the family dining table and many more locales, the chapters you are about to read reveal how inclusive practices that productively disable home, care, and family are foundational to building both the field and more accessible futures.

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Faye Ginsburg
Rayna Rapp

Acknowledgments

I have to begin by thanking my authors. This book emerged out of my own ruminations, lived experiences, and activist work, but it was the authors who worked to produce the vibrantly articulated chapters contained in this volume. I hoped that *Disabling Domesticity* would make an important intervention into disability studies and its constituent disciplines, and that this was an emerging area of interest for numerous scholars, activists, and community members. Yet when I sent out the call for chapter proposals, I was uncertain about what I might receive. I was thrilled and bolstered by the excitement and passionate dedication that I saw coming from a wide range of scholars whose interests drew them to this project.

The decisions were difficult, but in the end 16 authors from 12 different academic and professional backgrounds joined with me to produce the 13 chapters contained within *Disabling Domesticity*. Their commitment to the project never waned, even under the pressure of meeting deadlines. They remained open and receptive to my decisions and challenged me to think in new ways. This book was truly a collaborative project from beginning to end. Imagine my joy when Rayna Rapp and Faye Ginsburg, two stalwart pioneers in this area whose beautifully written prose and elegant arguments have been incredibly influential in my own thinking, teaching, and writing, agreed to join the project by writing a foreword to the book! I will be forever grateful. Working within such a wonderful group made this project possible. In the end, any errors, omissions, or oversights are wholly my own.

I also thank my friends, colleagues, and students in Buffalo and abroad. Susan Cahn and David Herzberg have been a miracle in my life. I cherish their friendship and the time we spend together talking about our work. They are always willing to read and to meet, despite their busy lives. I only hope that I have returned the support. David Gerber has been a valued friend and mentor for a number of years. Always accessible, his commitment to the UB Center for Disability Studies and to disability studies and disability history has had immeasurable effects, not only in my own life but in the field and at the university. I am lucky to count David and Carolyn Korsmeyer as friends. In addition, Jim Bono's unwavering support of my work and of disability studies has been a tremendous source of confidence. His tireless efforts to bridge the gaps between the humanities and the health sciences (both intellectually and institutionally) have brought a much-welcomed maturity to my own writing. I will always owe a huge debt of gratitude to Susan Burch, Cathy Kudlick, and Kim Nielsen. I also thank my graduate students, especially the Disability, Health, and Medicine graduate student writing group. Reading their work and having conversations with them keeps my mind fresh and engaged with the most recent scholarship. Finally, I thank the team at Palgrave, who remained enthusiastic about this project from the very beginning, despite a couple of deadline extensions.

This book was born out of my own experiences with kinship, family, and friends. It is to them that I am most deeply indebted. They quite literally are the reason I am alive. They are spread all over the world now, and some of them have left this earth. Social media has helped us maintain bonds forged in rehab centers, on college campuses, and on quad rugby courts; and there is always the telephone and the prized visit in person. I also now have a new community of friends and allies in Buffalo, from whom I learn so much and who offer much-needed support in my life. My mother, who has always watched over me, and my father, who supported our family in every conceivable way, are always in my thoughts. I can only imagine the conversations I would have had with my father while working on this book, and his muted sense of joy as he opened his complimentary copy when it arrived on the doorstep of our family home. I think of him every day. I also owe much to Amon-ni, Stephanie, Adenis, Stacey, and the many other folks who sustain me in more ways than they might ever know. For that I will always be thankful. And then of course, there are Carlos, Brie, Jordan, and Brodie—my love, my life. I owe them everything.

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CHAPTER 1

Introduction

Michael Rembis

When Terrin Ritcey, a young Nova Scotia woman with developmental disabilities, turned 19, her mother placed her on a housing wait list. Rather than wait for an unresponsive governmental system that had placed a moratorium on "small options homes" in the 1990s, Terrin's mom and three other families pooled their resources and began searching for a home for their family members. They sought to develop their own care program for their children. After much resistance from governmental officials in Halifax, Terrin's mom successfully placed her in a home where she lives with two roommates, David and Michelle. Another family was not so successful. The mother, Nancy Walker, is upset, "furious at a system" that forced her to make the wrenching decision to send her then 19-year-old son James from his family home to live in the Quest Regional Rehabilitation Centre outside Halifax, where, she says, he was "deprived of a home-like environment, of the basic freedoms in life and of the opportunity to grow."[1] The Walker family is not alone in its feelings of loss and sadness. In the United States, Child Protective Services and "the cops" showed up two hours after Sara's daughter Naomi was born. They coerced Sara, who has developmental disabilities, into signing a "relinquishment agree-

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ment" that forfeited her parental rights and provided her with a chance of seeing her daughter for two hours each year. "Someone" had "reported" Sara while she was pregnant. Child welfare officials issued Sara a "Reality Baby," which is a computerized doll with an internal monitor, to see if she could care for an infant. Sara had failed the test. "She [Naomi] is excited when she is with me," Sara said. "And it breaks my heart every day when I think about her. …She is my life and I miss her so much and I just would like her home and today was the last visit. And it broke my heart."[2]

Stories similar to these, those of families living with disabilities, are quite common. People living in the United States and Canada see almost daily, in newspapers and on television and social media, stories of nursing home scandals, disabled people losing their home health benefits and their right to parent, dwindling government supports to maintain "community living" for people with disabilities, elder abuse, the exploitation of disabled workers in "sheltered workshops," and more. Yet we have no sustained scholarly critique of these multiple domestic sites of disability oppression and resistance. Scholars in various fields within the humanities and social sciences have drawn attention to disability as an innovative category of analysis. They have used disability and the experiences of disabled people to critique sex and gender relations, modern notions of productivity, current and historical educational standards and pedagogies, and commonly held notions of illness, health, debility, and deformity. Yet disability studies' potential to fundamentally rethink Western Global North notions of domesticity and domestic labor has not yet been realized. *Disabling Domesticity* begins this crucial project by offering 13 chapters that focus on the daily negotiations and lived experiences of people with disabilities and their various kinship and care networks.

While the need for a more global study is evident, this book begins what should become a sustained analysis of domesticity and domestic life by focusing specifically on the United States and Canada.[3] Based on early twenty-first-century legal definitions and the 2010 Census, there are approximately 56.7 million people living with disabilities in the United States, about 19 % of the population. In Canada in 2012, 3.8 million adults, about 13.7 % of the adult population, reported being limited in their daily activities because of a disability. According to a report published in 2011, approximately one in seven or 14.3 % of all Canadians (4.4 million people) are living with various degrees of disability.[4] Analyses based on the US Census Bureau's 2013 American Community Survey estimate that among the "civilian noninstitutionalized population," there are about 2.9 million children under the age of 18, 19.4 million adults aged 18–64, and 14.8 million adults aged 65 and over living with various degrees of disability; presumably these 37.1 million "noninstitutionalized" Americans are living in a broad range of community and family settings.[5] The remaining 19.6 million "institutionalized" disabled Americans, overwhelmingly people of color and the elderly, also have families and homes. Population surveys in Canada and the United States have shown that 60–80 % of people with disabilities generally have their needs for assistance with everyday activities met through various means of support. Most support networks are informal and consist primarily of family and friends. Disabled people themselves also perform significant amounts of care work, as parents, family members, and friends—this is true historically, and it remains the case in the twenty-first century.[6] Analyses from the American Community Survey estimate that there are 6.6 million children under the age 18 being raised by a disabled parent—nearly 10 % of all children in the United States.[7] One survey of non-elderly adults living with disabilities in the United States found that 70 % relied on family and friends for assistance with daily activities, while only 8 % used home-health aides and personal assistants.[8] The US Department of Health and Human Services Administration for Community Living estimates that there are 4 million Americans living with intellectual and developmental disabilities, that 60 % of those receiving services live with their families, and that their families are their "primary support system."[9] People with disabilities and their families comprise a significant portion of the social and communal networks in the United States and Canada.

Even in the nineteenth and early twentieth centuries, when institutions dominated North America, people with disabilities lived at home or in the community.[10] Historians generally agree that from colonial times until about the 1850s, people with different disabilities lived with family or were forced by community members to remain at large. They managed as well as they could, moving from place to place, working and contributing to the family and the local economy. They received various forms of support when they needed them.[11] Specialized institutions promising "cure" through education and "moral treatment" began to emerge and expand during the 1830s and 1840s.[12] Increasing state control and the increasing institutionalization of people with disabilities marked the period from the 1850s to the 1950s. Tremendous increases in institutionalized populations had their roots in the medicalization and pathologization of human difference, rising immigration and other demographic shifts such as rural to urban migration, and the maturation of a burgeoning industrial economy, which made it more difficult for people with disabilities to remain "productive" members of their families and the community.[13] By the early decades of the twentieth century, most institutions had become large human warehouses, grossly underfunded and understaffed, dirty, wretched, and generally deplorable places. Reformers, government officials, parents and other family members, and disabled people themselves, spent the second half of the twentieth century working to close them and move disabled people into the community.[14] Throughout this history, it was not uncommon for a person to spend their entire life in an institution.[15] There were, however, many disabled people who entered the institution sporadically when they needed it or were forced into it—and who lived most of their lives in the community. Disabled people living with their families or on their own contributed to local and familial networks of support and care, to local economies, and to larger economic networks. They also relied on family, friends, community members, and the state for support.[16] These domestic relations form the core of the analysis in *Disabling Domesticity*.

Nine-year-old Jane, or Janie, as her mother liked to call her, is an example of someone who remained at home. Janie became the subject of a feature article written by her mother, Violet Ebb Lundquist, and published in *Bound*—"Iowa's Own Magazine"—in 1958. The article, "I'm Glad We Kept Janie at Home," begins with the declaration that Janie's "crudely-cut" Christmas gift for her parents—a calendar—strengthened "our conviction that we had chosen the right course for our family in spite of advice from specialists to the contrary." Janie was "a mongoloid, a mentally retarded child." Yet her parents, contrary to both popular and expert opinion, chose to rear her at home.[17] They were not alone. Although the rate of admission to public institutions for intellectually and developmentally disabled children under six years of age doubled, and children under six went from 9 to 19 % of all new admissions to institutions between 1945 and 1955, there were signs that institutionalization was no longer tolerable for many families. A 1950 survey found 88 local parents groups—most of which had been formed between 1946 and 1950—with 19,300 members in 19 states advocating community living. Also in 1950, local groups came together and formed the National Association for Retarded Children (NARC). By 1960, the NARC had 681 local affiliates and a membership of 62,000 people (at that time mostly parents) dedicated to finding alternative forms of care and education for their children.[18] Although she would not characterize herself that way, Janie's mother was one of those activist parents who would help hasten deinstitutionalization and promote the public education of intellectually and developmentally disabled children.[19]

A groundswell of activism beginning in the late 1960s and 1970s in the United States and Canada catalyzed deinstitutionalization. United Nations declarations and conventions, and a legislative sea change at home in turn led to increasing numbers of people with disabilities living on their own, with their families, or in other residential settings in the community.[20] By the last third of the twentieth century, people with disabilities began to coalesce around specific issues primarily related to education, employment, housing, and transportation. Tactics differed and movement participants never completely agreed on philosophies, but generally, activists within the parents movement, the mad peoples movement, and the disability rights/independent living movement utilized a "rights-based" approach and a then-nascent "social model of disability" to make claims on the state for increased access and equality within society.[21] The results were startling. Precise numbers are difficult to locate, but most scholars agree that the institutionalized population in the United States declined from a peak of over 550,000 in the mid-1950s to fewer than 40,000 by 2014. In Canada, various institutions housing people with developmental disabilities and what were considered "mental-health problems" began to deinstitutionalize in the mid-1960s. Canada's institutionalized population declined rather swiftly, from a peak of about 70,000 in the mid-1960s to approximately 20,000 by the early 1980s, when the national government began officially to promote deinstitutionalization.[22] Thereafter, the institutionalized population declined even further to only 3873 by 2006.[23] All large institutions in Ontario and Newfoundland were closed by 2009. In 2015, the Canadian Association for Community Living reported that since 1986, 90 % of Canada's large institutions had been closed.

Deinstitutionalization did not occur without problems. In fact, scholars in a number of disciplines argue that deinstitutionalization has been plagued with problems from the very beginning. A lack of adequate resources in the community and a general devaluing of disabled body/minds and lives meant that many deinstitutionalized people, especially people of color living in the United States, became homeless and ultimately found themselves incarcerated in the nation's jails and prisons.[24]

Moreover, many of the residential settings into which disabled people moved, such as group homes, nursing homes, and other assisted living facilities remained problematically institutional in their outlook and management, as well as their built environment. Finally, many disabled folks who depended on attendant care or other home health-related services were forced to invite the state and waged workers into their homes, creating an environment that was at once public and private, often in complex and occasionally damaging ways. *Disabling Domesticity* analyzes these dynamic sites of human interaction to provide readers with new ways of envisioning home, care, and family.

This book disables domesticity in at least two ways. First, it works actively to create a politicized theoretical space from which a disabling critique of dominant heteronormative ableist constructions and material manifestations of domestic life can be articulated.[25] Feminist, crip/queer, and critical race theory as well as a materialist disability studies analysis inform the work collected in these pages. Eschewing totalizing dismodernist notions of disability, the authors gathered here instead utilize a complexly embodied understanding of disability firmly grounded in its material realities and the dominant socioeconomic structures that pervade disabled people's lives.[26] Unlike David Mitchell's "nonnormative positivisms," which he (with Sharon Snyder) describes as a "non-dialectical materialist account of disability," that sees it as a "fleshy," "messy," "critical third rail," and as "something other than the oppressed product of social constraints," the theoretical framework created by the chapters collected in this volume recognizes that the subversive potential of disability and disabled experiences must always be measured dialectically in relation to their own shifting materiality and to the social structures and societal forces that shape them.[27] While the desire to move beyond what Mitchell calls the "two zones of negativity" that have dominated thinking in disability studies since its "founding moments in the 1970s"—namely that disability subjectivities are merely "characterized by socially imposed restrictions" (the social model of disability) or that disability imposes real embodied limitations (impairment effects)—is critical, we need not abandon a dialectical approach in favor of a new disability positivism to extricate ourselves from this philosophical quandary.[28] That the world's majority disabled population suffers daily abuses and oversights, lives in abject poverty, and lacks even the most basic necessities for human survival speaks to the need for a complexly embodied historical materialist analysis of disability.

Having established a hybridized intersectional theoretical base, this book disables domesticity by placing the lived experiences of people with disabilities and other representational accounts of disabled lives at the center of the analysis. Following Rayna Rapp and Faye Ginsburg's call to rewrite kinship and reimagine citizenship, *Disabling Domesticity* critically engages with popular notions and experiences of the built environment, home life, family, sex, sexuality, and care in the United States and Canada to begin to unravel and peel back the many (in most cases sedimented) layers of both ideological and physical matter that work together to produce the lived reality of the people that appear in (and haunt) these pages.[29] Rapp and Ginsburg argue that such a rewriting will enable "a more expansive sense of kinship across embodied difference that, [they] argue, is essential to the growing public presence of disability in contemporary postindustrial democracies."[30] For Rapp and Ginsberg, and the authors gathered in this book, kinship can extend well beyond the immediate nuclear family and the highly permeable walls and doors of our homes. The introduction of disability into a family, through birth, accident, or aging, represents an "occasion for meaning-making" that can last a lifetime and is often mediated through various technologies and public discourses, resulting in some cases in a "mediated kinship" among disabled people and disabled families who share no blood relations but find value and shared connection in similar lived experiences.[31] The "public storytelling" of these "disability narratives" is crucial to building a "social fund of knowledge about disability" that Rapp and Ginsburg argue is "foundational to the integration of disability into everyday life."[32] *Disabling Domesticity* builds on this foundational insight by pushing readers to think beyond integration, to recognize that weaving crip/queer, nonnormative disabled body/minds and lived experiences into the social fabric alters its texture permanently. These incremental changes accumulate and calcify and become codified in law and public policy, and over the course of years or decades produce significant and meaningful, though not always unproblematic, changes in our daily lives. The personal and the private are indeed political.[33]

Domesticity and domestic relations are central to all our lives. Yet disability studies scholars have been reluctant to engage with "domesticity" either as an organizing concept or as lived experience. For 40 years or more, activists and academics—which by no means are mutually exclusive identities—have focused on moving themselves, as well as other disabled people, out of their homes (or other institutionalized settings) into the wider world of work, school, and various forms of public accommodation and recreation. They also have sought to bear witness to the many violences committed against people with disabilities and reclaim, politicize, and empower disabled body/minds. Within the narrative constructions produced by both activists and academics, family and home became sites of ableist oppression that had to be avoided or actively dismantled. For many disabled people, the home and other domestic spaces remain dreaded sites of oppression. Yet recent work in disability studies and disability history is showing that disabled people's domestic lives are richly complex and varied, and that disabled people use the home or other "homelike" settings to carve out critically important spaces within which they not only empower themselves, but also form meaningful, life sustaining, and often transformative relationships.[34]

Contributors to *Disabling Domesticity* focus on the varied domestic sites where intimate—and interdependent—human relations are formed and maintained. These sites are at once private and public, and racially, economically, sexually, and politically inflected. They in turn make up the social, cultural, ideological, and physical locations where family, friends, workers, and lovers come together and form the bonds that sustain and in some cases destroy their varied existence. Analyzing domesticity through the lens of disability forces readers to think in new ways about family and household forms, care work, an ethic of care, reproductive labor, gendered and generational conflicts and cooperation, aging, dependence, and local and global economies and political systems, in part by bringing the notion of interdependence, which undergirds all of the chapters in this book, into the foreground. Although politically powerful and entirely essential to the disability rights movement in North America and places like the UK and Australia, the notion of "independent living" is not only a misnomer, it is deeply damaging to disabled people who might have to deny or dissemble certain aspects of their lives in an effort to seem more "independent"—or more "normal"—and to those disabled people who see state-funded mechanisms of support slashed in the name of austerity. The idea of independent living and the independent living movement can be equally oppressive to family, friends, allies, and support workers (usually women of color) whose labor remains undervalued, and in most cases goes completely unrecognized and unremunerated. *Disabling Domesticity* opens a space within which to discuss these important issues. It is time to start thinking of the independent living movement as the interdependent living movement.[35] This volume moves us closer to that goal.[36]

The analytical space created by this book is a relatively safe space. Although the authors collected in this volume engage with dominant theories in disability studies and other related areas, they do as much as they can to avoid the obfuscating language of the North American academy. As powerful and productive as many of the critiques within disability studies have been, they remain largely illegible to the world's majority disabled population.[37] When we venture outside North American disability studies, negotiating and articulating a "disability studies" critique becomes difficult. For the aging single mother of the 20-something-year-old group home resident, or the local self-advocates, or the blind man or the deaf woman living in India, or Brazilian disability rights activists, deciphering North American academic discourse becomes an incomprehensible, arduous, and in some cases futile task. As disability studies scholars, we should have a commitment to equity and social justice and a sense of fairness that informs our work and our lives more generally.

Given the absolute centrality of domestic relations in all our lives, it is surprising that such a book has not yet been published.[38] Existing literature within disability studies that takes a more domestic focus, concentrates on one of several key areas, namely reproduction, disabled mothering—usually of infants and toddlers—and the de/institutionalization of disabled children.[39] Within these critical areas of inquiry, authors most commonly work to expose past abuses, as well as various forms of resistance by people with disabilities and their families and other allies. Authors argue that disabled people, and especially disabled women, have historically been constructed as asexual, largely incompetent, and wholly dependent on their care providers, or as hypersexual and dangerously deviant, in need of control. Both renderings of disabled lives have been deployed to militate against disabled parenting, with healthcare and other professionals, as well as state officials and many family members, arguing that people with disabilities are unfit parents. Authors have also focused on the extent to which disability disrupts normative family structures, requiring the need for removal of disability from the family through abortion, institutionalization, adoption, or foster care. Recent authors document the ways in which people with disabilities (usually women) and disabled families (usually mothers) resist these oppressive ideologies and practices and maintain their families or parent against the current of normative expectations and in spite of structural limitations. *Disabling Domesticity* builds upon this richly eclectic writing by simultaneously strengthening and widening the analytical lens—by constructing an analytical home with a solid foundation that is adaptable enough to include a broader range of domestic spaces and lived experiences.

Disabling Domesticity is divided into three sections that model the interdisciplinary strengths of disability studies. The first section, “Home,” contains four chapters that explore the built environment and what might be called “home economies” from a historical perspective, focusing on the nineteenth and twentieth centuries. Among other things, the chapters in this section highlight the ways in which disability, class, and gender trouble common understandings of “home” and “homemaking.” Home is both a physical space and an ideological, discursive, and cultural construction. The book’s second chapter, “From ‘Blind Susan’ to *Incidents in the Life of a Blind Girl*: How Mary L. Day Disabled Domesticity,” written by professor of English Jennifer Thorn, situates an analysis of Mary Day’s life as it is recounted through her own memoir within the broader context of other contemporary fictional “blind girl stories” to create a stark counternarrative to the sentimentalized notions of family, girlhood, motherhood, and disability that seemed to dominate the nineteenth-century United States. In Chap. 3, “Crossing the Threshold: Disability and Modernist Housing,” Beth Tauke and Korydon Smith, both professors of architecture and design, use the innovative concept of “the threshold,” which they define as “three-dimensional and spatial,” and as “‘in-between,’ or liminal, spaces” to push us to consider how three historic homes and their designers can help us to reimagine the relationships among nonnormative bodies and domestic spaces. Chapter 4, historian Laura Micheletti Puaca’s, “The Largest Occupational Group of All the Disabled: Homemakers with Disabilities and Vocational Rehabilitation in Postwar America,” traces the history of post-World War II efforts to include primarily white middle-class women in the burgeoning US vocational rehabilitation industry as homemakers, which among other things gave rise to important arguments about the economic significance of women’s reproductive labor in the home and ultimately supported some disabled women’s efforts to pursue “independent living” and disability rights by the late 1960s and early 1970s. In the section’s final chapter, “Rethinking the American Dream Home: The Disability Rights Movement and the Cultural Politics of Accessible Housing in the United States,” American and disability studies scholar Andrew Marcum makes a powerful call for future researchers and activists to move away from an “uncritical embrace of access to the American dream home for people with disabilities” that leaves “intact the cultural norms, spatial practices, and multivalent structures of oppression that excluded people with disabilities from the 'dream home' in the first place."

The four chapters in the second section, "Care," which are more sociological in their methodology, demonstrate the importance of analyzing disability in conversations about care work, citizenship and the welfare state, aging and dementia, medical technologies and childcare, and finally sex and sexuality. In the section's first chapter, "A Feminist Technoscientific Approach to Disability and Caregiving in the Family," professor of women's and gender and disability studies Laura Mauldin issues a call for feminist disability studies scholars to take seriously both domestic caregiving and the important insights of feminist work being done in the area of science and technology studies. As Mauldin points out, the availability of technological innovations in the home has transformed care work most often conducted by family members in significant ways that have been woefully underinvestigated by disability studies scholars. In Chap. 7, "Inevitable Intersections: Care, Work, and Citizenship," Grace Chang, professor of feminist and ethnic studies, argues that the dilemmas posed by the current "crises of care" in the United States and other "wealthy" countries demand that disability rights and care worker rights scholars and organizers find common ground to confront the politicized and often heated conflicts among them. Chang argues that only by recognizing the shared vulnerabilities these groups face under similar oppressive ideologies and structures can we find "bases of alliance across these communities and movements" to transcend these divisions. In Chap. 8, "LGBTQ People with Attendant Care Dependent Mobility Impairments Reclaiming their Sexual Rights," professor of health sciences and social worker, Les Gallo-Silver, professor of health sciences and social psychologist, David Bimbi, and historian and disabilities studies scholar Michael Rembis, provide us with an analysis of the intimate relations of care developed among people with disabilities, their families, and paid caregivers. They find that while we must never minimize or negate the multiple oppressions and many violences experienced by LGBTQ people with disabilities, we must also acknowledge, engage with, and celebrate the many ways in which LGBTQ people with attendant care-dependent mobility impairments are empowering themselves through interdependent relations of care. The section's final chapter, "'Everybody Has Different Levels of Why They Are Here': Deconstructing Domestication in the Nursing Home Setting," co-authored by Katie Aubrecht (sociology) and Janice Keefe (family studies) focuses on person-centered dementia care among the elderly in nursing homes in Canada. Aubrecht and Keefe argue that “[w]hile person-centered dementia care is promising in its aims, it has been critiqued on the grounds that its underlying concept of personhood has yet to be fully clarified and empirically developed.” Drawing from van Manen (1990), they conclude that we must create a “counternarrative of dementia that orients to dementia as an expression of ‘faith in reciprocity and a shared life.’”[40]

The book’s third section, “Family,” which consists of five chapters, poses important theoretical considerations that challenge the very notion of “home life.” How might a new ethic of madness (or sanity) force us to redefine family and home? Similarly, how do “neuroqueer domesticities” “melt down” (or deconstruct or challenge) the family unit, especially for those families living on the autism spectrum? How do definitions of family and home change when disabled people are parents and providers of care, rather than children and recipients of care? Questions such as these are considered in the third and final section of the book. In Chap. 10, “Contesting the Neoliberal Affects of Disabled Parenting: Towards a Relational Emergence of Disability,” disability studies scholar Kelly Fritsch skillfully weaves her own lived experience with an insightful literature review and deft reading of two case studies drawn from popular culture to provide an intimate yet far-reaching assessment of the relationality of disability. In her chapter, Fritsch addresses the ways in which dominant cultural discourses of disabled parenting, with a particular focus on disabled mothering, re-enforce disability as located in an individual body. Fritsch shows how disabled people are hailed to feel good about being capacitated into ideal normative mothers through neoliberal forms of care and marks how relational approaches to disability can contest neoliberal forms of parenting. With his chapter, “The Mad Woman in the Garden: Decolonizing Domesticity in Shani Mootoo’s Cereus Blooms at Night,” professor of women’s and gender and disability studies Jeffry J. Iovannone provides us with a reading of Mootoo’s novel that explores the ways in which colonialism both produces and erases queer and disabled subjects within domestic spaces. The novel ultimately reimagines domestic reality so as to reimagine the lives of marginalized subjects in both private and public. The normalizing forces of colonialism are therefore resisted through the creation of alternative or queer domestic spaces, kinship arrangements, and modes of self-expression. In Chap. 12, “Gatekeepers of Normalcy: The Disablement of Families in the Master Narratives of Psychology,” Priya Lalvani, a developmental psychologist and professor of inclusive education, problematizes dominant assumptions about negative outcomes or “denial” among families of children with disabilities. Situating these dominant assumptions in the context of a historical pathologizing of this group of families by mental health professionals, Lalvani explicates the ways in which parents’ subjective interpretations of disability and normality are often obscured by the ableist interpretations of those in positions of power and control. In “Postfeminist Motherhood? Reading a Differential Deployment of Identity in American Women’s HIV Narrative,” the book’s penultimate chapter, disability studies professor Allyson Day argues that reading women’s HIV narratives for their differential deployment of identity creates a new affective landscape, which in turn complicates, in productive ways, commonly held notions of the relationship between motherhood and women’s health advocacy. Finally, disability studies scholar Zachary A. Richter concludes *Disabling Domesticity* with “Melting Down the Family Unit: A Neuroqueer Critique of Table-Readiness,” an innovative look at the table as a central site for heteronormative and ableist discipline over generally neurodivergent and more specifically Autistic bodies. In reversing the argument that claims autistic symptoms cause divorce, Richter argues that the demand of normalization as it echoes through a heteropatriarchal household infrastructure inflicts extra labors of discipline upon multiple members of the family unit and often breaks relations when rehabilitation becomes a greater priority than intimacy.

This book focuses on the United States and Canada, but it is clear that disability studies needs a sustained critique of domestic spaces and the lived experiences they engender in other parts of the world. As Nilika Mehrotra and Karen Nakamura have shown, family and extended kinship networks form a fundamental part of ideologies of disability and the lived experiences of disabled people in South and East Asia.[41] Family, home, and domestic life are equally important in the lives of people with disabilities in Central and South America, Africa, and throughout Europe.[42] Scholarship generated in these areas must be rooted in local histories and cultures, but must also be mindful, and critical of global contexts and constructs, including “global disability studies.” Visiting Research Fellow at Manchester Metropolitan University, Shaun Grech, and others, including Mehrotra have argued that “disability studies” remains a Global North, white, disability studies and they offered ways in which disability studies scholars might engage in a critical global disability studies.[43] It is my contention that focusing on family, home, and domestic life offers one way to move beyond the exportation of Global North research models and ideologies to the Global South and place various regions throughout the world in conversation with one another. Nothing seems more universal than the negotiation of our daily lives, including our struggles for survival, and our efforts to build and maintain community and kinship.[44] Mehrotra argues for example, that disabled women living in the state of Haryana and the city of Delhi, India engage in a type of "domestic citizenship."[45] What precisely does this mean in the Indian context? How might insights from India inform work being done in Guatemala, Poland, the United States, Scotland, or South Africa? How can this research and these lived experiences help us build a stronger sense of global community and stronger movements for equality and social justice? *Disabling Domesticity* is meant to mark the beginning of such scholarly and activist discussions.

In a brief essay on "Family," published in *Keywords for Disability Studies* (2015), Faye Ginsburg and Rayna Rapp argue that, "families are both flesh-and-blood collaborations and always acts of cultural imagination."[46] Likewise, the caring performed within diverse kinship networks and homes of various sorts is also made up of flesh-and-blood collaborations and cultural imaginaries. The home too, however it might be defined, is always rooted in the material, cultural, and social. When we disable dominant notions of domesticity, the human relations, material conditions, and structural forces that shape and are shaped by all three of these overlapping ways of knowing and being fall into stark relief. They open themselves up for analysis and provide an opportunity to create powerful counter-narratives that can help build the "social fund of knowledge about disability" advocated by Rapp and Ginsburg.[47] *Disabling Domesticity* makes it possible to revise and remold not only the way we imagine home, community, and kinship, but also the way we enact them in our daily lives, which ultimately is the greatest force for social change.

Notes

1. Investigative Workshop, University of King's College, "Warehoused: Nova Scotians with Intellectual Disabilities Face a Housing Crisis," *The Huffington Post Canada* Posted: 06/11/2013 5:36 am EDT/Updated: 06/11/2013 10:51 pm EDT http://www.huffingtonpost.ca/2013/06/11/intellectual-disabilities-housing_n_3342995.html (Accessed: 07/02/2015).

2. Ella Callow, “Disabled Mothers: Misadventures & Motherhood in the American Courts,” in Dena Taylor and Gloria Filax, eds. *Disabled Mothers: Stories and Scholarship by and About Mothers with Disabilities* (Bradford, ON: Demeter Press, 2014): 281–282.
3. The contributors to this volume, including its editor, are well aware of North American and UK (primarily British) dominance of disability studies scholarship and discourse, as well as the importance of the global disability rights movement and critical global disability studies. Domesticity, as it is being defined in this volume is indeed a Western concept. Yet, families and homes of various sorts are central in disabled people’s lives throughout the world. It is the editor’s hope that this volume marks a starting point and provides a foundation for future dialogue among scholars, activists, and artists in various parts of the world concerning the importance of domestic life in disabled people’s lives. For more on disability studies outside North America and the UK, see: Michael Rembis, “Disability Studies,” *The Year’s Work in Critical and Cultural Theory* (Oxford University Press: April 2015 online: doi:10.1093/ywcct/mbv007Z: Print Fall 2015).
4. Human Resources and Skills Development Canada, *Disability in Canada: A 2006 Profile* (2011).
5. U.S. Census Bureau: American FactFinder, http://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_13_5YR_DP02&prodType=table (Accessed 06/27/2015).
6. See, for example: Daniel Blackie, “Disability, Dependency, and the Family in the Early United States,” in Susan Burch and Michael Rembis, eds. *Disability Histories* (Urbana: University of Illinois Press, 2014): 17–34; Penny L. Richards, “Thomas Cameron’s ‘Pure and Guileless Life,’ 1806–1870: Affection and Developmental Disability in a North Carolina Family,” in Burch and Rembis, eds. *Disability Histories*, 35–57.
7. Paul Preston and Jean Jacob, “Disabled Mothers: Perspectives of Their Young Adult Children,” in Taylor and Filax, eds. *Disabled Mothers*, 317.
8. World Health Organization, *World Report on Disability* (WHO, 2011): 139,140.
9. Administration for Community Living, http://www.acl.gov/Data_Outcomes/Index.aspx (Accessed 06/27/2015). See also: Perkins, E. A., & Haley, W. E. “Emotional and Tangible Reciprocity

in Middle and Older-Aged Caregivers of Adults with Intellectual Disabilities," *Journal of Policy and Practice in Intellectual Disabilities,* 10 (2013): 334–344; Williamson, H. J. & Perkins, E. A. "Family Caregivers of Adults with Intellectual and Developmental Disabilities: Caregiver Outcomes Associated with U.S. Services and Supports," *Intellectual and Developmental Disabilities*, 52 (2014): 147–159.

10. Although the history of institutionalization varied among the different provinces in Canada, generally it had an experience similar to that of United States. Steven Noll has written about Canada, "The first institution specifically designed to house insane persons opened in 1836 in New Brunswick. Upper Canada (today Ontario) developed a facility in the 1830s that became the Toronto Asylum by 1850. According to historian Ian Dowbiggin, 'paralleling developments south of the border, Ontario had by the final third of the nineteenth century established an expansive mental health care system … at the center of [which] was the asylum and the physicians who staffed it.' In Nova Scotia, an institution opened after the impassioned visit of Dorothea Dix in 1850, although it took nine long years for the facility finally to admit its first patient. Specialized institutions for the feeble-minded opened in Canada in the last quarter of the nineteenth century. Ontario's Orillia Asylum opened in 1876 with the same promise and problems exhibited by similar institutions throughout North America. As early as the mid-1880s, the superintendent complained that, 'funding was the lowest in North America.'" Steven Noll, "Institutions in North America," in Michael Rembis, Catherine Kudlick, and Kim E. Nielsen, eds. *The Oxford Handbook of Disability History* (Oxford University Press, forthcoming): n.p.
11. See, for example: Janice Brockley, "Rearing the Child Who Never Grew: Ideologies of Parenting and Intellectual Disability in American History," in Steven Noll and James W. Trent, eds. *Mental Retardation in America: A Historical Reader* (New York: New York University Press, 2004): 130–164; Gerald N. Grob, *The Mad Among Us: A History of the Care of America's Mentally Ill* (New York: Free Press, 1994); Gerald N. Grob, *Mental Institutions in America; Social Policy to 1875* (New York: Free Press, 1972); Kim E. Nielsen, *A Disability History of the United States* (Boston: Beacon Press, 2012); Penny L. Richards, "Thomas Cameron's

'Pure and Guileless Life,' 1806–1870"; Penny Richards, "'Beside Her Sat Her Idiot Child': Families and Developmental Disability in Mid-Nineteenth-Century America," in Noll and Trent, eds. *Mental Retardation in America*, 65–84.

12. See, for example: R. A. R. Edwards, *Words Made Flesh Nineteenth-Century Deaf Education and the Growth of Deaf Culture* (New York University Press, 2012); Lawrence B. Goodheart, *Mad Yankees: The Hartford Retreat for the Insane and Nineteenth-Century Psychiatry.* (Amherst: University of Massachusetts Press, 2003); Gerald N. Grob, *Mental Institutions in America*; Constance M. McGovern, *Masters of Madness: Social Origins of the American Psychiatric Profession.* (Hanover, NH: Published for University of Vermont by University Press of New England, 1985); Nielsen, *A Disability History of the United States.*
13. Gerald N. Grob, *Mental Illness and American Society, 1875–1940.* (Princeton, NJ: Princeton University Press, 1983); Robert Whitaker, *Mad in America: Bad Science, Bad Medicine, and the Enduring Mistreatment of the Mentally Ill.* (Cambridge, MA: Perseus Pub, 2002).
14. Steven J. Taylor, *Acts of Conscience World War II, Mental Institutions, and Religious Objectors.* (Syracuse University Press, 2009).
15. Providing a "stable domestic life" and domestic "training" remained the stated goal of most institutions for almost one hundred years, sometimes with perverse ends. See, for example: Susan Burch and Hannah Joyner, *Unspeakable: The Story of Junius Wilson* (Chapel Hill: University of North Carolina Press, 2007).
16. Carla Yanni has found, for example, that "[i]n 1855 a report on the insane in Massachusetts stated that there were 1348 lunatics in institutions and 1284 at home," and that "[t]he census of 1880 calculated that of 91,959 insane persons in United States, 50,879 where incarcerated and the rest (about 45 percent) where 'at home or in private care.'" Carla Yanni, *The Architecture of Madness: Insane Asylums in the United States.* (Minneapolis: University of Minnesota Press, 2007): 6. Similarly, social historians of medicine who have studied both Canada and the United States have shown that many mad people who entered institutions—almost half in some cases—remained there for relatively short periods of time. David Wright, James Moran and Sean Gouglas, "The confinement

of the insane in Victorian Canada: the Hamilton and Toronto asylums, *c.* 1861–1891," in Roy Porter and David Wright, eds. *The Confinement of the Insane International Perspectives, 1800–1965.* (Cambridge, UK: Cambridge University Press, 2003): 100–128; David Wright, "Getting Out of the Asylum: Understanding the Confinement of the Insane in the Nineteenth Century," *Social History of Medicine,* 10: 1 (1997): 143–144. See also: Kim E. Nielsen, "Property, Disability, and the Making of the Incompetent Citizen in the United States, 1860s–1940s," in Burch and Rembis, eds. *Disability Histories*, 308–320.

17. According to Lundquist, one medical specialist stated, "This is the worst thing that could have happened to your child. She is a mongoloid." Another medical specialist stated, "Karen, the older sister, is the one you must think of. Her future must be your sole consideration." Yet another specialist stated, "Karen and her welfare are what you must consider from now on. She can't have a retarded younger sister around to embarrass and humiliate her." This same specialist went on to declare, "This child [Jane] must be placed in an institution immediately. By the time she's seven her features will become more grotesque." Violet Ebb Lundquist, "I'm Glad We Kept Janie at Home," *Bound* (June–July, 1958): 28–31.
18. Katherine Castles, "'Nice, Average Americans': Postwar Parents' Groups and the Defense of the Normal Family," in Noll and Trent, *Mental Retardation in America,* 351–370.
19. For more of the parents movement, the NARC, and the self-advocacy movement see: Allison C. Carey, "Parents and Professionals: Parents' Reflections on Professionals, the Support System, and the Family in the Twentieth-Century United States," in Burch and Rembis, eds. *Disability Histories*, 58–76; Allison C. Carey, *On the Margins of Citizenship: Intellectual Disability and Civil Rights in Twentieth-Century America*. (Philadelphia: Temple University Press, 2009).
20. For more on the disability right movement in the United States, see: Lindsey Patterson, "The Disability Rights Movement in the United States, 1930s-present," in Michael Rembis, Catherine Kudlick, and Kim E. Nielsen, eds. *The Oxford Handbook of Disability History.* (Oxford University Press, forthcoming): n.p. For more on the disability rights movement in Canada, see: Dustin Galer, *Working Toward Equity: Disability Rights Activism and*

Employment in Late Twentieth Century Canada. (University of Toronto Press, forthcoming).

21. Although it has been increasingly challenged and made more complex, most disability studies scholars adhere to some form of the "social model" of disability, which states that environmental and social barriers, as well as negative cultural perceptions and stigma disable people, not necessarily their impaired bodies. For more on the social model of disability, see: Tom Shakespeare, *Disability Rights and Wrongs Revisited.* (London; New York: Routledge, 2014); For a discussion of "rights" as they relate to people with intellectual or developmental disabilities and the parents and self-advocacy movements, see: Carey, *On the Margins of Citizenship.*
22. Dustin Galer, "'Hire the Handicapped!' Disability Rights, Economic Integration and Working Lives in Toronto, Ontario, 1962–2005" PhD diss., (Toronto: University of Toronto, 2014): 169.
23. Raymond A. Lemay, "Deinstitutionalization of People With Developmental Disabilities: A Review of the Literature," *Canadian Journal of Community Mental Health.*
24. Michael Rembis, "The New Asylums: Madness and Mass Incarceration in the Neoliberal Era," in Liat Ben-Moshe, Chris Chapman, and Allison Carey, eds., *Disability Incarcerated.* (New York: Palgrave, 2014): 139–159.
25. Goodley defines ableism as the structural omission of disabled people from a world built by and for non-disabled humans, while disablism consists of the individual acts of discrimination and marginalization that manifest on both an interpersonal and systemic or institutional level. Dan Goodley, *Dis/Ability Studies: Theorising Disablism and Ableism.* (New York: Routledge, Taylor & Francis Group, 2014).
26. Tobin Siebers, *Disability Theory.* (Ann Arbor: University of Michigan Press, 2008). For a more detailed critique of dismodernism, see: David T. Mitchell, *Biopolitics of Disability: Neoliberalism, Ablenationalism, and Peripheral Embodiment.* (Ann Arbor: University of Michigan Press, 2015): 28–32; Michael Rembis, "Disability Studies."
27. Mitchell, *Biopolitics of Disability,* 1–7.
28. Mitchell, *Biopolitics of Disability,* 1–7.

29. Rayna Rapp and Faye Ginsburg, “Enabling Disability: Rewriting Kinship, Reimagining Citizenship,” *Public Culture* 13:3 (Duke University Press, 2001): 533–556.
30. Rapp and Ginsburg, “Enabling Disability,” 534.
31. Rapp and Ginsburg, “Enabling Disability,” 536.
32. Rapp and Ginsburg, “Enabling Disability,” 537.
33. In the spirit of disabling domesticity and rewriting home, care, and family, I must reveal my own standpoint. I am a disabled dad. My son was five years old when this book went to press. When my former partner and I decided to have a child, it was clear—or at least I thought—that ours would be a “crip/queer,” nonnormative family and household that could very well exist in two locations and would involve at least three caregivers. Things did not work out as we had planned, and when this manuscript went to press, we were preparing to go to trial over custody and access issues. It became clear early on that my former partner had no intention of creating a crip/queer family and instead sought to create an upper-middle-class “traditional” heteronormative nuclear family, and cast me as an “uninvolved sperm donor”—something I never agreed to and an identity that I never assumed. She sought to oust me from our son’s life, and intended to use my disability against me in an effort to prevent me from gaining increased access and any measure of custody.
34. See, for example: Daniel Blackie, “Disability, Dependency, and the Family in the Early United States,” in Burch and Rembis, eds. *Disability Histories*, 17–34; Harold Braswell, “My Two Moms: Disability, Queer Kinship, and the Maternal Subject,” *Hypatia* 30, 1 (Winter 2015): 234–250; Brockley, “Martyred Mothers and Merciful Fathers”; Janice Brockley, “Rearing the Child Who Never Grew: Ideologies of Parenting and Intellectual Disability in American History,” in Noll and Trent, *Mental Retardation in America,* 130–164; Carey, “Parents and Professionals”; Castles, “‘Nice, Average Americans’”; Michael Carl Gill, *Already Doing It: Intellectual Disability and Sexual Agency.* (Minneapolis: University of Minnesota Press, 2015); Jordynn Jack, *Autism and Gender: From Refrigerator Mothers to Computer Geeks.* (Urbana: University of Illinois Press, 2014); Kathleen W. Jones, “Education for Children with Mental Retardation: Parent Activism, Public Policy, and Family Ideology in the 1950s,” in Noll and Trent, *Mental*

Retardation in America, 322–350; Alison Kafer, *Feminist, Queer, Crip.* (Bloomington: Indiana University Press, 2013); Susannah B. Mintz, ed. *Unruly Bodies: Life Writing by Women with Disabilities.* (Chapel Hill: University of North Carolina Press, 2007); Rapp and Ginsburg, "Enabling Disability"; Rembis, "Disability Studies"; Richards, "Thomas Cameron's 'Pure and Guileless Life,' 1806–1870"; Richards, "'Beside Her Sat Her Idiot Child'"; Penny Salvatori, Mary Tremblay, and Joyce Tryssenaar, "Living and Aging with a Developmental Disability: Perspectives of Individuals, Family Members and Service Providers," *Journal on Developmental Disabilities.* 10, 1 (2003): 1–19; Melinda Tankard Reist, *Defiant Birth: Women Who Resist Medical Eugenics.* (North Melbourne, Vic: Spinifex Press, 2006); Taylor and Filax, eds. *Disabled Mothers*; Bess Williamson, "Electric Moms and Quad Drivers: People with Disabilities Buying, Making, and Using Technology in Postwar America," *American Studies* 52:1 (2012): 5–29; Leila Zenderland, "The Parable of the Kallikak Family: Explaining the Meaning of Heredity in 1912," in Noll and Trent, eds. *Mental Retardation in America,* 165–185.

35. Disability studies scholars are increasingly recognizing and creating insightful analyses of people's interdependency with the environment, animals, and inanimate objects. See, for example: Mel Y. Chen, *Animacies: Biopolitics, Racial Mattering, and Queer Affect.* (Durham, NC: Duke University Press, 2012). For a fuller discussion of the ways in which disability reimagines care work and interdependence within families, see the work of Eva Feder Kittay, especially: Eva Feder Kittay, *Love's Labor: Essays on Women, Equality, and Dependency.* (New York: Routledge, 1999).
36. In many ways, this work picks up a thread of analysis that has been critical to women's history and feminist theorizing since the 1980s. Now classic texts in women's history such as Elaine Tyler May's *Homeward Bound* (Elaine Tyler May, *Homeward Bound: American Families in the Cold War Era.* (New York: Basic Books, 1988)) and Joanne J. Meyerowitz, *Not June Cleaver: Women and Gender in Postwar America, 1945–1960.* (Philadelphia: Temple University Press, 1994) forced US historians to acknowledge the critical importance of domesticity in mid-twentieth century US history and gave rise to an entire field of study. In similar ways, *Disabling Domesticity* refocuses if not redefines scholarship in disability studies.

37. On queer-crip critiques and crip theory, see: Robert McRuer, *Crip Theory Cultural Signs of Queerness and Disability.* (New York University Press, 2006).
38. An example of the timeliness of this project can be seen in the recent publication of Matt Cook, *Queer Domesticities: Homosexuality and Home Life in Twentieth-Century London* (Basingstoke: Palgrave Macmillan, 2014).
39. Brockley, "Martyred Mothers and Merciful Fathers"; Kim Q. Hall, *Feminist Disability Studies.* (Bloomington: Indiana University Press, 2011); Denise Sherer Jacobson & Anne Finger, "Alternative motherhoods," in Mintz, ed. *Unruly Bodies,* 137–182; Jack, *Autism and Gender*; Kafer, *Feminist, Queer, Crip*; Robert McRuer and Anna Mollow, eds. *Sex and Disability.* (Durham, NC: Duke University Press, 2012); Julie Avril Minich, *Accessible Citizenships: Disability, Nation, and the Cultural Politics of Greater Mexico.* (Philadelphia: Temple University Press, 2014); Rapp and Ginsburg, "Enabling Disability"; Rembis, "Disability Studies"; Bonnie G. Smith and Beth Hutchison, *Gendering Disability.* (New Brunswick, NJ: Rutgers University Press, 2004); Taylor and Filax, eds. *Disabled Mothers.*
40. Aubrecht and Keefe, "'Everybody Has Different Levels of Why They Are Here': Deconstructing Domestication in the Nursing Home Setting" (Michael Rembis, ed. *Disabling Domesticity*, 2016): n.p.
41. Nilika Mehrotra, *Disability, Gender, and State Policy: Exploring Margins.* (Jaipur: Rawat Publications, 2013); Karen Nakamura, *A Disability of the Soul an Ethnography of Schizophrenia and Mental Illness in Contemporary Japan* (Ithaca: Cornell University Press, 2013). For more on the importance of family and kin in places like India and Japan and also a discussion of how this work fits with the larger body of disability studies literature, see: Rembis, "Disability Studies."
42. See, for example: Sonia Cardenas, *Human Rights in Latin America: A Politics of Terror and Hope* (Philadelphia: University of Pennsylvania Press, 2010); Ilze Grobbelaar-du Plessis and Tobias van Reenen, eds., *Aspects of Disability Law in Africa* (Pretoria, South Africa: Pretoria University Law Press (PULP), 2011); Samuel Kabue, et. al., *Disability, Society, and Theology: Voices from*

Africa, (Limuru, Kenya: Zapf Chancery Publishers Africa, 2011); Jitendra Kumar Trivedi and Adarsh Tripathi, *Mental Health in South Asia: Ethics, Resources, Programs, and Legislation,* (Dordrecht: Springer, 2015); Shridevi Rao and Maya Kalyanpur, eds., *South Asia and Disability Studies: Redefining Boundaries and Extending Horizons*, (New York: Peter Lang, 2013); Brian Watermeyer, *Disability and Social Change: A South African Agenda* (Cape Town, South Africa: HSRC Press, 2006).

43. Shaun Grech, "The Spaces of Poverty: Renegotiating Place and Disability in the Global South," in Karen Soldatic, Hannah Morgan, and Alan Roulstone, eds. *Disability, Spaces and Places of Policy Exclusion*. (Abingdon, Oxon; New York, NY: Routledge, 2014): 48–63; Shaun Grech, "Disability, Communities of Poverty and the Global South: Debating through Social Capital", in A. Azzopardi and Shaun Grech, eds., *Inclusive Communities: A Critical Reader*, (The Netherlands: Sense Publishers, 2012): 69–84; Shaun Grech, "Disability, Poverty, the Majority World and the Neocolonial: Introducing Critical Global Disability Studies." in Dan Goodley, Bill Hughes, and Lennord Davis, eds., *Disability and Social Theory: New Developments and Directions.* (London: Palgrave Macmillan): 52–69; Shaun Grech and Dan Goodley, "Doing Disability Research in the Majority World: An Alternative Framework and the Quest for Decolonising Methods," *Journal of Human Development, Disability, and Social Change*, 19 2 (2012): 43–55; Shaun Grech, "Comment from the Field: Disability and the Majority World: Challenging Dominant Epistemologies," *Journal of Literary & Cultural Disability Studies*, 5 2 (2011): 217–220; Mehrotra, *Disability, Gender, and State Policy.*
44. Fay Ginsburg and Rayna Rapp echo this argument in a brief essay, "Family," published in *Keywords for Disability Studies.* Fay Ginsburg and Rayna Rapp "Family" in Rachel Adams, Benjamin Reiss, and David Serlin, eds. *Keywords for Disability Studies* (New York: NYU Press, 2015): 81–84.
45. Mehrotra, *Disability, Gender, and State Policy,* 43.
46. Ginsburg and Rapp "Family," 82.
47. Rapp and Ginsburg, "Enabling Disability," 537.

PART I

Home

CHAPTER 2

From “Blind Susan” to *Incidents in the Life of a Blind Girl*: How Mary L. Day Disabled Domesticity

Jennifer Thorn

Some time in the 1870s, as part of a national tour by rail to sell her 1859 memoir *Incidents in the Life of a Blind Girl*, Mary L. Day met famed suffragist Susan B. Anthony. In another memoir, *The World as I Have Found It* (1878), Day reports on that encounter with Anthony. Before Day had said a word to her, Anthony passionately declared the unfitness of the blind for reproduction: “Were you ever in Michigan? Are you married? I knew a blind woman there who had five children, and they were all deaf and dumb! I think Congress ought to pass a law to prevent these people from marrying and bringing these creatures into the world!”[1] The usually poised Day, initially stunned into silence, later pondered the seeming contradiction between Anthony’s “cruel words” and her brave defiance of convention to claim citizenship and public roles for women. How could such prejudice “have emanated from a woman who advocated the inviolable rights and bewailed the deep wrongs of her own sex, as if Congress

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had the power to exclude the blind from loving and following the holiest impulse of their nature, like other human beings!"[2]

Even as this exchange shows Day rejecting a bigotry derived in nineteenth-century ideas about home life, it also suggests the complexity of the ways that domesticity figured in this era as an ideological measure of human worth. Day counters Anthony's eugenicist belief that "these people" should not be permitted to reproduce by asserting the right of blind people to love and to experience their own and others' sexuality. She does so both empirically, noting the lived reality of the lives of blind people (she herself was happily married to a sighted businessman at the time of this exchange), and ideologically, figuring "loving" and "the hol[y] impulse" toward procreation as measures of human nature. In this passage, Day "disables domesticity" only by adding disabled people to a domesticity the value and nature of which she does not question. Those who are presumed problematic—disabled people—are to be assimilated into normative domestic life, and valued and defined as reproductive and familial. *The World as I Have Found It*, written when Day was 42—at ease in her homelife, with a life of travel as a tourist and a promoter of her books behind her—does not "disable domesticity" in the more profound sense that the era's domestic ideology would seem, to modern eyes, to require. That is, even as Day describes in *The World As I Have Known It*, a life of mobility, marriage, and community, the book does not question the assumptions about domesticity and normative human development that underlay prejudice like Anthony's.

Day's first memoir, *Incidents in the Life of a Blind Girl*, as well as *The World As I Have Found It*, are important evidence of the persistence, and indeed the domestic happiness, of blind people in the face of a prejudice-ridden society. Both are stories of the kind valued by Simi Linton—"stories of disabled people comfortable in their skins, those for whom disability is an integral but not despised element of life."[3] This chapter asserts *Incidents*' particular value as a text that helps us hone the conceptual tools with which we do the revisionist work of recovery. Day's focus on her childhood in *Incidents* makes us see how deeply ideas about childhood informed the civic and domestic ideals that "demanded" the stigmatization of disabled people, in particular ideas about the normative development of children, the maternal care that it allegedly required, and women's charitable activism outside the home. *Incidents*' account of Day's childhood experiences of poverty, abuse, serial domesticity, and nonnormative family life reveals the biases of class and region that inform the nineteenth-century glorification of motherhood, disabling domesticity in the sense of making domesticity itself better—more just, more accurate, more capacious—by virtue of the presence of disabled people.

In her encounter with Mary L. Day, Susan B. Anthony cried out for a law that would prevent blind people from having children: at the root of this outburst lay the inaccurate assumption that blind parents produced blind, deaf, and/or dumb children. Worrying about the possible production of flawed children, Anthony implies a biologized model of childhood, a view in keeping with the Darwinian evolutionary theory that had begun to emerge in the 1860s. In the decades described in *Incidents in the Life of a Blind Girl*, concepts of childhood and disability entwined instead with early nineteenth-century understandings of childhood identity rooted in nurture. Prior to the advent of Darwinian evolutionary theory and eugenics, the readiness to assess the value of children against a normative developmental model was of a piece with broad cultural shifts that led to both the spread of public education and the first state laws making such schooling compulsory.[4] As the nineteenth century gradually shed the traditional Calvinist notion of the child as marked by sin, schools came to be seen as necessary to mold them; schools would, as Steven Mintz notes, “instill the values and skills necessary in a rapidly changing society: basic literacy, punctuality, obedience, and self-discipline.”[5] This demand that nurture, in schools and at home, support children as they, in effect, acquired human nature had as correlate the standardization of their growth.[6] The demand that children progress through predictable phases meant that the public schools would provide “homogenous” curricula, practices that marginalized those children who did not progress in the expected developmental steps.[7]

Thus the expectation of a predictable maturation process provided a conceptual framework likely either to fault disabled and/or poor children as deviant or to deny their legibility as children. Though these forms of stigma affected boys and girls, other forms of stigma affected girls in particular, in part because the temporalization of childhood—the demand that children progress linearly and predictably from infancy to adulthood—affected sighted and middle-class girls differently than it did blind and/or poor girls. Girlhood was understood as both prior to, and distinct from, womanhood and also as continuous with it: as Gillian Brown has remarked, girls were to “embody the continuity between children and adults.”[8] Melanie Dawson’s scrutiny of the ways middle-class nineteenth-century girls and boys played finds similarly that girls’ play “reminded

[them] of their specialized—and, the suggestion then followed, *necessary*—function as family caretakers."[9] Dawson notes the "odd[ity]" of the characterization of young girls "by ideals that are inseparable from domestic womanhood."[10] In this sense, girls' identity was understood as both static (timelessly predictive of their later lives as women) and progressive (advancing them from immaturity to maturity).

Malleable children were to be nurtured in schools and also at home, where (middle-class) mothers' role was expanded and glorified. The Unitarian minister and abolitionist Theodore Parker, for example, cast mothers as the measure of "the greatness of human nature:" the bravery that a mother shows in "watch[ing] over a sickly child, and still bear[ing] up when the body craves food and rest, and she is sick at heart" is more heroic than "[t]he courage that wades to its neck in blood." This maternal selflessness and devotion made the home "a spot holy as the spot the sacred tread."[11] The Congregationalist minister and writer Horace Bushnell similarly saw "[h]ome and religion" as "kindred words; names both of love and reverence; home, because it is the seat of religion, religion, because it is the sacred element of home." Bushnell understood families as "so many little churches, only they are as much better, in many points, as they are more private, closer to the life of infancy, and more completely blended with the common affairs of life."[12] Here, somewhat paradoxically, women are both empowered and constrained by a reproductive imperative. Women are God-like, even as their moral force is to be exerted only at home.

This ambiguous empowerment of women rested upon their relationship to needy dependents, an idealization readily extended beyond the home. Thus the "Declaration of the Rights of Woman," read by Susan B. Anthony at centennial celebrations on July 4, 1876, in Philadelphia, blamed broken families, criminality, prostitution, disease, drunkenness, and the mistreatment of disabled people on social obstructions of women's innate morality, a logic that then demanded women's righteous struggle against both these ills and the unnatural stifling of women's nature that had created them: "Woman's degraded, helpless position is the weak point in our institutions to-day; a disturbing force everywhere, severing family ties, filling our asylums with the deaf, the dumb, and the blind; our prisons with criminals, our cities with drunkenness and prostitution; our homes with disease and death."[13] The lament in the "Declaration" is the flip side of Parker's and Bushnell's visions of ideally ordered, compassionate homes. As this passage makes clear, this exaltation of women as salvifically sympathetic and moral permitted their engagement in civic issues only if they were not themselves "deaf … dumb … [or] blind." Blind people, be they men or women, boys or girls, could figure in this moral economy only as objects of pity and protection that allowed moral mothers to perform the natural sympathy that domesticity expected of them.

In this way, nineteenth-century American domesticity, by casting women as custodians of a morally charged space of home in ways that sometimes also required their departure from this private sphere, offered some women a certain complex kind of power as creators and restorers of an idealized human nature. Disabled people, however, were categorically denied access to this complex empowerment. The domesticity that demanded that women care for the wide world as if it were a home required an impossible invulnerability; women could be citizen subjects only by virtue of their response to, even in a sense possession of, objectified dependents. In the 1830s, the United States Census counted blind inhabitants of the nation for the first time, making it the first nation to make an enumeration of disability a permanent part of its official record keeping.[14] The advent of a perceived need to locate blind people and to make blindness a primary marker of civic identity may have been, in part, a response to the new middle-class imperative of finding "objects" to rescue. Thus Anthony's wish that Day, as a blind woman, be kept by law from reproduction suggests two entwined roots of stigma: an irrational fear of the production of nonstandard children and a discomfort with Day's quiet refusal of the passive role of pitiable object of rescue.

"Finding Other Objects": The Lessons of Blind Girl Stories

The title *Incidents in the Life of a Blind Girl* marketed Day as "a blind girl:" what did this epithet mean to the book's first readers? The following section describes four representatives of this subgenre, popular in nineteenth-century periodicals, newspapers, poetry, children's literature, and popular music. Two of these stories—"Blind Susan" (1827) and "The Blind Child" (1833)—are associated with Lydia Maria Child, whose *Juvenile Miscellany* has been credited with the "creation" of American children's literature.[15] Child wrote "Blind Susan" for the November 1827 issue of *Juvenile Miscellany* and included "The Blind Child" in her edited volume *A Garland of Juvenile Poems* (1833). The third story, "The Blind Girl's Lament" (1841), first appeared in the *New Hampshire Patriot and*

State Gazette on May 14, 1841. The fourth, “Good Will; or, The Blind Girl,” appeared in the first issue of *Peter Parley’s Magazine*, which hoped both to capitalize on the market for juvenile periodicals that Child had largely created and to appeal to boys and girls. All three tales were regularly reprinted through the nineteenth century, not only in periodicals and books intended for children, but also in newspapers. These stories help us think about the correlate exclusion of blind girls and laboring-class girls as potential members of the audience, holding up for middling-class, sighted girls “blind girls” whose ineligibility for moral motherhood is to encourage the former to accept and embrace their own roles as moral-mothers-in-training.

Samuel Griswold Goodrich, the “first best-selling American children’s author,” had already sold over 12 million copies of his Peter Parley books when he launched the magazine named for his best-selling persona.[16] The periodical’s first issue of March 16, 1833, featured a story, “Good Will; or the Blind Girl,” that would be widely reprinted thereafter in newspapers for adults as well as in juvenile periodicals and anthologies. The protagonist of the story, Anna Talbot, dislikes school and “could not bear the trouble of learning by degrees, first to spell short words, and then … longer ones.” Caught in a rainstorm when she is out walking with her maid one day, Anna takes shelter in a cottage in which she sees only “a blind girl, about ten or twelve years old, who was knitting a stocking, and singing gaily at her work”—an image of plebeian joy in menial labor that, as Andrew O’Malley has noted, is a staple element of children’s literature as it emerged in late eighteenth-century Britain.[17] Anna is astonished to learn that the girl did not learn to knit before going blind; she was born blind. Her cheerful industry so deeply impresses Anna that the next day instead of complaining about her lessons, she sets to them with “a good will.”

The story of Anna Talbot and Peggy demonstrates one way that the responses to blindness created and reinforced opposition between both middle- and laboring-class children and disabled and nondisabled children. Peggy is rhetorically denied domesticity in multiple ways: she has no last name, what nurture she receives is communal and occasional, she does not go to school, and she is left alone during the day. Peggy learns “women’s work” not from a moral mother but from a neighbor, an old woman, who offered when Peggy was seven to teach her to knit. This training in knitting, remunerative labor that was deeply necessary in nineteenth-century households, is presented as simply affective: Peggy will learn "to knit stockings for [her] father to wear" so that she will be spared the "sad[ness]" of "think[ing] that while my sister was helping my father and mother, I could do nothing useful for any of them." She knits to show that she loves her family, an invocation of "love" that deflects the reader's attention from the isolation and exclusion from school that mark Peggy's days, signs of her poverty and her blindness. She does, however, seem to be aware that the purchasers of her knitted goods are buying the pleasure of a charitable self-image along with the stockings themselves: "People like to buy stockings that are the work of a poor blind girl." This class awareness informs Peggy's description of her parents' response to her blindness, which could be read as an indication that her potential noncontribution to her own support is a primary source of their grief: Peggy's parents are "very poor people, and work hard for their living. My blindness was great sorrow to them." Only middle-class families, it seems, could sublimate the economic realities of child-rearing in idealized, disembodied domestic spaces. It is the middle-class Anna, whose ability to progress is marked by her possession of a last name, parents in a nuclear family, and homework, who can, and does, achieve epiphany. "The next day she went to her lessons with a good will," earning "love, praise, and knowledge"—and fulfilling cultural expectations of "the child" and "the girl."

Peggy's work and her desire to knit stockings for her father make her a "miniature woman," to use Melanie Dawson's phrase, in that she engages in needle arts and is part of a family economy.[18] But this action, learning a skill of domestic labor, and this ethic of mutual support are occasional, not a step on the road to motherhood and heading her own household. Disabling this domesticity might require both challenging the story's implicit requirement of middle-class status for "family" and seeing Peggy and Anna Talbot as equally able, and likely, to marry and become mothers. It might also involve redefining family and intimacy so that ideology acknowledged the lived experience that is occluded. It might also mean allowing girls access to a valuable and more broadly defined domesticity that did not require marriage and reproduction. Thus the insertion of disabled people into domesticity (and recognition of the wide gap between cultural ideals and lived realities in all lives) brings to the foreground the damaging inaccuracy and close alliance with class hierarchy of "domesticity" as an ideal.

Steven Mintz's attention to the widening inequality between privileged and poorer children in the nineteenth century, the era in which "modern childhood" was, in his view, "invent[ed]," implies a series of causal steps.[19] He notes that "[t]he very period that freed middle-class children from work and allowed them to devote their childhood years to education also made the labor of poorer children more essential to their families' well-being than in the past, and greatly increased the exploitation that these children suffered."[20] A postrevolutionary revisionist will to replace the Calvinist sense of children's sinfulness with an optimistic sense of their plasticity produced the development of schools as "homogenous environments" to promote children's development through proper stages and the belief that the molding of children required their exemption from labor.[21] "Good Will; or, the Blind Girl" indirectly references something like these three steps—the redefinition of childhood in terms of educability, the formation of schools, an exclusion from remunerative labor—and resequences them. Here, it seems, Peggy is not fully legible as a child—and certainly is ineligible for status as protagonist, the tale's title notwithstanding—because she works and because she does so instead of going to school. The work that she does—knitting—was required of middle-class girls and women, too, and is depicted in other tales in relation not to economic productivity or the viability of the household but to character development, effacing economic realities of middle-class, as well as of poor people's households. Anna Talbot learns from Peggy's diligent knitting not to be a diligent knitter but to pay attention in school. Anna's labor positions her for adult responsibility; Peggy's does not. Peggy cannot be "a child" because she cannot be an adult; she cannot be an adult because she cannot be "a child."

If "Good Will" denies a laboring-class blind girl maternal nurture, school, and the ability to progress, other nineteenth-century blind girl stories entwined these associations in ways that required the beautifully pitiable deaths of middle-class girls. These seemingly generic sentimental deathbed scenes confirm the righteousness of their caretaking, sighted mothers and sisters. The function of blind girls as props in the dramas of middle-class legitimation in the three stories to which I now turn evoke the teacher-like maternal ideal extolled by Horace Bushnell through which mothers are uniquely equipped to do God's work of awakening the soul because their home-bound lives are "private, close[d] to the life of infancy, and … completely blended with the common affairs of life."[22]

David Mitchell and Sharon Snyder have decried the "fantasies of erasure, cure, or elimination of bodily difference" that too often undergird the "acceptance of disabled people," faulting such visions both for a narcissistic "longing … for human similitude" and for their avoidance of engagement with "the necessity of providing provisions for our meaningful inclusion in social life."[23] In just this way, "Blind Susan" offers a dream of cure that culpably individualizes the social norms and practices that marginalize its middling-class protagonist, and it dreams of "human similitude" not only by restoring a blind child's sight but also by killing her off. The story opens with an idealized domestic tableau that places the Mordant children and their mother in "employments" illustrative both of gender roles and of middle-class status. The three sighted daughters are little moral-mothers-to-be: Lucy, sitting near her mother, is hemming, "occasionally reminded of her work by a gentle tap from her mother's thimble."[24] Little Caroline is reading *Juvenile Miscellany*, and Isabel, the eldest sister, sits beside Susan and is "a sort of guardian angel to this unfortunate little girl."[25] All the children are homeschooled because Mrs. Mordant feared the "mortifications" that Susan might receive at public school, a bullying she does not seem to imagine might or should be challenged. Her belief that Susan would not "receive from her school-fellows that delicate attention which should always be shown to one in her situation" prepares readers to celebrate her own (moneyed) ability to provide such special care, and, soon enough, "the unwearied pains bestowed on [Susan] by her mother" give her a stock of knowledge beyond that of "many little girls who have all the advantages of sight."[26]

Susan is not permitted to be the protagonist even when she undergoes surgery to restore her sight: her siblings "striv[e] to make the scene pleasant to her who had been released, as it were, from prison."[27] Susan is no Peggy; she is encouraged neither to regret the burden her parents might carry by caring for her nor to learn to contribute to the household. Instead, her presumably ineradicable dependence makes her "a lovely flower … like one of those choice exotics which is sheltered with care, watched with assiduity, and loved and admired for its very delicacy."[28] Soon enough, she dies, as hymns are sung, promising reunion in a better world. The point of the story seems to be not Susan but Isabel, who returns to town to be "the guide and instructress of her younger sisters. The motherly narrator encourages her 'young readers,'" even those without blind sisters on whom to bestow their beneficence, to "copy [Isabel's] example," noting encouragingly the ease with which "other objects, on whom to exercise their benevolent affections" can be found. This training in domesticity is presented as training in activist work outside the home: "By cherishing and obliging dispensations in the family circle, they will be better prepared to perform kind offices to the wider world."[29]

"The Blind Child" and "The Blind Girl's Lament" offered readers a similarly sentimental vision of pitiable, useless middle-class blind girls whose value seems to lie only in the opportunity to demonstrate compassion that they provide their sighted family members and whose blindness disqualifies them for progress from girlhood to moral motherhood. "The Blind Child," a three-octave poem, assumes the point of view of a blind girl and entwines deification of a loving mother with a kind of death wish. The speaker opens by comparing heaven to her mother, first, as she imagines her eyes to be like "the broad heavens" and then as she imagines "the far-off land of bliss" as being like the experience of being held by her mother: "when my sad heart to thine is pressed" and "Sweet pleasure swarms my beating heart," she feels she is in heaven. The speaker then wonders if God could possibly be as kind as her mother—"Will he bestow such care and love // On a blind child like me?"—and asks her mother to accompany her to heaven. Here the rhetorical elevation of mothers to sanctification in a holy domestic space requires the radical disempowerment, even death, of beautifully helpless, useless blind girls: "Go with me when I die; // Lead thy blind daughter to the throne, // And stay in yonder sky."[30] Life is similarly not worth living for the eponymous "blind girl" of Mrs. C.H.W. Esling's "The Blind Girl's Lament" because she can see neither nature—God's expression of His greatness and love for humanity—nor the faces of her mother, father, and sisters. The only joy she feels in life is found at home: "Oh! if without, the world is drear, // Within, 'tis glad and bright, // While home and kindred claim me here, // Why mourn I for my sight?" The relief in her "darken'd days" she feels in the family circle predicts the greater relief that awaits her in heaven: "A brighter world awaits my gaze— // The blind shall see in heaven."[31]

"My Old Loved Home": Mary L. Day Is Not a "Blind Girl"

Soon after Mary L. Day was born, sighted, in 1836 in Baltimore, her mother's beloved hometown, the family was moved by her father, an adventure-loving tinsmith, to the Michigan frontier, where he built the family a log cabin in the small town of White Pigeon, not far from a lake around which "wigwams" were clustered. This was the era—the late 1830s and early 1840s—in which the Potawatomi of Michigan, Wisconsin, Indiana, and Illinois were, for the most part, removed by the government beyond the Mississippi. As a small girl, Day once hid in an oven to avoid encounter with "wild, fierce-looking savages;" her family, coming home one day, was astonished to be forced by "savages" to come to their settlement and eat venison, apparently as a gesture of neighborliness.[32] Among the griefs that the move caused Day's mother, "unaccustomed to hard or laborious work," was the loss of "faithful Aunt Patty, our servant, whom she had been obliged to leave behind on account of her being a slave."[33] Patty had been a wedding gift from a sister. These events, with which *Incidents in the Life of a Blind Girl* matter-of-factly begins, suggest both the wide world in which Day moved and its differentness from the politeness-pursuing New England urban life presumed by advice and juvenile literature in the early nineteenth century.[34] The western and southern settings of *Incidents* and the plots they provoke make Boston, the home of both Samuel Griswold Goodrich and Lydia Maria Child, seem exotic and irrelevant, providing "normalizing contexts" of the kind that Rosemarie Garland-Thomson notes tend to be stripped away in representations of disabled people as their lives are instead rhetorically "engulfed by a single stigmatic trait."[35]

Incidents describes Day's life from childhood to the age of 23; it concludes soon after she becomes a student at the Maryland Institution for the Blind. Its episodic nature and Day's youth and temperament allow *Incidents* to sidestep both the pernicious versions of blind girlhood prevalent in nineteenth-century popular culture and the equally unreal idealizations that Anne Finger has noted tend to entrap life narratives by disabled people, such as "the spunky cripple, the wounded hero, the tragic but brave overcomer."[36] The struggles that the book describes, including abandonment, abuse, poverty, and pain, do not provide it with a central plot generative of suspense and a happy ending (clichéd or otherwise). *Incidents* is instead as companionable and wide-ranging as are the railroad travels that recur in it, sometimes in pursuit of a cure, sometimes in pursuit of reconnection with family members. This structural looseness and Day's observant openness contrast sharply with the agenda-driven blind girl stories considered in the previous section and provide a structural metonym for the quality valued, and demonstrated, most steadily through the book: friendship, "as necessary to the happiness of the blind as to those who can recall glances of fond affection."[37] Friendship tends not to inspire the crisis-ridden plots that love and despair inspire, nor, perhaps, is it end-oriented in its temporality, seeking progress or resolution. To value it is both to be able to delight in a fellow traveler's companionship on a train trip and to see that friendship as different only in degree, not in kind, from familial intimacy.

This sustaining perception of family and friendship on a continuum is perhaps best exemplified by Day's experience of a train delay as she traveled alone from the Michigan frontier to be reunited with her sister in Chicago. Soon after the train derailed in an eight-foot snowbank, trapping passengers, Day was befriended by a gentleman who wondered if she needed help: they joke and share food and soon "it seemed as if I had always known him." A fellow traveler asks if they are related, another asks if he is her brother, and, when the train arrives finally in Chicago and they part, he refers to her as his sister.[38] This sustaining friendship does not extend beyond the days of the trip, and yet it is valued by Day and made part of her memoir. Day's nonsegregation of familial ties from other kinds of friendship is also evident in her appreciative remembrance of a friendly woman resident in a boarding house in which she had stayed: "I never loved a stranger as dearly as I did Mrs. Sherwood."[39] Day's experiences of friendship, with strangers and intimates alike, are nourishing because they are mutual; she provides and receives support, humor, and attention. This affirmation of the power of ephemeral kindness is credible because she attends as candidly to "incidents" of cruelty as to those of kindness; she does not overgeneralize her experiences of connection-in-transit as evidence of human nature or of conformity to ideals of gender or piety.

The blind girlhood that Day describes in *Incidents* differs markedly from that described in newspapers and advice and juvenile literature in several obvious ways, attributable in part simply to differences of genre. In *Incidents*, laboring-class children and blind children are not props in the idealized domestic dramas of middle-class mothers and sisters; instead every member of the two households in which Day finds family contributes toward survival, sharing equally in the pleasures of, for example, a thriving garden of beans. Blindness is common, recorded without comment. The initially impoverished Day, who starts life as a kind of Peggy (of "Good Will"), is not denied domesticity, though her experiences of familial support given by members of a laboring community are not unlike Peg's. At the same time, the rhetoric of blind girl stories does overlap with *Incidents* in two important ways: here, too, mothers are regarded as irreplaceable in their unique and necessary love, and here, too, girls are expected to acquire useful skills. But even in these two areas of similarity, crucial differences remain. Day bestows similarly intense sentimental effusions on both her birth mother and the woman who would today be called her adoptive mother, Mrs. Cook; and Day values her domestic skills in part for the way they allow her to run away from an abusive domestic setting, a household that makes Christianity seem hypocritical to her neighbors.[40]

Incidents also challenges blind girl stories in its attention both to the work involved in mothering and to the economic underpinnings of the cultural elevation of motherhood as the most important of affective ties. The Sarah Day (Mary’s mother) we see in *Incidents* is not an ideal or sentimental mother. As she lies ill in the family’s frontier home, her husband away looking for work, her five children go hungry, surviving only because they are able to find some root potatoes in the basement.[41] The “ecstasy” that family life brings the very young Mary Day, while her mother is alive, seems to reflect the joy of belonging to the group both in the positive sense of enjoyment of her siblings’ company and in the negative sense of not yet having been placed with strangers to work as a servant, as would be the immediate consequence of her mother’s death for all the children.[42] “Children, you are all together now, but may never be again,” asserts her father at Sarah’s deathbed, and Mary’s own lament for the loss of her mother is similarly voiced in the collective: “young as we were, we deeply felt our loss, yet the burden of our woe we realized not until years had sped away, proving how great a void is created in a child’s heart and life by a mother’s death!”[43] That “a family” requires a mother seems to be so deeply assumed that Day does not question her father’s abandonment of his children. When she meets her father again many years later, she cannot make herself “realize it was my father sitting by me.”[44] The lack of blame she feels suggests the superfluity of men to the constitution of families, be they good families or bad. Seeing her father again makes Day remember not her father as he was or her own younger self but the cruel woman with whom he’d left her. That it is only women who can be credited or blamed for family life extends and refracts the elevation of the moral mother praised by Theodore Parker, Horace Bushnell, and Susan B. Anthony.

Day’s birth family was dissolved by her mother’s death in 1846 because her father, unwilling or unable to care for his five children himself, immediately placed them with neighbors and left town. The six-year-old Day was placed in the household of an abusive woman, Mrs. Ruthven, whose cruelty is linked to her class pretentions. After two years of beatings and verbal abuse, Day ran away, living as a servant in a succession of households. When she was 12, she suddenly—within a 24-four-hour span—went blind.[45] For three months, the family with which she was living as a servant tried what remedies they could imagine before “threatening to send [her] to the poor-house.”[46]

That this family did not immediately presume Day's usefulness ended with her blindness, coupled with the description of Day's relationships with some six other blind people, reminds us both of the commonness of "blindness" in nineteenth-century America and of the wide range of conditions that caused it.[47] Mr. Cook, a stranger who happened to be on the premises as the disposal of Day was being discussed, brought her home to his wife and seven children, who warmly took her as one of their own and did so without extolling the special sanctity of home and without claiming compliance with religious precept.[48] Day's adoption by the Cooks and the forms that happy domesticity takes in their household do more than any other strand in the book to represent domesticity in terms that neither objectify blind people nor differentiate them from sighted people.

Where the high rhetoric of mother-love occurs in *Incidents*, it sentimentally casts mother-love as a kind of metaphor for time's passage and for loss. In *Incidents*, the pleasurable sadness that such rhetoric provokes is a vehicle not of incapacitating isolation but of friendship and community—a domestic intimacy regularly enacted in non-private settings and with atypical participants. Day befriends a flute-player who lodges with her sister, Jinnie, in Chicago and particularly enjoys his rendition of "Home, sweet, sweet Home," a song her mother loved. She records the lyrics—"I miss thee, my mother! Thy image is still // The deepest impressed on my heart, // And the tablet so faithful, in death must be chill, // Ere a line of that image depart"—and notes that the melody always reminded her of "the sad truth, she had left me, never to return!"[49] But the song, shared with a non-familial friend, prompts missing less of her mother, than of the time when Mary Day was one of five siblings, part of an "us" made possible by their mother's presence. Day values almost as greatly the comforting friendship made possible by the performance and hearing of the song. A similar commodification of mother-love in music enables nondomestic intimacy when the gravely ill David Loughery, the headmaster of the Maryland Institution for the Blind, shares with the teenaged Day a poem he has written, "My Mother's Parting Tear," which celebrates the sustaining memory of a mother's "fond look" over time and distance.[50] They talk about and listen to the poem, which another (blind) professor has put to music, and its thematization of memory and loss brings them closer and helps Day accept her beloved teacher's imminent demise. Mother-love thus serves as a kind of lingua franca that matters more in its function, enabling interpersonal connection, than in its literal content.

Incidents honors only some aspects of the nineteenth-century idealization of motherhood. Mothers are their children's best friends, and this mothering can be accepted from and offered to strangers as well as familial intimates, by men and women, boys and girls. Though Day never calls Mrs. Cook "mother"—although Mr. Cook tells his wife, when he brings the 12-year-old Day home, to "be as a mother to her"—she is unquestionably the emotional heart of *Incidents.*[51] Rather than the advice and discipline given by the mothers in blind girl stories, Mrs. Cook gives attention, and she is characterized independently rather than as part of an idealized dyadic relationship of caregiver and dependent. On her first morning in the Cook household, Day is overwhelmed by the warm clothes that Mrs. Cook gives her; Mrs. Cook also curls her hair, an act particularly evocative of pleasure, exceeding the necessities.[52] Mrs. Cook teaches Day to knit, helping her with "sweet and encouraging tones" to persist through a year of frustration.[53] The confidence this new skill gives Day leads her to ask a neighbor if she could do her winter knitting for her, for pay, so that she can help the struggling Cook family; Mrs. Cook is concerned but accedes to Day's wishes, and Day, proud of the dollar a week she now makes, strains as she knits to hear her adoptive mother's voice through the orchard that separates the two houses: "the sweetest … were the tones of her own loved voice."[54] When, after three years, a letter arrives from Day's sister, who is now married and keeping a boarding house in Chicago, Day "felt as though [she] could not tear [her]self away from [her] dear friends who had so faithfully supplied the place of father, mother, brothers, and sisters."[55] After two more years of imploring letters, Day decides to rejoin her sister; the tipping point is her sister's mention of an oculist who might be able to help her regain her sight. Mr. and Mrs. Cook take her aside on the day of her parting to remind her of their love for her and of the importance of integrity; her final moment is "fraught with anguish," and left at the train station by Mr. Cook, she feels again "a lonely wanderer among strangers."[56] But Mrs. Cook has packed her a big lunch, and this homely act of love sustains Day as she moves into the next chapter of her peripatetic life.

Day's happy domestic life with the Cooks is presented as different in degree but not kind from the sustaining intimacy she finds and cultivates with those she meets on trains, in her sister's boarding house, in doctors' offices, and doing errands. Mrs. Cook's singular and supreme significance to Mary rests upon her delight in and dependence upon Mary and the mutuality that is also evident in more casual acquaintanceships. In this way, the domestic intimacy of the Cook household is presented as friendship, not as confirmation of piety or social status. Mrs. Cook's regular letters "afford [Day] unutterable delight," attesting to Mrs. Cook's own delight in Day.[57] She is supported through difficulty by this reality: "Oh! How I longed to be once more in my country home!"[58] It is Day's occasional longing to "go to Mrs. Cook, and never leave her again" that helps her keep going.[59] The terms in which she later generalizes friendship, the value of which runs steadily through the book, apply as well to Mrs. Cook as to the conversation with her fellow students in the Maryland Institution for the Blind that inspire them: "Sweet Friendship, with her fond endearments, is as necessary to the happiness of the blind as to those who can recall glances of fond affection."[60] It is, in a way, the ephemerality of these "endearments" that makes them potent; each "act of kindness" attests to momentary attention and connection, not to the achievement of self-congratulatory power over another: "Persons are but faintly appreciative of the sensitiveness of the blind to acts of kindness. Though trifling in themselves, little acts or little words breathing tenderness will endear a stranger to them at once."[61]

Mrs. Fannie Cook's death should be understood as the climax of *Incidents*. As we have seen, the middle-class blind girls imagined in juvenile and advice literature often die sentimentalized deaths that suggest an inability to imagine adult blind women as heads of households. The sad deathbed scenes in *Incidents* contrast revealingly with the style and substance of that formula. After three years in Chicago, Day travels back to the Cooks' for a visit. She feels feverish as she boards the train but does not realize that she has caught typhoid. Mrs. Cook greets her happily when she arrives and urges her to rest after her travels: "my head was pillowed on her bosom, and I was nearly smothered with kisses from the girls."[62] They soon realize that she is seriously ill. Day is "happy in thinking I would die in my old loved home, and be buried in the quiet grave on the hillside," a portrait of a blind girl on her deathbed in which she is the narrating subject and that attests not to any sense of the uselessness of a blind woman's life but rather confirms her humility, borne of her early poverty.[63] She understands herself to be vulnerable as are all around her to disease, a humility that contrasts sharply from the entitlement to progress associated with the fictional protagonists of blind girl stories.

As Day faces death, she thinks about the family she loves—the Cooks and her sister, Jinnie, to whom a letter has been sent urging her immediate travel to be with Mary. Even as the unique potency of Mrs. Cook's steady love is affirmed in these scenes of sickness, she is described only as "like a mother:" "Mrs. Cook arranged my pillow with all a mother's tender care. How like a mother she had seemed to me in my desolate orphanage."[64] Day remembers several stanzas of an 1844 poem by the English author Eliza Cook that was reprinted, often uncredited, in newspapers and in anthologies throughout the nineteenth century:

> I miss thee, my mother, when young health has fled,
> And I sink in the languor of pain;
> Where, where, is the arm that once pillowed my head,
> And the ear that once heard me complain?
> Other hands may support me, gentle accents may fall,
> For the fond and the true are still mine:
> I've a blessing for each; I am grateful to all,
> But whose care *can* be as soothing as thine?[65]

No reason is given for Day's relocation in a carriage to a neighbor's; that reason may have been Mrs. Cook's own illness, possibly with the typhoid that Day brought from Chicago. Mary Day would never again see Fannie Cook. For during the few weeks of Mary Day's slow recovery, Mrs. Cook grew sick and died: "her pure spirit went home, that she reap the reward promised the faithful."[66] This death registers all the more deeply for the simplicity with which it is recorded, accepting loss as part of life and refusing the generic furbelows of sentiment.

Near the end of *Incidents*, Day addresses the educability of blind people, calling for an education that involved reading, household skills, and the acquisition of marketable skills not unlike the education reserved for the middle classes in the blind girl stories considered above. She demands education for blind people in the name of their human sociality and will to independence, deeming helplessness, isolation, and sadness to be unnatural creations of social arrangements that can and must be changed. If domestic feminism sought restoration of a natural female morality and social force, Day's model of education restores and preserves the natural intelligence and agency of blind people:

> The educated blind in their own homes are as useful and industrious as are those who have not been deprived of their sight. They are handy and ingenious. Generally speaking, they are cheerful and happy in their disposition, social in their feelings, cherishing the most delicate sympathy for each other.[67]

Education reveals human nature here; it does not, as in the children's literature considered earlier, create it in those children eligible for it by virtue of nondisability and class standing.

This direct challenge to the era's stereotypes of blind girls, articulating views implied by Day's story of her childhood and early teen years, makes the preface particularly disappointing, if not surprising. In the preface, Day's uncle, Rev. Charles F. Deems, casts his niece as a kind of Peggy, suggesting to the middle-class readers he imagines that they read the book as a kind of sermon against "idleness." "[A]ll our young ladies, daughters of loving parents, daughters who have no care for the morrow, daughters of delicious ease and happy opportunity" should "let their consciences ask them" how they would fare "at the judgment seat of Christ, in contrast with this blind girl's industry, fidelity, and perseverance."[68] Deems may presume a sighted readership, but Day does not; Deems may define his niece by her blindness, but Day herself does not do so. This mediation of the text suggests both the pervasiveness of blind girl stories and Day's success in narrating her life differently. For to read Mary Day's "blind girl story" as one in a series is to see clearly its critique of domesticity, as shifting and even contradictory as this ideal was and is.

Disability Studies has long attended to the ways that discrimination against disabled people is often deflected into other categories of identity that disability is held to distort.[69] It is time to add childhood to imbricated strands of self-narration with which we consider the domestic lives of blind people. Read from this perspective, *Incidents in the Life of a Blind Girl* pushes us to see that the project of understanding the imbrication of domesticity and disability in the nineteenth century requires close attention to class, gender, and region, the axes of identity that produced the new model of childhood that *Incidents* so powerfully challenges.

Notes

1. Mary L. Day, *The World as I Have Found It* (Baltimore: James Deems, 1878), 180.
2. Day, *The World as I Have Found It*, 181.
3. Simi Linton, *Claiming Disability: Knowledge and Identity* (New York: New York University Press, 1998), 114.
4. Beth English, "Child Labor." in Eric Arneson, ed., *Encyclopedia of U.S. Labor and Working-Class History*, volume 1 (New York: Routledge, 2007), 237.

5. Steven Mintz, *Huck's Raft: A Cultural History of American Childhood* (Cambridge: Harvard University Press, 2004), 91.
6. Mintz, *Huck's Raft*, 91.
7. Mintz, *Huck's Raft*, 91.
8. Gillian Brown, "Child's Play," in Caroline F. Levander and Carol Singley, eds., *The American Child: A Cultural Studies Reader* (Brunswick, NJ: Rutgers University Press, 2003), 25.
9. Melanie Dawson, "The Miniaturizing of Girlhood: Nineteenth-Century Playtime and Gendered Theories of Development," in Levander and Singley, *The American Child*, 64.
10. Dawson, "Miniaturizing," 66.
11. Theodore Parker, "A Sermon of Man" (1841), in *West Roxbury Sermons of Theodore Parker (1837–1848)* (Boston: Roberts Brothers, 1892), 98–99.
12. Horace Bushnell, "Family Prayers," in Horace Bushnell, *Christian Nurture* (New York: Scribner, Armstrong & Co., 1871), 406.
13. Susan B. Anthony, ed., *History of Woman Suffrage*, Volume III (1876–1885). (Rochester, NY: Charles Mann, 1886), 34.
14. United States Bureau of the Census. *The Blind in the US, 1910* (Washington, D.C.: Government Printing Office), 1917, 11.
15. Carolyn L. Karcher, *The First Woman in the Republic: A Cultural Biography of Lydia Maria Child* (Durham: Duke University Press, 1998), 57.
16. James Marten, *Children and Youth in a New Nation* (New York: New York University Press, 2009), 3.
17. See Andrew O'Malley, *The Making of the Modern Child: Children's Literature and Childhood in the Late Eighteenth Century* (New York: Routledge, 2004), 48. Writing of Thomas Day's late-eighteenth-century English works for children, O'Malley writes, "Such happy examples of honest laborers teach middle-class children … that the poor have no desire to become rich."
18. Dawson, "Miniaturizing," 64.
19. Mintz, *Huck's Raft*, 76.
20. Mintz, *Huck's Raft*, 92.
21. Mintz, *Huck's Raft*, 90–91.
22. Bushnell, "Family Prayers," 406.
23. David Mitchell and Sharon Snyder, "'Jesus Thrown Everything Off Balance': Disability and Redemption in Biblical Literature," in *This Abled Body: Rethinking Disabilities in Biblical Studies*, ed.

Hector Avalos, Sarah J. Melcher, and Jeremy Schipper (Atlanta: Society of Biblical Literature, 2007), 183.
24. Lydia Maria Child, "Blind Susan" in the Juvenile Miscellany 3, 2 (November 1827), 127.
25. "Blind Susan," 128.
26. "Blind Susan," 128.
27. "Blind Susan," 135.
28. "Blind Susan," 138.
29. "Blind Susan," 138–139.
30. Mrs. (Felicia) Hemans, "The Blind Child," *Farmer's Cabinet* 38:47, July 17, 1840, [1].
31. Mrs. C.H.W. Esling, "The Blind Girl's Lament," *New Hampshire Patriot and State Gazette*, May 14, 1841, 4.
32. Mary L. Day, *Incidents in the Life of a Blind Girl* (Baltimore: James Young, 1859), 26, 12.
33. Day, *Incidents*, 10, 8.
34. See Michael Piersen's attribution of the "contested" status of domestic feminism in terms of its "small demographic base," centered in the northeast. *Free Hearts and Free Home: Gender and Antislavery Politics* (Chapel Hill: University of North Carolina Press, 2003), 12.
35. Rosemarie Garland Thomas, *Extraordinary Bodies: Signifying Disability in American Culture and Literature* (New York: Columbia University Press, 1997), 11.
36. Anne Finger, "Writing Disabled Lives: Beyond the Singular," *PMLA* 120, 2 (March 2005), 613.
37. Day, *Incidents*, 177.
38. Day, *Incidents*, 80, 83, 85.
39. Day, *Incidents*, 160.
40. Day, *Incidents*, 63.
41. Day, *Incidents*, 18.
42. Day, *Incidents*, 24.
43. Day, *Incidents*, 31, 28.
44. Day, *Incidents*, 149.
45. Her description of the "cloud" that descended on her vision, the weeping, inflamed eyes that followed, and her total loss of vision after only 24 hours makes it likely that she lost her vision to trachoma, an inflammation caused by a bacterium that is carried by gnats and flies and that to this day robs people, especially in

developing countries, of their sight by causing scarring of the eyelids and rotation of the eyelashes inward.

46. Day, *Incidents*, 69.
47. Mr. Lee, who had studied law and boards with Mrs. Ruthven, defends Mary Day against her abuse (39). Mr. Cook has a blind niece, Almeada, whom Mary Day befriends (73). In New York to investigate a surgical cure, Day meets a boy, Willie, who had accidentally blinded himself by "stick[ing] a knife in [his] eye" (156). The other students in the Baltimore Institution for the Blind—Mary Vernon, Anna Buckler, Mary Poteet—are blind, as is the music teacher, J.E.S. Magruder, and the headmaster, David Loughery.
48. Adoption not "formalized as a legal procedure with concern for children's welfare" until the mid-nineteenth century; in 1851, some five years after Day was taken in by the Cook family, Massachusetts became the first state to institute such laws. See Imagining Adoption (Novy 4).
49. Day, *Incidents*, 100.
50. Day, *Incidents*, 172.
51. Day, *Incidents*, 69.
52. Day, *Incidents*, 71.
53. Day, *Incidents*, 72.
54. Day, *Incidents*, 75.
55. Day, *Incidents*, 76.
56. Day, *Incidents*, 78, 79.
57. Day, *Incidents*, 95.
58. Day, *Incidents*, 94.
59. Day, *Incidents*, 94.
60. Day, *Incidents*, 177.
61. Day, *Incidents*, 176.
62. Day, *Incidents*, 109.
63. Day, *Incidents*, 110.
64. Day, *Incidents*, 111.
65. Day, *Incidents*, 111–112. Day does not credit Eliza Cook; she may have encountered the poem in one of its many anonymous reprintings—for example, The Suffolk Literary Chronicle, Vol. 1 (Ipswich, MA: John King, 1838), 12. The poem appeared in Cook's Melaia, and Other Poems (New York: J. and H.G. Langley, 1844), 152–153.

66. Day, *Incidents*, 112.
67. Day, *Incidents*, 175–176.
68. Day, *Incidents*, 4.
69. See Mitchell and Snyder's discussion of the way that "the presence of disability often impairs the normative expectations of other foundational social roles such as gender" in "'Jesus Thrown," 175.

CHAPTER 3

Crossing the Threshold: Disability and Modernist Housing

Beth Tauke and Korydon Smith

"Home" is a common yet highly complicated term. As social and political scientist Shelley Mallett reminds us, "The term home functions as a repository for complex, inter-related and at times contradictory socio-cultural ideas about people's relationship(s) with one another … and with places, spaces, and things."[1] Concepts of "home" and philosophies of home design are as varied as the geographies and histories of human civilizations; and scholars have analyzed the meaning of home from positivist, constructivist, deconstructionist, feminist, and other perspectives. Analyses and interpretations of home from a disability studies perspective are far more recent, despite the fact that physical/mental well-being is intimately tied to one's home (country, city, neighborhood, and residence).[2]

Parallel to "home," is "house," its commonly used architectural surrogate. "House" has been examined through economic, technological, environmental, and policy lenses, and according to each of its constituent elements—walls, floor, and roof; bathroom, kitchen, and bedroom; lighting and acoustics, and so on. Yet one of the most significant functional and psychosocial elements of the house, the threshold, remains relatively

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understudied, particularly from a disability studies perspective. In home design, thresholds (or transitional spaces) play an especially critical role in establishing or communicating a variety of dualities—public/private, open/closed, and so on—and their designs significantly impact the experiences of people across disability groups. This includes mobility, dexterity, perception, and cognition. While much has been researched and written about the impacts of threshold design on users of mobility devices or individuals with visual impairments, the importance of threshold design has, more recently, also been linked to the functioning and experiences of individuals living on the autism spectrum and those living with other cognitive disabilities.[3]

The importance of the psychological and emotive qualities of architectural experiences cannot be overstated, though their complexities are difficult to untangle. In this chapter, we refer to the aesthetic experience of architecture. Aesthetics, like our definition of thresholds, is not regarded as a two-dimensional, stylistic, vision-only concept; nor is it perfectly synonymous with beauty.[4] In analyzing the houses included in this chapter, we define aesthetics as the holistic sentiment of—the fairly immediate cognitive, affective, and corporeal reaction to and interaction with—an artistic work. For the architect-as-artist, space, geometry, structure, and materials are used to modulate light, sound, smell, texture, and embodiment. Physical structures, the material objects housed inside them, and the humans (and other life forms) residing in them work together to construct meaning and value. Cultural symbolism and individual ideologies are critical in these interactions, influencing the degree to which an architectural work resonates (or is dissonant) with an inhabitant. No place is this more significant than the home, which holds such immediate and emotion-laden meanings.

While the colloquial meaning of threshold is two-dimensional, often referring to the board, stone, or other material that rests at the bottom of an entry or doorway, the discipline of architecture views thresholds as three-dimensional and spatial. Most simply, thresholds are “in-between,” or liminal spaces that serve both to separate and connect adjoining spaces. Depending on how it is designed, a threshold may promote a feeling of being “here-and-there” or a sense of being “neither-here-nor-there.” The resultant perceptual effects depend on the spatial syntax deployed. Classical architects, for example, often utilized definitive spatial boundaries (e.g., four-walled rooms with minimal openings), while modernist architects often designed ambiguous spatial boundaries (e.g., independent planar elements with large spaces between them), as exemplified in Mies van der Rohe's German Pavilion at Barcelona (1929). The founding assumption of this chapter, therefore, is that focused analyses of threshold spaces can provide unique and valuable insights into the meaning of home and the interpretation of disability.

We have chosen to discuss three archetypal houses of the early twentieth century—the Darwin D. Martin House (1904, Buffalo, NY, USA), Villa Savoye (1931, Poissy, France), and the Rietveld-Schröder House (1924, Utrecht, Netherlands). All three houses are considered masterworks of the leading architects of the time: Frank Lloyd Wright, Le Corbusier, and Gerrit Rietveld. Though all are considered modernist, each house is demonstrative of one archetypal approach to space-making and design. All have been well documented and researched in architectural history, yet, to our knowledge, none have been analyzed from a disability studies perspective focused on threshold design. At first glance, this selection of houses may appear unusual because none of them meet current accessibility standards. From a historical perspective, however, each home charts new ground in the creation of domestic spaces and marks a significant step toward built environments that meet the needs of more people, especially individuals with various physical, sensory, and cognitive abilities.

The design and construction of the three homes explored in this essay can be explained in part through technological advances made at the end of the nineteenth century that made new building configurations possible, which, in turn, changed the ways that people perceived and occupied various dwellings. Moving away from wood and stone toward steel and reinforced concrete allowed for larger, more-open spaces. New methods of production enabled steel, which was much lighter than iron, wood, or stone, to be rolled into girders of longer length. Buildings no longer had to rely on walls for support. New structures with steel skeletons could then be clad in a variety of materials, including larger swaths of glass, thereby increasing physical and visual connectivity between interior and exterior spaces. In addition, steel technologies gave new life to an ancient material, concrete. Strong in compression but weak in tension, concrete, when integrated with steel reinforcement, became strong in both compression and tension.[5] Advancements in reinforced concrete, structural steel, and plate glass led to rapid architectural explorations and innovations in early skyscrapers in Chicago and New York. Contemporaries and successors to these architects realized the creative possibilities that these building technologies offered to domestic architecture.

The reconceptualization of the threshold lies at the heart of these technological innovations. Modernist dwellings had more open and fluid plan (interior) configurations than their Colonial or Victorian counterparts, which had cellular (individual, walled-off) room arrangements. Also, by comparison, Modernist facades (exteriors) were more porous. Both the design of the plan and the façade allowed greater physical, visual, and acoustic connectivity between inside and outside, as well as among interior spaces. In short, the hierarchy between room and threshold was inverted. Thus, the experiential power of threshold spaces emerged as a driving architectural force that not only continues in home design today but also has tremendous implications for disability and domesticity.

Darwin D. Martin House

Although he was well aware of architectural innovation in Europe, Frank Lloyd Wright's sensibilities were primarily influenced by the themes of nineteenth-century romantic writers such as Thoreau, Emerson, Melville, and Whitman. Wright embraced the wide, flat, open spaces of the rural USA and sought to create an American modern architecture that embodied democracy, honest expression, a pioneering sensibility, freedom of the individual, and equal opportunity. This thinking led Wright to develop the Prairie Style using the principles of horizontality, sympathy with the site, material expression, spatial continuity, domestic symbolism, and individual character.[6]

The Martin House Complex, built for the wealthy Buffalo businessman Darwin D. Martin, his wife Isabella, his sister Delores, and her husband George F. Barton, is considered one of the most developed of the Prairie Houses. Built between 1903 and 1905, Wright considered it to be his "opus." The complex consists of a series of connected buildings: the Martin House proper, a pergola that connects the house with a conservatory, and a carriage house and stable. A smaller residence, the Barton House and a gardener's cottage are part of the overall composition but are not connected to the main structures. Given their spatial innovation and attendant social consequences, the primary spaces on the first floor of the Martin House are the focus for this discussion.[7]

Spatial Syntax

The library, living, and dining rooms are the main spaces of the Martin House; they look out onto a covered veranda and framed view of the neighborhood. In these spaces, thresholds are liberated from their typical configurations as openings in walls and material (or elevation) changes on the floor. Instead, thresholds are assigned to the ceilings only and act as indicators of spatial change rather than physical separation. Wright wrote about his Prairie Style intentions for the house, which included a rationale for the placement of thresholds near or on the ceilings:

- To reduce the number of necessary parts of the house and the separate rooms to a minimum, and make all come together as an enclosed space—so divided that light, air and vista permeated the whole with a sense of unity.
- To eliminate the room as a box and the house as another by making all walls enclosing screens—the ceiling and floors and enclosing screens to flow into each other as one large enclosure of space, with minor subdivisions only.
- [To] make all house proportions more liberally human, with less wasted space in structure, and structure more appropriate to material, and so the whole more liberal.
- To harmonize all necessary openings to "outside" or to "inside" with good human proportions and make them occur naturally—singly or as a series in the scheme of the whole building.[8]

For Wright, a new architecture meant creating a "more liberally human" dwelling along with "less wasted space." A paradox by today's standards, the former was an assertion of democracy and a departure from the palaces, cathedrals, and other monuments of the past meant to please royalty, the clergy, and the gods, while the latter stemmed from efficiency, utility, and "good human proportions," common in evolutionary and eugenics discourses at the time, as well as in architectural and engineering ideals concerning factory design (Fig. 3.1).

Practically speaking, new structural materials and systems made it possible for Wright to realize his ideals by relegating both the visual and physical thresholds to beams, detachable curtains, and moldings. This creates what architectural theorist Jean LaMarche calls "phantom walls"—the implication that walls have been removed:

> Whenever subjects moved through the framework defined by these elements, they passed through traces of former barriers, now phenomenally "transparent," and emerged on the other side without any resistance whatsoever,

Fig. 3.1 Interior view of the Darwin D. Martin House from the dining room toward the living room, veranda, and library. The living room appears in the foreground, framed by brick columns and ceiling details. On the left, an area with a lower ceiling connects the living room to the exterior veranda. Photographer: Biff Henrich/IMG_INK, Courtesy Martin House Restoration Corporation

> except for that created by the mental drag of familiar, unconscious expectations of conventional separations between rooms or functions. This manifested a new architectural experience of freedom.[9]

The sensorial and affective experiences created through Wright's design were markedly different than previous eras. This new modern sensual experience was also achieved by moving structural loads away from the exterior walls, which allowed for thresholds of glass. In the Martin House, this takes the form of rows of French doors between the living room and veranda. The full-length art glass curtain of doors establishes a nearly transparent threshold from "inside" to "outside." The tile on the interior floor continues onto the veranda, and the no-step entrance ensures even flow from one space into the other. When the doors are open, the space is expansive, exaggerated by the low overhang covering the veranda. The threshold between interior and exterior has all but disappeared, creating an initial and immediately felt disorientation in the occupant of the home—because it is so "different." Yet, as time passes, the spatial continuity evokes a liberating sense of being able to move, while also maintaining a sense of boundedness rooted in varying human potentialities—something that no social model of disability or design approach had yet (potentially, *has* yet) achieved. La Marche contends that "the elimination of barriers and the reduction of physical thresholds created at least two opportunities for the new architecture to present experiences of freedom in the Martin House. These were the freedom to move and the freedom to see."[10]

Implications for Mobility, Perception, and Cognition

The Martin House is not "accessible" according to present-day architectural standards in the USA, UK, and elsewhere, particularly due to the stepped entry sequence and second-floor sleeping spaces. Yet it offers disability studies scholars and architects interested in thinking critically about disability numerous possibilities for interrogating the design of domestic and other social spaces. The entry porch aside, the open and non-stepped ground floor promotes continuity of and movement between spaces. This is particularly the case for the linear arrangement of the dining, living, and library spaces. The strategy of utilizing the ceiling, rather than the floor or walls, to communicate primary spatial information makes for reading a single, long space that has been subdivided and allows for level, unencumbered movement.

Visual and acoustic connectivity among the spaces is also achieved, while the articulation of the ceiling, the openness of walls, and the presence of furnishings and textiles diminish reverberation. Although the extent to which Martin or Wright thought in these terms is uncertain, the positioning of furnishings and other material objects also provides important markers for people with visual disabilities, while the open spaces facilitate signed and other forms of embodied communication.[11] The threshold spaces between these rooms are particularly "intimate" in their acoustic and visual properties.[12] The alternating rhythm of rooms and threshold spaces, along with their respective acoustic properties, also (presumably) offers choices to residents and guests seeking different levels of interaction.[13] As science has shed more light on the variety of psychological and behavioral "traits" (inborn tendencies) and "states" (situational attributes) of humans, the field of environmental psychology, as well, has illuminated how various traits and states play out in the built environment, particularly in domestic and social settings, and how spatial characteristics inflect behavior. The Martin House offers the choice of being at the center or perimeter of each space, i.e., to be an active participant or a passive observer. The threshold or boundary spaces, in particular, provide an "at-home" experience for someone who is reserved or introverted, as the alignment of seating with the lowered ceiling provides separation from the center of the activity while still allowing visual and auditory access to it.

These types of threshold spaces have even been linked to alleviating body image aberrations such as fragmented coenaesthesis—feelings of a segmented, rather than whole body, and a loss of the sense of body boundaries—that people diagnosed with schizophrenia commonly experience.[14] A contemporary of Wright and student of Freud, psychiatrist Paul Schilder, wrote of a client who described a loss of body-image unity:

> When I get this anxiety I cannot walk further… It breaks me into pieces. I am like a spray. I lose my centre of gravity… I have gone to pieces. I am like a marionette. I lack something to hold me together. I am not on the earth; I am somewhere else; I am in between.

She continues, "When I am melting I have no hands, [and] I go into a doorway [a threshold space] in order not to be trampled on. Everything is flying away from me. In the doorway I can gather together the pieces of my body."[15] Though it has not been studied regarding schizophrenia, it is plausible, from research in areas such as Alzheimer's disease, that threshold spaces of some types may facilitate the retention of cognitive maps.[16] Complex circulation patterns or cellular room arrangements necessitate that the occupant retain a memory of the arrangement and proximities of spaces. Because of the visual connectivity between spaces in designs like the Martin House, there is a lesser burden on spatial memory. Research in 2011, for example, revealed that the act of walking through doorways to move from one room to another can hinder short-term memory.[17] Researchers referred to doorways as "event boundaries" that result, psychologically, in "event segmentation," that one's memory of recently experienced objects or events "is affected by the structure of the surrounding environment," notably thresholds. In an interview, the lead scholar, Gabriel Radvansky, quipped, "Doorways are bad. Avoid them at all costs."[18]

For the design of the primary spaces of the Martin House, this is what Wright did—avoid doorways. There is no evidence to state definitively that Wright's emphasis on spatial continuity and spatially deep, rather than abrupt, thresholds was psychological in origin. Nevertheless, architectural historian and theorist, Vincent Scully, drew parallels between the work of Freud and Wright, stating that the former sought to unravel the secrets of psychology that might heal society and that the latter, "moving from the opposite direction," sought to construct "the ideal, sane environment" for society.[19] Spatial continuity, nevertheless, as evidenced in the Martin House, has been thought to offer continuity of psyche. Likewise, the connection to the exterior promotes a sense of freedom, of not being bound to the interior, a phenomenon that many individuals with mobility, cognitive, emotional, and sensorial disabilities experience. This continuity is most evident in the cross axis that links the living space to the veranda, where the series of five leaded-glass doors provides a porous relationship between interior and exterior spaces, while the walled-in veranda with its low-hanging roof provides a sense of security that might alleviate anxieties brought on by open spaces with no clear boundaries. The transitional space enables both functional mobility—with ample room for approach and passage—and the perception of projected (or prospective) mobility, of occupying the veranda in one's mind, and, in that sense, the space becomes enabling rather than disabling.

Villa Savoye

In contrast to Wright, Le Corbusier, arguably the most influential architect of the Modern Movement, found most of his influences in machine production and the resultant artifacts and images of industrial society. A proponent of the scientific method and social engineering, he favored logic, clarity, and economy in his work. To that end, he developed a rational method for the design of houses based on a systematic analysis of the traditional European home. He termed this new approach "the five points of architecture: *pilotis* (columns), free plan, free facade, horizontal ribbon windows, and roof gardens."[20] Villa Savoye is considered to be the prime example of Le Corbusier's elucidation of the "five points." Designed by Le Corbusier and his cousin, Pierre Jeanneret, the reinforced concrete house was commissioned by the Savoye family as a weekend country house in Poissy, just outside of Paris. The villa is one of the most famous of modernist houses, and is, perhaps, the best example of Le Corbusier's claim that "a house is a machine for living in."[21]

Spatial Syntax

Built between 1928 and 1931, Villa Savoye is based on a modular plan that reflects Le Corbusier's profound interest in movement through space. He wrote, "In this house, we are presented with a real architectural promenade, offering prospects which are constantly changing and unexpected, even astonishing."[22] (Figs. 3.2 and 3.3)

Because the ground floor area blends into the site, Villa Savoye, supported by *pilotis*, seems to float in a forested backdrop. The curved façade on the lower level mimics the turning radius of automobiles of the day, and allows the motorist to enter into the driveway and garage with ease. Inside the entrance is a ramp on the central axis flanked by service spaces. The ramp moves up to the main living spaces, which are banded with ribbon windows on all sides, and proceeds all the way to the roof garden and curved solarium. A companion spiral staircase acts as another mode of vertical circulation between all levels, but is considered subservient to the ramp. The ramp, stairs, ribbon windows, and open terrace on the main floor provide openings that let light and air enter throughout the house.

The ramp is the primary threshold in Villa Savoye; it negates the notion of threshold as a line or plane, and extends it into a long, continuous transition in space and time that defines the experience of the house. Colin Davies, scholar of twentieth-century housing, asserts: "The ramp is key. From the austere, factory-glazed entrance hall it rises in two stages to the *piano nobile*, where it steps out onto the terrace and rises another two stages to the solarium… The proper way to enjoy the spaces is by means of the slow, continuous, ceremonial procession of the ramp."[23] At the end of each run, Le Corbusier and Jeanneret framed a hint of the next space, beckoning those on the journey upwards to continue. As such, the ramp is a transitional place of anticipation, a threshold that blurs inside and outside. As the centerpiece of the house, it suggests "a pervasive movement, upwards and outwards, towards the landscape and the sky; towards nature."[24]

The ramp in Le Corbusier's work reflects his interest in mechanization, specifically motorized travel within the modern city. With roots in antiquity, the ramp extends forward "as an instrument of a twentieth-century ritual … manifesting a transcendence, whereby the active participant

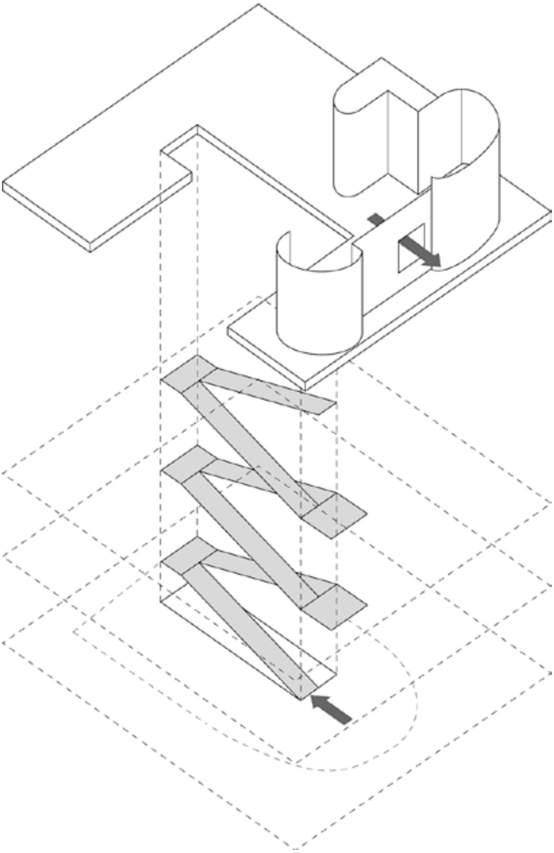

Fig. 3.2 Illustration of Villa Savoye ramp to roof garden and solarium, and diagram of ramp moving through the floors. The photograph positions the viewer on the ramp ascending to the roof garden with a view to both the sky above and the solarium below. The ramp is situated at the central access of the house and is the primary access between the floors. Illustrator: Megan Basnak, 2015, CC BY-SA 2.0 (https://www.flickr.com/photos/roryrory/2520027795/in/photolist-4QFNt6-52YWbw-4QL18j-557mNx-557mHR-4QFNAk-4QKZWY-56w76y-4QFNhr-4QFNDB-4QFNBF-58TdCi-4QFNiZ-56w6Ro-56w7bf-5aGT6x-5aMa6y-4ZjtPE-5aGT2r-526mxC-53JLX4-53hafu-522868-56rWuv-58TdPp-4QKZPq-4ZknRm-53JLZ2-5aGTbp-4Zfg6x-51NwGg-56rWnD-4Zfg3e-52282i-5HKDwR-mXsVJM-2G9bVY-2G9aS5-2G99su-2G4SK4-fkpEgs-2G99C5-mXvism-fjKtPh-2G9bdS-2G9aEs-2G4Ps4-2G4RNa-fiPSSa-2G9a9E)

Fig. 3.3 Photograph of Villa Savoye ramp to roof garden and solarium, and diagram of ramp moving through the floors. The photograph positions the viewer on the ramp ascending to the roof garden with a view to both the sky above and the solarium below. The ramp is situated at the central axis of the house and is the primary access between the floors. Photographer: Rory Hyde, Le Corbusier—Villa Savoye, 1928–1930, CC BY-SA 2.0 (https://www.flickr.com/photos/rory-rory/2520027795/in/photolist-4QFNt6-52YWbw-4QL18j-557mNx-557mHR-4QFNAk-4QKZWY-56w76y-4QFNhr-4QFNDB-4QFNBF-58TdCi-4QFNiZ-56w6Ro-56w7bf-5aGT6x-5aMa6y-4ZjtPE-5aGT2r-526mxC-53JLX4-53hafu-522868-56rWuv-58TdPp-4QKZPq-4ZknRm-53JLZ2-5aGTbp-4Zfg6x-51NwGg-56rWnD-4Zfg3e-52282i-5HKDwR-mXsVJM-2G9bVY-2G9aS5-2G99su-2G4SK4-fkpEgs-2G99C5-mXvism-fjKtPh-2G9bdS-2G9aEs-2G4Ps4-2G4RNa-fiPSSa-2G9a9E)

glides into the realm of the thoroughly modern."[25] This interpretation of the ramp deems the threshold as a space–time continuum, a dynamic space of speculation that changes the hierarchy of traditional housing design. Traditional houses emphasize the design of rooms and diminish the importance of circulation spaces, while, in the Villa Savoye, Le Corbusier designed the ramp as the feature with the greatest organizational and experiential importance.

Implications for Mobility, Perception, and Cognition

Ramps have become ubiquitous architectural tools to achieving accessibility between spaces at different levels for various user groups—ambulatory occupants, users of wheeled mobility devices (wheelchairs, power scooters, baby strollers, etc.), and individuals with a shuffling gait or mobility aids. Not only do ramps provide functionality, they have become symbolic of accessibility, though this was not always the case. The use of ramps as an integral design element dates, at least, to Ancient Egypt and ramps have been variously used throughout history and across geographies, quite famously in Wright's design of the Guggenheim Museum in New York City (1959). Some ramps—specifically the ad hoc, nonintegrated additions prevalent throughout rural America—have a negative and stigmatizing quality, conveying a message that the ramp, and, by extension, the inhabitant, is out of place (not at home).[26] Other ramps have a more positive (or neutral) symbolic presentation.

Such is the case of the ramp in Villa Savoye. The design, along with Le Corbusier's own writings, emphasizes the ramp as "the most characteristic feature" of the house. In contrast to the stair, which "separates one floor from another," Le Corbusier viewed the ramp as an element that "links them together," emphasizing a spatial experience of movement over stasis, continuity over segmentation, and variety over homogeneity.[27] Its positioning as an interior element, and, more importantly, its alignment with the structural grid and central (entry) axis of the plan, connects—physically, visually, and acoustically—the ramp to the primary spaces of the house. The stair, counter to both traditional and contemporary conventions, is placed in a secondary, objectified position. While not designed with disability in mind, this strategy exemplifies the notion that disability is largely an environmental construct, a design consequence. It also demonstrates the possibilities of what might be if architects, contractors, and governments thought beyond basic accommodation and minimum standards of accessibility to something that places nonnormative embodiments at the center of planning and construction. From an emancipatory paradigm, the inversion of the conventional roles of stair and ramp results in a redefinition of disability, where "abled" and "disabled" user groups are given equivalency. The ascension of the ramp offers "the best" experience of the house—increasingly broad swaths of sunlight and widening glimpses into adjoining spaces that culminate in a release onto the roof garden with distant views of the landscape and sky.

The aesthetic experience is a physical uplifting of the body and a metaphysical uplifting of the psyche. The expanse of nature—landscape and sky—is brought into contact with the immediacy of the body and the building. This drawing together and negotiation of scalar extremes is what modernist housing sought to achieve. The capacity for architecture to modulate human emotions further emphasizes the importance and challenge of designing domestic spaces. Inadequate, inequitable, or ill-suited housing, which people across disability groups commonly experience, can evoke parallel feelings of inadequacy, discrimination, or discontent. By contrast, modernist architects such as Le Corbusier contended that architecture could lift the human spirit and evoke responses not present in previous architectural works (or other art forms). Established twenty-first-century architect and theorist Juhani Pallasmaa asserts that beauty is an essential part of architecture, as beauty brings with it hope, dignity, and idealization. “Man [*sic*] is able to construct only if he has hope: Hope is the patron saint of architecture.”[28] Regarding domesticity, he further states: “We still need houses that reinforce our sense of human reality and the essential hierarchies of life. The art of architecture can still produce houses that enable us to live with dignity.”[29] Villa Savoye, then, is seen as an exemplar: “Without … Le Corbusier’s Villa Savoye … to concretize the possibilities of human habitation, our understanding of modernity, and of ourselves, would be considerably weaker.”[30] Though not designed for disability, the extended threshold space of Villa Savoye provides material evidence of the possibility for redefining the lived experiences of disability, when nonnormative modes of occupying and traversing space reside at the core of design.

Rietveld-Schröder House

Gerrit Rietveld was the most prominent architect of the Dutch De Stijl (The Style), a movement founded in 1917 dedicated to the unification of art with life in protest of the horrors of WWI. Through the pursuit of dynamic balance, De Stijl artists and designers sought purity in a new society. They argued that symmetry was stasis, and seeking equilibrium was more akin to the realities of life. Their disciplined palette, consisting only of vertical and horizontal lines and primary colors and achromatics (white, black, and grays), utilized a minimum of elements to uncover the basic principles governing the harmony of the world. Painter Piet Mondrian, one of the primary figures of the movement, wrote: "The De Stijl artists who focus entirely on the 'absolute,' see life in all its facets as a search for balance between extreme contrasts: man-woman, objective-subjective, universal-individual, internal-external etc. Sometimes one is dominant and sometimes the other."[31]

Rietveld and many of his artist colleagues were heavily influenced by Wright's utopian ideas about the merging of art with daily living.[32] It is well documented that Wright "pioneered the use of reinforced concrete, extreme cantilevers, and a theory of using geometry, specifically intersecting horizontal, and vertical lines/planes," particularly evident in the roof lines, interiors, and detailing of the Prairie homes. The Unity Temple (1904) in Oak Park, Illinois, initiated this logic, which Wright further refined in the famed Falling Water (1935). Both the ideals and the clarity of execution appear in Rietveld's work.[33] This is especially true in the Rietveld-Schröder House, where cantilevered concrete balconies emerge from a structure of intersecting lines and planes.

In 1924, Truss Schröder, who decided to build a new house that reflected how a woman might live in a more modern and liberated way, commissioned Rietveld.[34] She resisted a home that "imposed a specific lifestyle on her. Instead, she wanted a space that could change with her—a space that could develop and satisfy her cravings for independence."[35] She closely collaborated with Rietveld on the house, proposed many of its primary elements, and is considered a co-designer.[36] Schröder later recalled:

> After my husband died, and I had full custody of the children, I thought a lot about how we should live together. So when Rietveld made a sketch of the rooms, I asked, "Can those walls go too?" To which he answered, "With pleasure, away with those walls!"…That's how we ended with the one large space.[37]

The Rietveld-Schröder House, an icon of the Modern Movement and Rietveld's most famous work, exemplifies De Stijl founder Theo Van Doesburg's "Sixteen Points of a Plastic Architecture," including design that is "elementary, economic and functional, unmonumental and dynamic, anti-cubic in its form, and anti-decorative in its colour."[38] True to Schröder's desires, the house interwove the interior and exterior, and all rooms could serve multiple functions—eating, sleeping, reading, conversing, and so on. As stated in its UNESCO Heritage Site nomination, the Rietveld-Schröder House was "conceived as a manifesto from the beginning; Mrs. Schröder and Rietveld commissioned a full photographic documentation of the architecture. Their intention was to make sure the new approach to architecture and living were presented to reflect their intended ideas."[39]

Spatial Syntax

The use of separating and interlocking planes was particularly common among modernist architects. The arrangement of the major vertical and horizontal planar elements, combined with the overall scale (relatively small) and proportions of the Rietveld-Schröder House, results in several key spatial phenomena. All spaces present an ambiguous balance between being enclosed and open; all spaces have a direct connection to the outside; and, most importantly here, all spaces are transitional—they are all thresholds. There are no terminal spaces. Effectively, the hierarchy between room and threshold has been transgressed, where every room is a threshold, especially evident on the upper level. While not specifically intended, these characteristics directly reflect De Stijl principles of plasticity, not in the sense of curvilinear form, but in achieving indeterminate, flexible, multifunctioning spaces.[40] The two-story structure is a modified four-square plan resulting, generally, in eight larger transitional spaces—bedrooms, living spaces, and so on—and a variety of secondary elements—bathrooms, storage, and so on. Not unlike Villa Savoye, a vertical space, punctuated with a skylight and enclosing the stair, resides at the center of the house.

The ground floor of the house is quite conventional, fixed in place, because "Rietveld was forced to meet Dutch regulations in order to acquire a building permit."[41] The top floor, where Mrs. Schröder lived, is more experimental; it is one open space with sliding walls and foldable panels that allow numerous spatial configurations, again, reflecting the tenets Van Doesburg set forth:

> The whole consists of a single space that is subdivided according to functional requirements. This subdivision is effected by means of separating planes (interior) or sheltering planes (exterior). The former, which separate the various functional spaces from one another, may be mobile …,' the separating planes (former internal walls) may be replaced by moveable screens or slabs.[42]

In addition, the top floor uses color on the floor, walls, and ceilings to establish thresholds that are spatial and visual, but not physical. Unlike their predecessors, De Stijl artists and designers considered "color planes integral to form… The equilibrium of architectural relationships first becomes visible reality through color."[43] Various color planes in the house make space that is equal (an even ceiling surface, for example) appear closer or further away depending on the specific hue. Thus, there is a conflict between the material or physical reality and the visual appearance of the space. This discrepancy serves as an activator—yet another way that the house demonstrates plasticity.

The flexibility of spatial arrangements establishes a set of dynamic interactions, which, by their transformational nature, "take account not only of space, but also of time as an accent of architecture."[44] Thus, the Rietveld-Schröder House embraces Wright's interest in interrogating the conventional threshold between inside and outside and Le Corbusier's interest in reconciling the thresholds between industrialized and domestic space. In addition, it acknowledges that people require and are susceptible to change, and, thereby, emphasizes the many temporal thresholds that are required throughout life. As the dwellers change, the spaces change.

Implications for Mobility, Perception, and Cognition

It must be noted that the stair and bathrooms, among other features of the house, do not meet today's architectural standards for safety, usability, and accessibility. There are, however, numerous lessons to be gleaned from the transitional spaces of the Rietveld-Schröder house. Like the ground floor of the Martin House, the second level of the Schröder House is comprised of open, unimpeded access between spaces. Different than the Martin House, the second-level spaces of the Schröder House can be made discrete through the use of the movable partitions rather than curtains. This enables modification to the light, acoustics, and visual permeability of each space. The house, therefore, accommodates personal preferences and varying levels of privacy and interaction.

Privacy and its complement, social interaction, are fundamental concepts in housing and critical concerns in design for disability, as individuals across disability groups often experience privacy infringements. This includes both the recent trend in securing personal information and, more applicable to this chapter, the significance of spatial and bodily privacy. Privacy dilemmas for people with disabilities have been identified in both group-home and single-family settings.[45] In parallel, privacy can be discussed both internally to the home, how privacy is achieved among residents, and in the relationship of the home to its surroundings and outsiders. Given the density of the surrounding context and the close proximity to the street, Rietveld and Schröder gave particular care to the programming of spaces, the positioning of openings, and the design of the exterior landscape in order to ensure adequate privacy. For Mrs. Schröder, a widowed mother of three, the house even allowed for the secure delivery of goods through a lockable aperture. On the interior, the sliding partitions allow for multiple spatial configurations, and accommodate the dynamics of privacy and the changing activities throughout the day, month, year, and lifetime. The most important aspect of the Rietveld-Schröder House is that Mrs. Schröder recognized the need for a house to adapt to the changing needs of life. To our knowledge, she is the first designer clearly to state that spatial thresholds needed to correspond to life thresholds, and that flexibility was the key to this adaptation.

A key lesson emerges. Changes in ability and health occur throughout the life span. While unique to each person, disability, aging, temporary illness, chronic disease, and so on, are not unusual in any given household; they are commonplace, normal. Just as homes are designed to accommodate the daily preparation of meals and other routines, homes need to have designed-in flexibility to accommodate changes in the needs of their residents.

Conclusion

Maslow's Hierarchy of Needs, first articulated in the decade after the construction of Villa Savoye, is a useful tool in revealing the multiple roles the home plays—providing (or not) adequate shelter, security, intimacy, dignity, and imagination. Both the experiences of one's home life and the design of one's home are critical to identity development and independence, though many homes hinder, rather than foster, these objectives, particularly regarding individuals with cognitive, mobility, and perceptual disabilities, and those who lack economic resources. The three homes discussed here, on the other hand, illustrate an architecture of aspirations as well as possibilities for what home design for disability might be, provided one were able to afford it economically.

Common to all three houses is a certain level of self-determination among their occupants, choice regarding where, when, and how to occupy their spaces. The homes enable, rather than disable domesticity for those who have the means to occupy such spaces. This is achieved primarily through the reimagination of threshold spaces. To achieve a sense of home, the aforementioned concepts—choice, privacy, dignity, continuity, and so on—must be integrated into it. As Annison asserted for people with intellectual disability, and equally relevant to individuals and families across disability groups, "genuine homes" include the "recognition of the multi-faceted nature of home."[46]

This was not the case in late-nineteenth-century housing typologies in Europe and the USA, where multivalent living conditions were constrained. Instead, the norms of the day favored vertically oriented residences that housed "boxes beside or inside other boxes, called 'rooms.' Each domestic function was properly set inside a box."[47] Wright, Le Corbusier and Jeanneret, and Rietveld and Schröder broke away from these restrictions, and, in the process, reinvented the concepts, capabilities, and construction of the home. Wright addressed the threshold between human-made space and nature, which opened interior space and interior-to-exterior space, physically, visually, and conceptually. Le Corbusier and Jeanneret focused on the threshold between industrialized space (autos/steamers) and domestic space, which blended, smoothed, and extended vertical circulation. Rietveld and Schröder concentrated their efforts on the threshold between present and future life requirements. All of these architects and designers reduced boundaries and opened possibilities for physical, sensory, and cognitive navigation and imagination. All promoted social inclusion. In the process, they destabilized the status quo, and liberated the house from unnecessary barriers. They regarded the threshold not only as "a space … but also [as] a constitutive term, a category of experience that organizes thinking and feeling in lived reality."[48] Their work paved the way for the development of "yet more crossing points, to proliferate into thresholds of other kinds—cognitive, representational, and even critical."[49] These changes rejected stagnant modes of domesticity, and proposed new flexible approaches that acknowledged the spectrum of human variation and anticipated equity and human rights for people of all abilities.

NOTES

1. Shelley Mallett, "Understanding Home: A Critical Review of the Literature," *The Sociological Review* 52 (2004): 84.
2. Rob Imrie, "Disability, Embodiment and the Meaning of Home," *Housing Studies* 19 (2004): 745–763.
3. See, for example: Alexey Mokhov, "Guidelines for Design of Learning Environments for Children on the Autistic Spectrum" (M.Arch. thesis, University at Buffalo, 2014), 32.
4. For more on disability aesthetics, see: Tobin Siebers, *Disability Aesthetics* (Ann Arbor: University of Michigan Press, 2010).
5. Compression and tension are two fundamental, and opposite, forces that act on building structures. Tension refers to pulling or stretching forces, while compression refers to squeezing or crushing forces.
6. Edgar Kaufmann and Ben Raeburn, eds., *Frank Lloyd Wright: Writings and Buildings* (New York: New American Library, 1960), 45–47.
7. Reyner Banham, Charles Beveridge, and Henry-Russel Hitchcock, *Buffalo Architecture: A Guide* (Buffalo: MIT Press, 1981), 195–197.
8. Ibid., 45–47.
9. Jean La Marche, *The Familiar and the Unfamiliar in Twentieth Century Architecture* (Chicago: University of Illinois Press, 2003), 27.
10. Ibid., 26.
11. Mrs. Martin had low vision, but it is uncertain how much this influenced the design of the Martin House. On the other hand, the design of Graycliff (1931), on the shores of Lake Erie southwest of Buffalo, was designed with abundant sunlight to accommodate Mrs. Martin's low vision. Chuck LaChiusa, "Graycliff, Introduction and History." Accessed July 22, 2015, http://buffaloah.com/a/DERBY/oldlake/6472/hist/.
12. The term "intimate" refers to a feeling of closeness. A sense of acoustic intimacy is achieved when (a) the time between the direct sound, such as a person talking, and the first reflected sound is short, nearly imperceptible, in duration, and (b) sound is evenly dispersed to minimize echo and long reverberation times.
13. While the field of environmental psychology, along with common life experiences, has shown relationships between human behavior

and spatial characteristics, to our knowledge, no study of this sort has been done in the context of the Martin House. As such, we use the parenthetical term "presumably."

14. For information on body-image aberration in schizophrenia, see: Reiko Koide and Akira Tamaoka, "Body Image Deviation in Chronic Schizophrenia: New Research," in *Body Image: New Research*, ed. Marlene V. Kindes (New York: Nova Science Publishers, 2006), 145–197.
15. Paul Schilder, *The Image and Appearance of the Human Body* (New York: International Universities Press, 1950), 159.
16. Studies show that individuals with Alzheimer's disease and other forms of dementia have impaired spatial memories. While anecdotal evidence suggests that building design plays a role in wayfinding among people with and without dementia, to our knowledge, comprehensive best practices have not been fully studied for individuals with Alzheimer's or similar diseases. See, for example: Carla C. Guariglia, "Spatial Working Memory in Alzheimer's Disease: A Study Using the Corsi Block-tapping Test," *Dementia and Neuropsychologia* 1 (2007): 392–395; and Roy P. Kessels, Amy van Doormaal, and Gabriele Janzen, "Landmark Recognition in Alzheimer's Dementia: Spared Implicit Memory for Objects Relevant for Navigation," *PLoS ONE* 6 (2011): 1–5.
17. Gabriel A. Radvansky, Sabine A. Krawietz, and Andrea K. Tamplin, "Walking through Doorways Causes Forgetting: Further Explorations," *The Quarterly Journal of Experimental Psychology* 64 (2011): 1632–1645.
18. Douglas Main, in an online blog for *Discover* titled "Ever Enter a Room and Forget Why You Went There? Blame the Doorway," November 22, 2011, attributed this quote to an interview with *Postmedia News*. Accessed June 8, 2015. http://blogs.discovermagazine.com/80beats/2011/11/22/ever-enter-a-room-forget-why-you-went-there-blame-the-doorway/#.VXX0IM9VhBc.
19. Vincent Scully, "Frank Lloyd Wright and the Stuff of Dreams," *Perspecta* 16 (1980): 13.
20. Le Corbusier explained his points: (1) The supports. The earlier foundations, on which the building rested without a mathematical check, are replaced by individual foundations and the walls by individual supports. Both supports and support foundations are precisely calculated according to the burdens they are called upon to

carry. These supports are spaced out at specific, equal intervals, with no thought for the interior arrangement of the building. (2) The roof gardens. The flat roof demands in the first place systematic utilization for domestic purposes: roof terrace, roof garden. The roof gardens will display highly luxuriant vegetation. In this way the roof garden will become the most favoured place in the building. (3) The free designing of the ground-plan. There are no longer any supporting walls but only membranes of any thickness required. The result of this is absolute freedom in designing the ground-plan. (4) The horizontal window. The window extends from support to support and thus becomes a horizontal window. Stilted vertical windows consequently disappear, as do unpleasant mullions. In this way, rooms are equably lit from wall to wall. Le Corbusier, "Five Points Towards a New Architecture" (1926), translated in Ulrich Conrad's Programmes and Manifestos on twentieth-Century Architecture (London: Lund Humphries, 1970), 146.

21. Le Corbusier's birth name was Charles-Edouard Jeanneret-Gris. He changed his name in 1920, when, along with Amédée Ozenfant and Paul Dermée, he established the purist journal *L'Esprit Nouveau* (*The New Spirit*), an avant-garde review. In the first issue of the new publication, "he assumed the pseudonym Le Corbusier, an alteration of his grandfather's last name, to reflect his belief that anyone could reinvent himself. Also, adopting a single name to represent oneself artistically was particularly en vogue at the time, especially in Paris." *Le Corbusier Biography*. Accessed May 28, 2015.http://www.biography.com/people/le-corbusier-9376609#th,e-move-to-paris; and Le Corbusier, *Towards a New Architecture*, trans. Frederick Etchells, 13th edition (New York: Dover Publications, 1989), 4.
22. Le Corbusier and Pierre Jeanneret, *Oeuvre Complète, 1929–1934* (Zurich: Editions H. Girsberger, 1935), 24.
23. Colin Davies, *Key Houses of the Twentieth Century: Plans, Sections and Elevations* (New York: W.W. Norton, 2006), 80.
24. Richard Weston, *Key Buildings of the Twentieth Century: Plans, Sections and Elevations* (New York: W.W. Norton & Co., 2010), 62–63.
25. Stanislaus von Moos, *Le Corbusier, Elements of a Synthesis* (Cambridge: The MIT Press, 1979), 87.

26. Korydon H. Smith, “Redefining Home,” in *Just Below the Line: Disability, Housing, and Equity in the South*, Korydon H. Smith, Jennifer Webb, and Brent T. Williams (Fayetteville, AR: University of Arkansas Press, 2010), 133–161.
27. See the subsection titled “The Ramp” in Jacques Sbriglio, *Le Corbusier: La Villa Savoye* (Basel: Birkhäuser, 1999), 62–65.
28. Juhani Pallasmaa, “Lived Space,” in *Encounters: Architectural Essays*, ed. Peter MacKeith (Helsinki: Rakennustieto Oy, 2005), 134.
29. Juhani Pallasmaa, “Identity, Intimacy, and Domicile,” in *Encounters: Architectural Essays*, ed. Peter MacKeith (Helsinki: Rakennustieto Oy, 2005), 126.
30. Ibid., 125.
31. Piet Mondrian, ‘Cercle et Carré ‘ *De Stijl* 2 (Paris,1930): 34.
32. Kenneth Frampton, *Modern Architecture: A Critical History* (London: Oxford University Press, 1980), 143.
33. Suzanne Merchant, Jim Shi, Stephen Ru, Nicole Ratajczak, “The Rietveld-Schröder House: An Architectural Case Study.” Accessed May29,2015.http://rietveldhouse.com/2012/12/understanding-domesticity-of-rietveld_10.html.
34. Truss Schröder, a mother of three, commissioned Rietveld in the year following her husband’s death. According to Overy, “Although she was adequately provided for it was necessary to leave [her previous residence] and look for a smaller, cheaper and more convenient house.” It is important to note that Mrs. Schröder, as well as her husband, disliked the bourgeois life style. See: Paul Overy, “Introduction,” in *The Rietveld Schröder House*, eds. Paul Overy, Lenneke Büller, Frank den Oudsten, and Bertus Mulder (Houten: De Haan, 1988), 22; as well as the interview with Mrs. Schröder in the same book. It is also worth noting that all three houses discussed in this chapter were for wealthy clients. While economic status and the cost of custom homes are relevant to disability research and policy, it is outside the scope of this chapter.
35. Ibid.
36. Mrs. Schröder went on to collaborate with Rietveld on several projects, including Glass Radio Cabinet (1924), Hanging Glass Cabinet (1926), Project for Standardized Housing and the interiors for the Birza House (1927), Van Urk House and the Desk (1930–1931), Houses on Erasmuslaan (1934), Vreeburg Cinema

and Movable Summer Houses (1936), and Ekano interiors in Haarlem (1938). Ibid.

37. Alice Friedman, *Women and the Making of the Modern House: A Social and Architectural History* (New Haven: Yale University Press, 2007), 76.
38. Frampton, *Modern Architecture,* 145.
39. "Rietveld Schröderhuis (Rietveld Schröder House)," UNESCO Heritage Center. Accessed May 28, 2015. http://whc.unesco.org/archive/advisory_body_evaluation/965.pdf.
40. Theo van Doesburg, *De Stijl*, Vol. VI, No. 6/7 (Paris, 1924), 78–83.
41. "Rietveld Schröderhuis."
42. van Doesburg, *De Stijl*, 78–83.
43. Ibid.
44. Ibid.
45. See, for example: Andrea Hollomotz, "May We Please Have Sex Tonight?: People with Learning Difficulties Pursuing Privacy in Residential Group Settings," *British Journal of Learning Disabilities* 37 (2009): 91–97; and Marie Holmberg, Gudrun Valmari, and Solveig Lundgren, "Patients' Experiences of Homecare Nursing: Balancing the Duality between Obtaining Care and to Maintain Dignity and Self-determination," *Scandinavian Journal of Caring Sciences* 26 (2012): 705–712.
46. John E. Annison, "Towards a Clearer Understanding of the Meaning of 'Home,'" *Journal of Intellectual and Developmental Disability* 25 (2000): 259.
47. Edgar Kaufmann and Ben Raeburn, eds., *Frank Lloyd Wright: Writings and Buildings* (New York: New American Library, 1960), 44.
48. Subha Mukherji, *Thinking on Thresholds* (London: Anthem Press, 2013), xxvi.
49. Ibid., viii.

CHAPTER 4

The Largest Occupational Group of All the Disabled: Homemakers with Disabilities and Vocational Rehabilitation in Postwar America

Laura Micheletti Puaca

In a July 1947 *New York Times* article, rehabilitation expert and medical doctor Howard A. Rusk outlined major trends in the rehabilitation of Americans with disabilities. He noted, approvingly, that the government had assumed responsibility for assisting disabled veterans, while industry had taken an increased interest in rehabilitating workers in that sector. Yet what Rusk termed "the largest occupational group" "of all the disabled in America," or homemakers, had been virtually ignored. Lambasting the serial neglect of this population of 5,000,000 women, he called for increased support for their rehabilitation, which he deemed as necessary to the functioning of the home, family life, and society.[1]

Rusk was part of a growing network of medical experts, policymakers, home economists, inventors, and other professionals who increasingly turned their attention to this subject in the post-World War II period.

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Amid the marriage boom and baby boom, they eagerly embarked on a range of initiatives designed to rehabilitate disabled homemakers by helping them to fulfill their domestic duties independently and to carry out "normal" lives. These professionals were often assisted in their effort by disabled homemakers themselves, whose input they frequently solicited when designing assistive devices and work methods. Such innovations served as the basis of a growing number of homemaker rehabilitation programs, workshops, and studies, which by the end of the 1950s had sprung up across the country in such far-flung places as New York, Connecticut, Maryland, Michigan, Ohio, Wisconsin, Nebraska, Colorado, and California.[2] A number of these projects benefited from the broadening of state and federal legislation, such as the 1954 Vocational Rehabilitation Act Amendments, that provided increased funds for assisting homemakers with disabilities and thus drew homemakers into the vocational rehabilitation system in new ways.

Most homemaker rehabilitation initiatives tended to reflect the demographics of American homemakers, who were overwhelmingly white and middle class. In the postwar period, for example, white middle-class women were less likely than black middle-class women to work outside of the home. As historian Stephanie Coontz has argued, "in 1960, almost 60 percent of black middle-class families were two-earner households, compared to less than 40 percent of white middle-class families."[3] Coontz has also found that while white upper middle-class mothers were the least likely of all white mothers to work outside the home, the reverse was true for African American women. Indeed, black mothers in the upper middle class were the most likely among black mothers to work outside the home. According to Coontz, "sixty-four percent of black upper middle-class mothers had jobs in 1960, compared to only 27 percent of white upper-middle-class mothers and 35 percent of white lower middle-class mothers."[4] Homemaker rehabilitation in many ways mirrored these trends: although African American women were included in homemaker rehabilitation programs and studies, they appeared far less frequently than their white counterparts. Their precise numbers, moreover, are not known as few rehabilitation programs broke down their participation rates by race.[5]

While many of the efforts to rehabilitate disabled homemakers bolstered white middle-class gender roles, postwar domesticity, and able-bodied normality, they also posed challenges to them. In part, many homemaker rehabilitation programs that aimed at assisting women with disabilities to carry out their work independently often incorporated strategies already developed by disabled homemakers, thereby forging connections to the independent living movement of the 1970s. At the same time, efforts to integrate homemakers into the vocational rehabilitation system hinged on a redefinition of homemakers as workers. Throughout the postwar period, this argument gained increasing attention and traction, culminating in the activities of the new Women's Committee that was established in 1962 to extend the work of the much older President's Committee on Employment of the Handicapped. A special subcommittee of the Women's Committee, which focused largely on women's work inside the home, drew together leaders in the field of homemaker rehabilitation. Building on their efforts from the previous decade, members called attention to the economic value and precise monetary worth of housework in ways that would be echoed by feminists in the late 1960s and 1970s.

By highlighting these networks of reformers, and especially their efforts to include homemakers in the larger vocational rehabilitation system, this chapter sheds light on the construction of both disability and domesticity in postwar America. It also draws important connections between the movements for disability rights and women's rights that emerged during this period.

Vocational Rehabilitation in the Twentieth-Century United States

Vocational rehabilitation, or the process of assisting individuals with disabilities to enter or resume employment, developed slowly and unevenly over the course of the early twentieth century. Until the 1910s, disabled Americans could rely on few sources of public support other than veterans' pensions; consequently, their care usually fell to family members, philanthropic organizations, church groups, and local governments.[6] During and immediately following the World War I, the federal government instituted a number of measures that aimed to provide not only financial but also vocational assistance to individuals with disabilities. One of the earliest examples can be found in the War Risk Insurance Act Amendments of 1917, which marked the official beginning of federal support for the vocational rehabilitation of disabled veterans. In addition to disability compensation that was designed to offset future losses of income, the legislation promised that veterans disabled in the war would receive vocational rehabilitation. It did not, however, make provisions for the creation or administration of an actual program.[7] The institutionalization of vocational rehabilitation for disabled veterans came the following year with the Smith-Sears Vocational Rehabilitation Act of 1918. Known also as the Soldier's Rehabilitation Act, the legislation entrusted in the newly formed Federal Board for Vocational Education (FBVE) responsibility for training disabled soldiers for employment. The FBVE carried out this charge until 1921, when Congress moved the veteran rehabilitation program to the new US Veterans Bureau, the precursor to the Veterans Administration, which centralized nearly all aspects of disabled veterans' compensation and rehabilitation.[8] By 1928, nearly 130,000 veterans had been rehabilitated under the federal program.[9]

The World War I era also saw new efforts to assist disabled civilians, especially industrial workers, whose situation had attracted particular attention from Progressive reformers. Amidst rapid industrialization and corporate capitalism, the high rate of industrial accidents elicited growing concern. In response, nearly every state as well as the federal government enacted some kind of workers' compensation law by 1920.[10] But while these provided a measure of economic relief, they did little to ease reentry into the workforce. Mindful of such limitations, a handful of states sought ways to supplement workers' compensation and, in May 1918, Massachusetts enacted the first state vocational rehabilitation law. Over the next 22 months, 11 other states followed suit by passing their own vocational rehabilitation legislation.[11]

Support for the vocational rehabilitation of civilians was expanded again in June 1920 when President Woodrow Wilson signed into law the Smith-Fess Act, or Civilian Vocational Rehabilitation Act, which authorized vocational training, job placement, and counseling for "persons disabled in industry or otherwise" in an effort to facilitate "their return to civil employment."[12] In addition to placing the new civilian program under the authority of the FBVE, it established the federal-state vocational rehabilitation model that made federal funds available to states on a matching basis. This cost-sharing plan provided a powerful incentive for states to support vocational rehabilitation and, by 1922, nearly three dozen states had passed the vocational rehabilitation legislation necessary to receive federal funds. It would take another decade and half, however, before all of the states could claim operational programs.[13] The fact that the federal legislation depended on periodic reauthorizations also rendered uncertain the future of civilian vocational rehabilitation and it was only with the 1935 Social Security Act that support for it was made permanent.

Four years later, in 1939, the civilian vocational rehabilitation program, as well as the Office of Education where it was then housed, moved to the new Federal Security Agency.[14] But despite the increased institutionalization of vocational rehabilitation for civilians, the program was limited in size and scope when compared with services for veterans. In its first ten years of operation, for example, the civilian program rehabilitated less than 50,000 people, not even half the population of veterans rehabilitated over the same course of time.[15] Although the number of rehabilitated civilians did grow significantly, from just 524 in the program's first year to over 5800 in 1924, that number stayed relatively steady and in some cases declined in subsequent years leading up to 1934.[16] Between 1935 and 1941, the number of rehabilitated civilians increased more sharply but even then the civilian rehabilitation program never served more than 15,000 of the 250,000 individuals who were disabled each year.[17]

The next major change took place during World War II with the Barden-LaFollette Act, or the Vocational Rehabilitation Act Amendments of 1943. The legislation, which was driven largely by a desire to facilitate the employment of disabled citizens in war production, enlarged the range of services provided as well as populations served. In addition to expanding vocational rehabilitation to include individuals with not only physical disabilities but also cognitive and psychological ones, it made available a number of medical and reconstructive services not previously covered. At the same time, the legislation created within the Federal Security Agency a new Office of Vocational Rehabilitation (OVR).[18] Although vocational rehabilitation services for civilians remained less expansive than the veterans' program (which had been placed under the authority of the Veterans Administration earlier in 1943, with Public Law 16), these changes drastically enlarged their comprehensiveness and reach. Within a year, the number of rehabilitated individuals roughly doubled, jumping from 21,757 in 1942 to 42,618 in 1943.[19]

Despite the different histories and trajectories of the civilian and veterans' programs, what they had in common was a strong economic underpinning. The same can be said of vocational rehabilitation more generally, which had long been associated with increasing the employability of disabled people. Legislative staples, such as vocational counseling and job training, overwhelmingly aimed to assist both veterans and civilians with disabilities in pursing gainful employment, a hallmark of economic citizenship. By reducing dependency, vocational rehabilitation proponents hoped that their programs would strengthen not only the well-being of individuals but also the well-being of society. This sentiment was so thoroughly embedded in vocational rehabilitation efforts that even legislation enacted during World War II, such as the 1943 Barden-LaFollette Act which notably included a new emphasis on the medical and psychological aspects of rehabilitation that went well beyond a narrow focus on job training, nevertheless justified these expanded services as a means "to render a disabled individual fit to engage in a remunerative occupation."[20]

According to historian Sarah Rose, many of these early vocational rehabilitation efforts that aimed to discourage dependency were accompanied by the twin goal of encouraging male breadwinning. One example can be seen in the War Risk Insurance Act Amendments of 1917, which compensated disabled veterans based on their degree of impairment and number of dependents. As a result, according to Rose, "the act affirmed a traditional middle-class vision of family and gender relations: compensation would allow…even severely disabled American veterans…to marry and support children."[21] A focus on male breadwinning can also be viewed in the populations served by vocational rehabilitation initiatives. The first civilian program enacted after World War I focused on individuals who were regarded as socially acceptable workers and who stood the greatest chance of securing employment. As political scientist Ruth O'Brien explains, "[v]ocational rehabilitation, therefore, mirrored the existing societal prejudices against minorities, women, and the aged—all people who had less chance of being gainfully employed."[22] Consequently, between 1925 and 1943, over 91 percent of rehabilitated individuals were white and the overwhelming majority were men.[23] The few women who were rehabilitated tended to be drawn primarily from the ranks of industrial laborers and workers in other wage-earning occupations. While homemakers were technically included in the civilian rehabilitation program, they comprised a tiny minority. In 1945, homemakers accounted for just 156 of the 41,925 people who received rehabilitation services that year.[24]

In the context of the post-World War II period, however, homemaking attracted increased attention from vocational rehabilitation proponents as well as society more generally. The recent return of male veterans, rise in young marriage rates, and resulting "baby boom" all bolstered the perceived importance of the nuclear family and white middle-class gender roles. Despite the fact that women's labor force participation grew steadily throughout much of the postwar era, this trend was largely belied by popular culture, where homemaking and domesticity were routinely glamorized. The emerging Cold War intensified this development.

The articulation and elevation of dominant domestic ideals served as a way to differentiate the United States from the Soviet Union, where full-time homemaking was held in little regard. At the same time, homemaking was touted as a bulwark against communism. By molding young citizens, building stable family lives, and strengthening the moral fibers of their communities, homemakers seemed to provide much-needed security in the face of Cold War threats.[25]

Consequently, in the post-World War II United States, the rehabilitation of homemakers assumed new importance and urgency. Advocating the need to expand vocational rehabilitation far beyond its traditional base of veterans and industrial workers, proponents such as Howard Rusk carefully balanced long-standing economic prerogatives with homemaking's heightened significance. In his July 1947 *New York Times* article where he made his case for new research on the needs of disabled homemakers, Rusk not only warned against "invalidism and dependency" but also added that "the dividends of such a program would not be confined to economy alone" and "would be reflected in the prevention of juvenile delinquency, improved domestic relations and happier home environment."[26]

Efforts to expand homemakers' participation in vocational rehabilitation also involved a revaluation of homemaking itself. In explaining the need for rehabilitating disabled homemakers, some vocational rehabilitation proponents supported their argument by likening homemaking to dangerous wage-earning occupations. In the same 1947 article, Rusk argued that homemakers worked "longer and harder hours than workers in any other occupational group." The wear on their bodies was not insignificant. According to Rusk, "The housewife experiences more illness at every age than the woman worker, the accident rate for housewives exceeds those for men workers by 132 percent, and the accident rate for housewives is much higher than for women workers. Housewives sustain a third of all serious injuries, and the occurrence of orthopedic impairments, varicose veins, liver disorders and other chronic ailments are two to five times as great among housewives as among their husbands." Yet homemakers did not enjoy the same protections extended to other workers. As Rusk explained, "they will not benefit from group insurance, health and accident prevention programs and medical care in their place of work."[27] Rusk characterized this consequence as a great tragedy, and one that was inherently unfair. His portrayal of homemakers as workers deserving of restitution suggested not only that they were on par with other workers, but also that neglecting them would have dire social, political, and economic consequences. Other vocational rehabilitation proponents, who increasingly devoted their efforts to rehabilitating disabled homemakers in the post-World War II period, shared this sentiment.

Vocational Rehabilitation for Disabled Homemakers

Although Rusk emerged as a principal advocate for the vocational rehabilitation of homemakers in the postwar period, his interest in the subject was rather new, as was his work in vocational rehabilitation and the emerging field of rehabilitation medicine that he helped to found. He was first drawn to rehabilitation during World War II, when he treated injured soldiers. In August 1942, the Missouri native left his private practice in St. Louis to join the Army Air Force as a major. He was assigned to nearby Jefferson Barracks, where he became Chief of Medical Services at its 1000-bed hospital. In this capacity, he familiarized himself with the physical, psychological, and vocational needs of patients and devised an integrated "reconditioning" program that spoke to these concerns.[28] Military officials lauded Rusk's "whole man" approach, which drew on the expertise of a team of professionals. He was soon promoted to chief of the Army Air Force Reconditioning and Recreation Program in Washington, DC, where he was put in charge of creating a network of convalescent centers based on the model he used at Jefferson Barracks.[29]

Rusk's wartime work also brought him to the attention of New York University (NYU), which in March 1945 invited him to head up a new department of physical medicine and rehabilitation. The department promised to be one of the first of its kind in the world.[30] Such an opportunity would enable Rusk not only to build on his wartime findings but also to reach new populations of disabled individuals. By the time that NYU approached him, Rusk later recalled, "I had already begun thinking about establishing a rehabilitation institute for civilians. I knew that for every veteran who needed such help there were a dozen more civilians who needed it. The veterans were going to get it, through the Veterans Administration, but very little was being done for civilians with disabilities."[31] After some deliberation, Rusk accepted the offer. He moved to New York City in December 1945, joined the NYU faculty shortly thereafter, and began building up the university's physical medicine and rehabilitation department. He also started to plan and fund-raise for a rehabilitation institute that would be connected to NYU. He was soon successful in acquiring clinical space at various locations across the city, including wards at the Bellevue and Goldwater hospitals in addition to an old building near NYU on East 38th Street, where a temporary institute was opened in March 1948. Rusk's permanent Institute of Physical Medicine and Rehabilitation opened three years later, in 1951, and became the first unit of the NYU-Bellevue Medical Center.[32]

Much of Rusk's work at NYU aimed to assist what he famously termed "the forgotten casualty," meaning the disabled civilian population.[33] From early on, he expanded his "whole man" approach to include women as well. His initial facility at Bellevue consisted of two wards: one for men that was painted blue and one for women that was painted pink.[34] In both cases, Rusk promoted a rehabilitation model that drew together a team of medical experts and other professionals who worked together in helping individuals with disabilities go "from the bed to the job."[35] At first, however, Rusk's definition of work was construed narrowly, and his efforts to expand the rehabilitation of women focused on helping them to enter wage-earning occupations. It was reported that he had originally planned only a small "research corner" on issues affecting disabled homemakers. But by the end of the 1940s, he had already embarked on a full-fledged research program to investigate the topic more thoroughly.[36]

Rusk's growing interest in the rehabilitation of disabled homemakers can be attributed in large part to his relationship with Lillian Moller Gilbreth, who he frequently credited with inspiring his disabled homemaker project at NYU.[37] The famed industrial engineer, psychologist, and efficiency expert with whom Rusk began collaborating in the early postwar period was especially well known for her work in motion studies, a component of scientific management that she had helped to pioneer with her late husband, Frank Gilbreth. In the two decades following their marriage in 1904, Lillian and Frank Gilbreth coauthored dozens of lectures, articles, and books documenting ways to increase worker productivity by decreasing the number of discrete movements required to carry out any given task. In the early 1910s, they gained particular acclaim for their studies of "work simplification" in factories, which catapulted their family consulting business. During World War I, they focused their attention on assisting disabled veterans resume wage-earning jobs by employing similar techniques. They even applied their methods to their own home and raising their 11 living children, as later popularized in the book and feature film, *Cheaper by the Dozen*.[38]

Following Frank's untimely death in 1924, Lillian Gilbreth soon found herself rebuffed from industrial employment, as many of the factory owners who had contracts with her husband cancelled them. In an effort to keep the family firm afloat, Lillian increasingly focused on more feminine fields, where she encountered less resistance. During the 1920s and 1930s, Lillian Gilbreth taught scientific management classes (as teaching seemed sufficiently suitable for a woman) and served as a consultant to a variety of businesses with large numbers of female workers or consumers, such as department stores. At the same time, she devoted an increasing share of her own research to the application of work simplification principles to the home. Beginning in 1926, she served as a consultant to departments of home economics at universities across the country that were developing their own home management courses and she enjoyed particular acclaim after the publication of her 1927 *The Home-Maker and Her Job*. Utility companies also sought her expertise, and during the late 1920s and early 1930s the New York Herald Tribune Institute (a homemaking research branch of the newspaper) hired Gilbreth to design efficiency kitchens in the hope that they would increase consumer demand and advertising revenues.[39] Many of their features would later be incorporated into the kitchens that she designed for disabled homemakers in the post-World War II period.

Gilbreth's earliest contribution to the rehabilitation of homemakers with disabilities can be seen in the 1948 Heart Kitchen for cardiac homemakers. The project grew out of a World War II-era New York Heart Association subcommittee that Gilbreth chaired. Initially tasked with studying industry's utilization of men with cardiovascular disease, the group, which consisted of experts in home economics, family relations, rehabilitation, architecture, and a number of other fields, gradually expanded its focus to include the problems faced by similarly afflicted homemakers, a largely unexplored topic at the time.[40] The design of the kitchen clearly drew on motion study principles, aiming to reduce fatigue by eliminating unnecessary movements. For example, the stove and the sink were strategically placed near the dinette entrance for ease of serving and returning dishes, while smaller devices were housed at the point of first use (the rolling pin was located near the work area for making pastries, for instance).[41] Such innovations, which decreased the number of steps needed to carry out food preparation by fifty to sixty percent, were hailed as a motion study feat and boon for disabled homemakers. In October 1948, the Heart Kitchen attracted particular fanfare (including a feature in the *New York Times*), when it was showcased at the Museum of Natural History in Manhattan as part of "National Employ the Handicapped Week."[42] Shortly after the exhibit closed, the kitchen was relocated to NYU's Institute of Physical Medicine and Rehabilitation, where it became an important component of Howard Rusk's program for disabled homemakers.[43]

During the late 1940s and early 1950s, Rusk's staff embarked on several studies of homemaker rehabilitation, an undertaking that enjoyed support not only from Lillian Gilbreth, who served as a consultant, but also from a number of the nation's utility companies. In 1948, General Electric agreed to furnish cooking, cleaning, and other household equipment for the institute's new course for teaching disabled homemakers motion-saving work techniques. Utility companies also made up the bulk of contributors to the Disabled Homemakers' Research Fund, which sponsored the institute's Disabled Homemakers Research Project beginning in the 1950s.[44] According to Julia Judson, the physical therapist and home economist who coordinated the project, its aims were three fold: to provide patient training, to train vocational rehabilitation professionals, and to conduct research in the field.[45] While the project included cardiac patients, it was not restricted to them. Rather, it sought to assist a wide range of homemakers "limited in their energy capacity," as well as those with impaired mobility.[46] Homemakers with lower extremity disabilities, such as wheelchair and crutch users, constituted one target group, while homemakers with limited use of one or both hands comprised another.[47]

Although the precise techniques and assistive devices recommended for each population of disabled homemakers varied, the overarching justification for their rehabilitation remained consistent, at least according to Rusk, Judson, and other members of the institute staff. As they explained in their 1955 *Manual for Training the Disabled Homemaker*, which summarized the first five years of NYU's Disabled Homemakers Research Project, homemaker rehabilitation deserved more attention than it historically or currently received. Setting out to explain "why special help for the disabled homemaker" was needed, they drew on dominant gender discourses, lauding "the role of wife and mother as the keystone of family life." Yet at the same time that Rusk and his staff upheld traditional gender roles, they also contested them. They made clear that homemakers' contributions to the family were by no means limited to their social or cultural dimensions but instead had significant economic ramifications. They noted, for example, that "a permanent disability is a continuing financial drain if the homemaker cannot carry on her usual responsibility" and echoed Rusk's earlier characterization of homemakers as "the largest occupational group among the disabled."[48] Defining homemakers as economic actors served both to complicate models of middle-class domesticity as well as to justify the need for increased attention to homemaking in the expanding vocational rehabilitation system.

These early homemaker rehabilitation initiatives, the key individuals associated with them, and the justifications used to support them, helped to inspire similar investigations in other parts of the country.[49] Throughout the 1950s, state heart associations widely adopted their own heart kitchens, while graduate students and professors connected to home economics programs undertook lengthy studies.[50] Building on this burgeoning interest, the University of Connecticut convened a "Handicapped Homemakers" workshop in June 1953. The seven-day gathering, which aimed "to acquaint leaders concerned with the problems of homemakers with various types of disability…with some of the principles, tools and techniques of work simplification as used in industry and their application to household tasks," drew together home economists, physical therapists, public health officials, medical experts, and local residents in a variety of fields.[51] Participants enjoyed addresses by noted authorities such as Lillian Gilbreth, whom organizers credited with inspiring and guiding plans for the workshop, as well as Julia Judson, who provided an overview of the Disabled Homemakers Research Project at NYU's Institute of Physical Medicine and Rehabilitation. The project's contributions to homemaker rehabilitation were also showcased in an exhibit featuring some of its tools for one-handed homemakers. Other displays included a scale model of the Heart Kitchen that was used by the Connecticut Heart Association as well as an array of devices for visually impaired cooks (such as Braille labels for canned goods and recipe cards) that had been loaned by the American Foundation for the Blind.[52]

Most of the participants' time was spent observing the application of motion study principles to household work. This was accomplished, in part, through the use of instructional films that the University of Connecticut had been producing in the six months leading up to the workshop. Featured titles included "Physically Handicapped Women Keeping House," "Motion Economy Applied to the Kitchen," and "Transferring Eggs (For Film Analysis)."[53] Participants also attended demonstrations at the university's Motion and Time Study Laboratory as well as the School of Home Economics' Home Management Houses and Equipment Laboratory, where much of the workshop was held. There, they were taught how to adjust kitchen equipment "to suit the particular needs of homemakers with various disabilities."[54] Although coordinated by conference planners, these laboratory sessions relied heavily on the participation of disabled women themselves, who demonstrated many of the devices and work techniques. A homemaker on crutches, for example, showed how to use an elevated oven. Other participants included a wheelchair-user, a woman with long leg braces, a cardiac patient, and two women who had each lost an arm.[55]

The inclusion of disabled homemakers in the workshop reflected the belief of at least some of its planners that women with disabilities had much to teach vocational rehabilitation "experts" about the rehabilitation process and should be involved accordingly. Julia Judson, who oversaw two of the demonstrations, was in fact quite accustomed to soliciting input from the same women who she saw herself as helping. In her 1949 master's thesis, a study of "Home Management Aids for Women with Physical Limitations" completed at the Ohio State University several years earlier, Judson surveyed fifty disabled women in order to learn which household tasks and bodily motions they considered most difficult. She then drew her conclusions and formulated recommendations based on their responses.[56] Similarly, at NYU's Institute of Physical Medicine and Rehabilitation, Judson relied on case histories, which she described as "a record of the families [*sic*] whys, whats, wheres, whens and whos used in motion studies" and found the "spirit of sharing problems and solutions" essential to the effectiveness of her work.[57]

A recognition of the need to consult disabled homemakers when devising vocational rehabilitation programs was shared by the workshop's principal organizer and University of Connecticut Dean of the School of Home Economics, Elizabeth Eckhardt May. A native of Folsom, New Jersey, May earned her first degree from the Trenton State Normal School and her B.S., M.A., and Ph.D. degrees in education from Columbia University Teachers College. She began her career with the West Virginia University Agricultural Extension Service, where she worked from 1921 to 1937. Later, during World War II, she served as Executive Secretary of the National Citizens Committee of the White House Conference on Children in a Democracy and, in 1943, was named Academic Dean and Dean of Faculty at Hood College in Frederick, Maryland. In 1952, she joined the faculty at the University of Connecticut, where she would serve as the Dean of the School of Home Economics until her retirement in 1964. Much of her work there, as well as in her early retirement, focused on the rehabilitation of disabled homemakers, whose input she and her staff routinely solicited. Indeed, many of her findings and recommendations reflected methods that disabled women had developed themselves.[58]

The 1953 "Handicapped Homemakers" workshop represented some of May's earliest efforts at Connecticut to generate interest in and encourage knowledge about homemaker rehabilitation. In planning the event, she enlisted wide support not only from her university, where the schools of home economics, business administration, and physical therapy served as cosponsors, but also from a range of organizations and agencies. These included local and state-based ones, such as the Connecticut Heart Association, the Connecticut Society for Crippled Children and Adults, and the Connecticut State Department of Education's Bureau of Vocational Rehabilitation, as well as the federal government's Office of Vocational Rehabilitation.[59]

The OVR's support for the workshop, as well as the rehabilitation of disabled homemakers more generally, was informed largely by its director, Mary Elizabeth Switzer. Born in 1900 in Upper Newton Falls, Massachusetts, near Boston, Switzer was exposed early on to political activism through her Irish immigrant family. Particularly influential was her maternal uncle, Michael Moore, a socialist and strong supporter of Irish independence who encouraged her to be socially conscious and politically involved. Following high school, Switzer received a scholarship to attend Radcliffe College, to which she commuted from her family's home. There, she became friends with Elizabeth Brandeis, daughter of Supreme Court justice Louis D. Brandeis, and it was through that connection that Switzer embarked on a career in the federal government following graduation from Radcliffe in 1921.[60]

Shortly after moving to Washington to work for the District of Columbia Minimum Wage Board, Switzer became friends with Tracy Copp, an administrator with the new civilian vocational rehabilitation program. Although Switzer did not enter the field of rehabilitation herself for more than a decade, her relationship with Copp would prove critical to that eventual decision, as Copp not only introduced her to the subject, but would also keep her posted on key developments for years to come.[61] When the minimum wage board where Switzer worked was declared unconstitutional and disbanded in 1922, Switzer served a short stint as executive secretary of the Women's International League for Peace and Freedom before joining the Treasury Department later that year. One of the most important moments in Switzer's career came in the mid-1930s when she became the assistant to Josephine Roche, the newly appointed director of the Public Health Service which was then part of the Treasury Department. In that capacity, she worked with Roche on the Social Security Act of 1935 as well as the monumental National Health Survey conducted in 1935–1936 that quantified and clarified on a large scale the prevalence of disability in American society, as well as the need for government involvement. In 1939, Switzer, along with the Public Health Service, moved to the newly established Federal Security Agency that oversaw the civilian rehabilitation program. She served as assistant to several administrators before being named director of the agency's Office of Vocational Rehabilitation in December 1950.[62]

Although Switzer was not present at the 1953 University of Connecticut "Handicapped Homemakers" workshop, her office, which had recently become part of the new Department of Health, Education and Welfare (HEW), provided support for it. Switzer also penned the foreword to the final workshop proceedings that the HEW printed the following year. Switzer lauded the workshop's aims, noting that "the special problems of disabled homemakers cause[d] serious social strains" that affected the family and society more generally.[63] In a reference to middle-class gender roles and expectations about motherhood, Switzer argued that homemaker rehabilitation would, in part, guard against "the broken home" and "delinquency" by assisting women to carry out their culturally prescribed duties. Switzer also made clear her expectation that homemaker rehabilitation would reduce "dependency," a long-standing goal of vocational rehabilitationists.[64]

Switzer's interest in including homemakers in vocational rehabilitation was bolstered through her connection to Howard Rusk, who she first met during World War II when he appeared before the Procurement and Assignment Board to explain his Army Air Force rehabilitation program. Impressed by his integrative approach, she became a strong supporter of rehabilitation medicine and a key ally in the federal government who championed his ideas. Rusk, likewise, worked to assist Switzer, who benefited greatly from having a respected rehabilitation authority on her side. She not only wrote him routinely on rehabilitation matters, but even brought him along to a number of high-level meetings at the Federal Security Agency. Moreover, it was Rusk who advanced Switzer's candidacy for head of the OVR.[65] After Switzer assumed her new position, her collaboration with Rusk continued and the two, according to historian Edward Berkowitz, "entered what was almost a partnership to run the vocational rehabilitation program."[66]

One example of their joint efforts can be seen in the 1953 pamphlet, *Doing Something for the Disabled*, that they coauthored. Aimed at a general audience, the informational piece sought to drum up support for an interdisciplinary model of rehabilitation that, in line with Rusk's earlier work, brought together medical experts, social workers, job counselors, and other professionals in an effort to help "[restore] people to lives of productivity and satisfaction."[67] Rehabilitation, Switzer and Rusk promised, would assist individuals with disabilities to carry out meaningful lives while also reducing their reliance on public assistance in the long term.[68] While much of their discussion focused on wage earners, they included a special section on the rehabilitation of homemakers that highlighted their various contributions to family life and society. According to Switzer and Rusk, "The disability of a wife and mother can destroy a home, cast children adrift, exhaust the husband's earnings, and produce public costs which are so large and so prolonged as to be almost immeasurable."[69] Thus, at the same time that they reinforced the primacy of gender roles to the functioning of the family, they also helped to call attention to the economic importance of women's work inside the home. The insinuation that the family's income could be depleted by the loss of a homemaker's contributions suggested that they were not only culturally but also economically valuable. Switzer and Rusk also reiterated Rusk's earlier characterization of homemakers as "the largest single occupational group" of the disabled and concluded that "the disabled wife, returned as a homemaker, presents the most dramatic and moving demonstration to a community of the far-reaching effects of rehabilitation."[70]

Expanding Support for Homemakers

Doing Something for the Disabled not only helped to raise awareness of vocational rehabilitation in general, but also helped to pave the way for the 1954 Vocational Rehabilitation Act Amendments that Switzer was instrumental in crafting. Both she and Rusk were in attendance when President Dwight Eisenhower authorized the legislation in a signing ceremony that August, thereby putting in motion the substantial expansion of the nation's vocational rehabilitation program.[71] The legislation, which aimed "to promote and assist in the extension and improvement of vocational rehabilitation services," increased funding for research, training, and the establishment of rehabilitation centers nationwide.[72] In the process, it aided Switzer in stretching what historian Jonathan Hughes terms "the old and inflexible" vocational rehabilitation rules.[73] Under her direction, the OVR funded a slew of research and demonstration project proposals from not only establishment types but also "mavericks" that helped to enlarge the purview of vocational rehabilitation.[74] Notably, these included investigations of homemaker rehabilitation.

Among the first and largest of these was a five-year study on "Work Simplification in the Area of Child Care for Physically Handicapped Women" that was carried out at the University of Connecticut between 1955 and 1960. An outgrowth of Connecticut's 1953 workshop, the "Handicapped Homemaker" project, as it was known, was directed by Elizabeth Eckhardt May, who enlisted both Lillian Gilbreth and Julia Judson as consultants. Their ongoing interest in work simplification was especially felt, as was their insistence on soliciting the input of disabled women.[75] Over the course of the project, researchers crisscrossed the state, interviewing more than 100 disabled mothers to determine not only the problems that they faced but also to survey the strategies that they had already developed for themselves.[76] Their responses became the basis for the extended report, books, pamphlets, and conferences that May and her team of home economists, medical professionals, social workers, and sociologists put together. Also instrumental in this effort was the project's research coordinator, Neva R. Waggoner, who was herself disabled.[77]

The "Handicapped Homemaker" project provided disabled women with public validation of their homemaking strategies, assisted other disabled women to streamline their own work processes and, according to historian Audra Jennings, "provided useful information and guidelines that enabled the federal-state rehabilitation program increasingly to offer training and aid to disabled homemakers."[78] During the late 1950s and early 1960s interest in homemaker rehabilitation and funding for it swelled. The OVR supported an increasing number of projects that analyzed work processes in the home, developed assistive housework devices, and designed children's clothing. The number of homemakers who were rehabilitated through the federal-state program also expanded. In 1956 alone, 6790 homemakers were rehabilitated, making up nearly a third of all rehabilitated women that year.[79] By 1958, homemakers comprised 13 percent of all rehabilitation recipients, regardless of gender.[80]

These efforts to rehabilitate homemakers represented a notable expansion of a vocational rehabilitation system that had been initially based on the needs of overwhelmingly male veterans and wage earners. They also gave rise to more pointed critiques of the status of homemaking within the vocational rehabilitation system and society more generally. At a June 1960 homemaker rehabilitation workshop where Elizabeth Eckhart May touted Switzer's liberal interpretation of the 1954 Vocational Rehabilitation Act Amendments to include homemaking, she raised concerns that not all states had yet embraced it. She suspected that part of the reason for their ongoing reluctance was because "those who make appropriations are likely to be much more impressed by the reports on the number of men and women rehabilitated for business and industry than by the number rehabilitated for homemaking." But an even larger problem, May insisted, was a general lack of regard for homemaking itself that went far beyond policymakers. "Although we are inclined in America to be sentimental about 'home and mother,'" she remarked, "we give little prestige to homemaking as a vocation: consider how many census takers must have heard, 'Oh, I'm just a homemaker,' in answer to the question of 'What is your occupation?'"[81] What May's comments made clear was that the fuller inclusion of homemaking in vocational rehabilitation would require increased efforts to establish homemakers as an occupational group and to call attention to the value of their work.

Consequently, the revaluation of homemaking from an economic perspective became increasingly important to May, as well as other vocational rehabilitationists, many of whom were connected to the President's Committee on Employment of the Handicapped. Dating back to the 1940s, the committee grew out of National Employ the Physically Handicapped Week, which President Truman had declared in 1945. Two years later, at the urging of disability activists and Department of Labor officials, a President's Committee was formed to coordinate the week's activities and to promote the employment of people with disabilities. In 1952, Truman changed the name of the committee to the President's Committee on Employment of the Physically Handicapped and, ten years later, in 1962, the word "physically" was dropped under an executive order from President John F. Kennedy.[82] That same year, a women's committee was created in an effort to mobilize individual women and women's organizations in pursuit of the Committee's larger goals. Some 30 women comprised the Women's Committee's roster of organization representatives, individual members, and consultants, including Mary Switzer and Lillian Gilbreth. Elizabeth May also advised the committee before becoming a member at large.[83]

The Women's Committee decided early on to devote special attention to homemaker rehabilitation, a move that was largely influenced by May herself.[84] In spring 1962, shortly after the committee was formed, May prepared for the group a short position paper, "Consider the 'Labor Force' in the Home," where she called for renewed attention to homemaker rehabilitation. She lamented that, despite recent advances, homemaking was "still the most neglected area of rehabilitation." She also urged the committee to think more concretely about the economic value of homemaking, noting that "it takes only a little imagination and an elementary knowledge of arithmetic to see what can happen to the family budget and what may be involved in tax and welfare dollars if the mother is unable to do their [*sic*] job."[85] These themes became the basis for the homemaker rehabilitation subcommittee that the women's committee later formed. May played a particularly decisive role in this new group, which she agreed to chair in 1965.[86]

Under her leadership, the subcommittee intensified its emphasis on the economic aspects of homemaking. In 1966, the group announced that one of its primary goals was "to promote the recognition of the homemaker as a worker."[87] To that end, the group also produced and circulated a flyer, "What's a Homemaker Worth?" that assigned a monetary value to various tasks related to the upkeep of the home and family, exclusive of child care. Using statistics prepared for the group by the Women's Division of the Institute of Life Insurance in 1965, the flyer totaled up the weekly value of meal preparation, after meal cleanup, family care, house care, washing clothes, ironing, management, and marketing, which came out to $61.32, or $3188.64 per year (as a point of comparison, the median salary for female professional nurses reported a few years earlier, in 1959, was $3186). The flyer also contained information on a recent legal judgment pertaining to the loss of wife and mother where "the cost of the father of providing substitute homemaking and childcare for 20 years" was determined to be $120,000, or $6000 per year. By accounting for childcare, this figure further elevated the economic value of women's work inside the home and reflected the fact that women's domestic responsibilities often surpassed 40-hour workweeks.[88] These findings are significant not only because they highlighted the importance of rehabilitating homemakers with disabilities, but also because they served as a precursor to later feminist efforts to monetize work inside the home, such as the international "Wages for Housework" campaign that was launched in 1972.[89]

The revaluation of homemaking from an economic perspective is an important legacy of efforts to rehabilitate homemakers in the post-World War II period. The gradual expansion of the vocational rehabilitation system to include more than 184,000 disabled homemakers by 1966 drew heavily on two seemingly contradictory concerns.[90] On one hand, homemaker rehabilitation was justified by Cold War domesticity and gender roles that reinforced female dependency on male breadwinners. On the other hand, it recognized that women's homemaking roles carried not only cultural but also economic weight and that a family's financial well-being was not solely based on the income of its wage earners. By ascribing economic importance to women's unpaid work, vocational rehabilitationists challenged the presumed primacy of male breadwinners and paved the way for similar feminist critiques later on.

The early history of homemaker rehabilitation also uncovers a network of medical professionals, policymakers, educators, inventors, and others who concerned themselves with some of the challenges facing disabled homemakers. By devising and promoting new ways for them to carry out their work, these reformers hoped to provide women with disabilities the same opportunity as their able-bodied counterparts to pursue and to reap the social acceptance of "normal" lives. The fact that many of these reformers found it necessary and valuable to solicit the input of disabled women themselves is also significant, as it disrupts the assumption that rehabilitation efforts always took place from the top down. These early collaborations helped to bring visibility to disabled women, promote their own work strategies, and advance a larger shared goal of assisting disabled women to live and work independently—goals that underpinned the independent living movement most commonly associated with the 1970s.[91] Although homemaker rehabilitationists rarely used the term "rights," their efforts intersected with and lent support to later movements aimed at improving the lives of both women and disabled people.

NOTES

1. Howard A. "Rusk, Research in Developing Techniques and the Equipment for Them Held Needed," *New York Times*, July 13, 1947, 25.
2. Many of these are cited in Mary C. Callender and Susan Pike Corcoran, "Bibliography on Home Management with Emphasis on Work Simplification for Physically Handicapped Homemakers"

(Storrs, CT: University of Connecticut, 1960). See also Pauline Rehder, "Trends in Management," paper written for Mechanical Engineering 180 at the University of Wisconsin [ca. 1952], folder 2, box 52, MSP 7, Frank and Lillian Gilbreth Papers, Archives and Special Collections, Purdue University Libraries (hereafter cited as Gilbreth papers).

3. Stephanie Coontz, *A Strange Stirring: The Feminine Mystique and the American Women at the Dawn of the 1960s* (New York: Basic Books, 2011), 125.
4. Coontz, *A Strange Stirring*, 125.
5. See, for example, Elizabeth Eckhardt May, Neva R. Waggoner, and Eleanor M. Boettke, ed., *Homemaking for the Handicapped* (New York: Dodd, Mead & Company, 1966), which contains several photographs of African American disabled homemakers. It does not, however, explicitly discuss the concerns of African American homemakers or even the rate of their participation in vocational rehabilitation.
6. C. Esco Obermann, *A History of Vocational Rehabilitation in America* (Minneapolis: T.S. Denison & Company, 1965), 73–114.
7. Obermann, *A History of Vocational Rehabilitation in America*, 147–150; Sarah Frances Rose, "No Right to Be Idle: The Invention of Disability, 1850–1930" (Ph.D. dissertation, University of Illinois at Chicago, 2008), 262–263, 271, 274.
8. Obermann, *A History of Vocational Rehabilitation in America*, 154–171; Audra R. Jennings, "With Minds Fixed on the Horrors of War: Liberalism and Disability Activism, 1940–1960" (Ph.D. dissertation, The Ohio State University, 2008), 30. For a fascinating discussion of the role of race in the rehabilitation of African American veterans following World War I, see Paul R.D. Lawrie, "'Salvaging the Negro': Race, Rehabilitation, and the Body Politics in World War I America, 1917–1924," in *Disability Histories*, ed. Susan Burch and Michael Rembis (Urbana: University of Illinois Press, 2014), 321–344.
9. Obermann, *A History of Vocational Rehabilitation in America*, 174.
10. Jennings, "With Minds Fixed on the Horrors of War," 28–30. See also Edward David Berkowitz, *Rehabilitation: The Federal Government's Response to Disability 1935–1954* (New York: Arno Press, 1980), 83–84, for his discussion of vocational rehabilitation

as "an outgrowth of workers' compensation." For a more detailed summary of the history of workers' compensation, see disability policy analyst Scott Szymendera, "Reviewing Workers' Compensation for Federal Employees," Statement, United States House of Representatives, Committee on Education and the Workforce, May 12, 2011, 1, 1 (n. 1) and 4–8: http://edworkforce.house.gov/uploadedfiles/05.12.11_szymendera.pdf (accessed December 16, 2014). According to Szymendera, "The first workers' compensation law for federal employees was enacted in 1882 and provided up to two years of salary to any member of the federal United States Life Saving Service disabled in the line of duty and two years of salary to his or her survivors in case of a line of duty death. In 1908, Congress passed a more comprehensive workers' compensation law for federal employees engaged in certain hazardous occupations." Szymendera refers to the 1908 legislation as "the first general workers' compensation law in the United States." See Szymendera, 1 (n.1) and 5–6.

11. Federal Board for Vocational Education, "Present Status of Industrial Rehabilitation," *The Vocational Summary* 3, no. 6 (October 1920): 83–86.
12. Public Law 236, 66th Congress (2 June 1920), in "Text of Act Providing for Rehabilitation of Persons Disabled in Industry or Otherwise," *The Vocational Summary* 3, no. 4 (August 1920):54–55.
13. Richard Scotch, *From Good Will to Civil Rights: Transforming Federal Disability Policy*, second edition (Philadelphia: Temple University Press, 2001), 20–21; Obermann, *A History of Vocational Rehabilitation in America*, 234; Chancy Croft, "Something More Important Than Money—Vocational Rehabilitation in Workers' Compensation Cases," *Alaska Law Review* 3, no. 49 (1986): 57. Funding was also based on population.
14. Scotch, *From Good Will to Civil Rights*, 20–21.
15. Obermann, *A History of Vocational Rehabilitation in America*, 174; Jennings, "With Minds Fixed on the Horrors of War," 44. An overview of legislative milestones can also be found in Nathan Lesowitz, *Statistical History: Federal State Program of Vocational Rehabilitation, 1920–1969* (Washington, DC: GPO, 1970). See p. 8 for statistics on the number of people rehabilitated.
16. Berkowitz, *Rehabilitation*, 89.

17. Jennings, "With Minds Fixed on the Horrors of War," 31, 44; Lesowitz, *Statistical History*, 8; Ruth O'Brien, *Crippled Justice: The History of Modern Disability Policy in the Workplace* (Chicago: University of Chicago Press, 2001), 65.
18. Obermann, *A History of Vocational Rehabilitation in America*, 286–287; Scotch, *From Good Will to Civil Rights*, 21–22; Kathlyn L. Reed, "History of Federal Legislation for Persons With Disabilities," *American Journal of Occupational Therapy* 46, no. 5 (May 1992): 400.
19. Obermann, *A History of Vocational Rehabilitation in America*, 179–182, 288; Lesowitz, *Statistical History*, 8.
20. Public Law 113 (Vocational Rehabilitation Act Amendments of 1943), quoted in Obermann, *A History of Vocational Rehabilitation in America*, 286.
21. Rose, "No Right to Be Idle," 271.
22. O'Brien, *Crippled Justice*, 65.
23. O'Brien, *Crippled Justice*, 239 (n. 8). O'Brien explains that "throughout the 1920s and 1930s, the average rehabilitated person was white, male, and thirty-one years old." See O'Brien, 65.
24. Federal Board for Vocational Education, "Women and the Industrial Rehabilitation Act," *The Vocational Summary* 3, no. 6 (October 1920): 86–87; Scotch, *From Good Will to Civil Rights*, 20; Audra Jennings, "Engendering and Regendering Disability: Gender and Disability Activism in Postwar America," in Burch and Rembis, *Disability Histories*, 350.
25. See Elaine Tyler May, *Homeward Bound: American Families in the Cold War Era* (New York: Basic Books, Inc., 1988), especially 3, 10, 12–13, and Jennings, "Engendering and Regendering Disability," 347–348.
26. Rusk, "Research in Developing Techniques and the Equipment for Them Held Needed," 25.
27. Rusk, "Research in Developing Techniques and the Equipment for Them Held Needed," 25.
28. Berkowitz, *Rehabilitation*, 110–111; Richard Verville, *War, Politics, and Philanthropy: The History of Rehabilitation Medicine* (Lantham, MD: University Press of America, Inc., 2009), 62–63; Nava Blum and Elizabeth Fee, "Howard A. Rusk (1901–1989) From Military Medicine to Comprehensive Rehabilitation," *American Journal of Public Health* 98, no. 2 (February 2008):

256. See also Howard A. Rusk, *A World to Care for: The Autobiography of Howard A. Rusk, M.D.* (New York: Random House, 1972).

29. Verville, *War, Politics, and Philanthropy*, 63; Berkowitz, *Rehabilitation*, 111; "Howard A. Rusk (1901–1989)," in Ross M. Mullner, *Health and Medicine* (USA: SAGE Publications, 2011), 194.
30. Rusk, *A World to Care for*, 99. See also Howard A. Rusk, "New Institute at Bellevue to Fill Gap in Medical Care," *New York Times*, January 12, 1947, 50, where Rusk asserts that the department was "the first in any medical school in the world."
31. Rusk, *A World to Care for*, 99.
32. Verville, *War, Politics, and Philanthropy*, 92–94; Rusk, *A World to Care for*, 106, 143, 179. Rusk's center was later renamed the Rusk Institute of Rehabilitation Medicine. See also Howard A. Rusk, "New Institute at Bellevue to Fill Gap in Medical Care," *New York Times*, January 12, 1947, 50.
33. Howard A. Rusk, "Forgotten Casualty: The Disabled Civilian," *New York Times*, May 12, 1946, 11.
34. Rusk, "Forgotten Casualty," 11; Rusk, *A World to Care for*, 115, 120.
35. Howard A. Rusk, "Rehabilitation and Convalescence: The Third Phase of Medical Care," in *Contributions Toward Medical Psychology: Theory and Psychodiagnostic Methods*, vol. 1, ed. Arthur Weider (New York: Ronald Press Company, 1953), 438–455.
36. Rusk, "Forgotten Casualty," 11; Eva vB.Hansl, "The Gilbreth Projects" and attached letter from Hansl to Lillian Moller Gilbreth, January 25, 1968, folder 8, box 10, Gilbreth papers; Eva vB.Hansl to Howard A. Rusk, September 2, 1947, folder: correspondence 1947, box 2, Eva Hansl Papers, Special Collections Research Center, Syracuse University Libraries. See also Mary E. Switzer and Howard A. Rusk, *Doing Something for the Disabled* (Public Affairs Committee, Incorporated: 1953), 14, where they report that Rusk's Institute of Physical Medicine and Rehabilitation had spent the past three years studying the problems of disabled homemakers.
37. Howard A. Rusk, Edith L. Kristeller, Julia S. Judson, Gladys M. Hunt, and Muriel E. Zimmerman, *A Manual for Training the Disabled Homemaker* (New York: New York University-Bellevue

Medical Center Institute of Physical Medicine and Rehabilitation, 1955), introduction (not paginated). See also Eva vB.Hansl to Lillian Gilbreth, November 12, 1966, folder 8, box 10, Gilbreth Papers.

38. Ruth Schwartz Cowan, "Lillian Moller Gilbreth," in *Notable American Women: The Modern Period*, ed. Barbara Sicherman and Carol Hurd Green (Cambridge, MA: Belknap Press of Harvard University Press, 1980), 272–273; and Margaret W. Rossiter, *Women Scientists in America*, vol. 1, *Struggles and Strategies to 1940* (Baltimore: Johns Hopkins University Press, 1982), 262. See also Frank Gilbreth, Jr. and Ernestine Gilbreth Carey, *Cheaper by the Dozen* (New York: Thomas Y. Crowell and Co., 1948). Although she was included in her sibling's retelling of their childhood in *Cheaper by the Dozen*, Mary, a twelfth child, had died of diphtheria in 1912.
39. Cowan, "Lillian Moller Gilbreth," 272; Laurel Graham, *Managing on Her Own: Dr. Lillian Gilbreth and Women's Work in the Interwar Era* (Norcross, GA: Engineering and Management Press, 1998), 4–5, 179–182; "Mrs. Lillian Moller Gilbreth" (annotated resume), folder 1, box 20, Gilbreth papers.
40. American Heart Association, *Heart of the Home* (New York: American Heart Association, 1948), preface, folder 2, box 52; "Biographical Data on Dr. Lillian Moller Gilbreth," [ca. 1963], folder 3, box 20; and Elizabeth Eckhardt May, "Expanding the Services of the Home Economist in Rehabilitation, Address given at the Pre-Convention Workshop on Homemaker Rehabilitation sponsored by the American Home Economics Association and the American Dietetic Association, June 27, 1960, folder 1, box 13, all in Gilbreth papers.
41. "News of Food: Kitchen That Saves Time and Energy Featured at Employ-the-Disabled Show," *New York Times*, October 5, 1948, 29.
42. "News of Food," 29;" American Heart Association, *Heart of the Home* kodachrome supplement (New York: American Heart Association, [ca. 1950]), unpaginated; and Rehder, "Trends in Management," both in folder 2, box 52, Gilbreth papers.
43. "Biographical Data on Dr. Lillian Moller Gilbreth," [ca. 1963], folder 3, box 20, Gilbreth papers; Rusk, *A World to Care for*, 143–144; "Disabled Women Will Get Home Aid: N.Y.U., General

Electric Join Forces to Help Housewives in Rehabilitation Course," *New York Times*, February 4, 1948, 20.

44. "Disabled Women Will Get Home Aid," 20; Rusk et al., *A Manual for Training the Disabled Homemaker*, acknowledgments (unpaginated), 1; Howard A. Rusk and Eugene J. Taylor, *Living with a Disability* (Garden City, NY: The Blakiston Company, Inc., 1953), 7–8; Howard A. Rusk to Contributors, Disabled Homemakers Research Fund [ca. 1956], folder 2, box 52, Gilbreth papers. Rusk letter also mentions several other kitchens for disabled homemakers across the country.
45. "Excerpts from Talks Made During the Workshop," 10, in "Handicapped Homemakers," proceedings, Leader's Workshop on Principles of Work Simplification Applied to Problems of Physically Handicapped Homemakers, University of Connecticut, June 14–20, 1953.
46. Rusk, et al., *A Manual for Training the Disabled Homemaker*, 37.
47. See especially Chap. IV, "Re-Training the Homemaker with Hand Difficulties" and Chap. VI, "Retraining the Homemaker with Lower Extremity Disabilities," in Rusk, et al., *A Manual for Training the Disabled Homemaker*, 77–111 and 112–148. Early findings were also shared in the short booklet, Institute of Physical Medicine and Rehabilitation, *Rx for the Disabled Housewife*, 1952. A revised version was printed in 1961. Here, the focus on the medical and psychological aspects of rehabilitation is especially apparent.
48. Rusk, et al., *A Manual for Training the Disabled Homemaker*, introduction (unpaginated).
49. Rehder, "Trends in Management" [ca. 1952] and Rusk to Contributors, Disabled Homemakers Research Fund [ca 1956], both in folder 2, box 52, Gilbreth papers.
50. Lancaster, *Making Time*, 318; Callender and "Bibliography on Home Management with Emphasis on Work Simplification for Physically Handicapped Homemakers."
51. Elizabeth Eckhardt May, "Purpose and Plan for the Workshop," 1, in "Handicapped Homemakers," proceedings.
52. May, "Purpose and Plan for the Workshop," 1–3, "Exhibits," 8–9, "Directory of Participants," 20–22, and "Directory of Visitors," 26–28, all in "Handicapped Homemakers," proceedings. Although the organizers had capped the number of participants at thirty,

they allowed for another fifty visitors to attend special programs on the last two days.

53. May, “Purpose and Plan for the Workshop,” 1–2 and “Agenda of Workshop Program,” 14–19 and 23–25, both in “Handicapped Homemakers,” proceedings. A description of the films can be found on pages 32 and 33.
54. May, “Purpose and Plan for the Workshop,” 1 and “Agenda of Workshop Program,” 18, both in “Handicapped Homemakers” proceedings.
55. May, “Purpose and Plan for the Workshop,” 2 and photograph, “Homemaker on crutches demonstrates the advantages of a high oven,” both in “Handicapped Homemakers” proceedings.
56. May, “Purpose and Plan for the Workshop,” 2, “Agenda of Workshop Program,” 18, and Ruth Cresswell Kettunen, “A Limited Survey of Research Studies and Pertinent Material Bearing Upon the Problems of the Cardiac Homemaker,” 91–92, all in “Handicapped Homemakers” proceedings. See also Julia S. Judson, “Home Management Aids for Women with Physical Limitations” (master’s thesis, The Ohio State University, 1949).
57. Julia Judson, “Work Simplification for the Disabled,” 59–60, in “Handicapped Homemakers” proceedings. See also Rusk and Taylor, *Living with a Disability*, 8, where they thank not only their patients but also all of the disabled individuals who assisted with their ideas and in the testing of the institute’s suggestions. They concluded that “the primary credit must go to them.” Judson is listed a collaborator on this publication.
58. “May. Elizabeth Eckhardt,” *Hartford Courant*, October 29, 1996, http://articles.courant.com/1996-10-29/news/9610290271_1_handicapped-hood-college-home-economics (accessed January 6, 2015); Audra Jennings, “May, Elizabeth Eckhardt,” in *Encyclopedia of American Disability History*, ed. Susan Burch (New York: Facts On File, Inc., 2009) http://www.fofweb.com/activelink2.asp?ItemID=WE52&iPin=EADH0446&SingleRecord=True (accessed January 6, 2015).
59. May, “Purpose and Plan for the Workshop,” 1, in “Handicapped Homemakers” proceedings.
60. Martha Lentz Walker, *Beyond Bureaucracy: Mary Elizabeth Switzer and Rehabilitation* (Lantham, MD: University Press of America, 1985), xii–xiii, 13–14, 21–24; Richard K. Scotch, “Switzer, Mary

Elizabeth," in *Encyclopedia of American Disability History*, ed. Susan Burch (New York: Facts On File, Inc., 2009) http://www.fofweb.com/History/MainPrintPage.asp?iPin=EADH0684&DataType=AmericanHistory&WinType=Free%5D (accessed January 6, 2015). Walker reports that Switzer's Uncle took her to meetings of the Gaelic Society and to Ford Hall to see Helen Keller and Anne Sullivan Macy. See Walker, 9–10.

61. Walker, *Beyond Bureaucracy*, xiii; Berkowitz, *Rehabilitation*, 237.
62. Walker, *Beyond Bureaucracy*, xiii, xiv, 26–28, 33–36, 46–48, 142; Berkowitz, *Rehabilitation*, 42–43, 238, 242, 244; Scotch, "Switzer, Mary Elizabeth."
63. Mary E. Switzer, "Foreword," iii, in "Handicapped Homemakers" proceedings.
64. Switzer, "Foreword," iii, in "Handicapped Homemakers" proceedings.
65. O'Brien, *Crippled Justice*, 71; Walker, *Beyond Bureaucracy*, xv; Berkowitz, *Rehabilitation*, 246–248 (quotation on 247).
66. Berkowitz, *Rehabilitation*, 247.
67. Switzer and Rusk, *Doing Something for the Disabled*, 2–3, 13–14, 22–23 (quotation on 8).
68. Switzer and Rusk, *Doing Something for the Disabled*, 5–8.
69. Switzer and Rusk, *Doing Something for the Disabled*, 7, 12–15 (quotation on 12).
70. Switzer and Rusk, *Doing Something for the Disabled*, 12–13.
71. O'Brien, *Crippled Justice*, 82.
72. Margaret A. Turk and Nancy R. Mudrick, *Rehabilitation Interventions* (U.S.A.: Sage Publications, Inc., 2013), 196; Public Law 565 (August 3, 1954) *HeinOnline* *http://0-heinonline.org.read.cnu.edu/HOL/Page?handle=hein.statute/sal068&collection=statute684&id=684* (accessed February 10, 2015).

    Scotch, *From Good Will to Civil Rights*, 22; Obermann, *A History of Vocational Rehabilitation in America*, 316–320; O'Brien, *Crippled Justice*, 83–84; Verville, *War, Politics, and Philanthropy*, 141; Public Law 565 (August 3, 1954) *HeinOnline* *http://0-heinonline.org.read.cnu.edu/HOL/Page?handle=hein.statute/sal068&collection=statute684&id=684* (accessed February 10, 2015)
73. Jonathan Hughes, *The Vital Few: The Entrepreneur and American Economic Progress* (New York: Oxford University Press, 1986), 485.

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75. Elizabeth Eckhardt May and Neva R. Waggoner, "Work Simplification in the Area of Child Care for Physically Handicapped Women," 1961, foreword, folder 1, box 13, Gilbreth papers.
76. May and Waggoner, "Work Simplification," 8; Audra Jennings, "Handicapped Homemaker Project," in *Encyclopedia of American Disability History*, ed. Susan Burch (New York: Facts On File, Inc., 2009) http://www.fofweb.com/History/MainPrintPage.asp?iPin=EADH0316&DataType=AmericanHistory&WinType=Free (accessed February 16, 2015).
77. Jennings, "Handicapped Homemaker Project."
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79. Women's Bureau, *Help for Handicapped Women* (Washington, DC: GPO, 1958), 5, 20.
80. Jennings, "Engendering and Regendering Disability, 350.
81. Elizabeth Eckhardt May, "Expanding the Services of the Home Economist in Rehabilitation," address given at the Pre-Convention Workshop on Homemaker Rehabilitation, sponsored by the American Home Economics Association and the American Dietetics Association, Denver, Colorado, June 27, 1960, folder 1, box 13, Gilbreth papers.
82. Jennings, "Out of the Horrors of War," 156–159, 161; Obermann, *A History of Vocational Rehabilitation in America*, 345–352.
83. Mary Switzer, Director's Letter Number 63–66, October 11, 1962, to Divisions of Vocational Rehabilitation, Committee and other Agencies for the Blind re: Women's Committee of the President's Committee on Employment of the Handicapped and membership roster, "Membership—Women's Committee," September, 1962, both in folder 6, box 17, Gilbreth papers; Elizabeth May to "Friends Far and Near," December 31, 1965, folder 1, box 13, Gilbreth papers.
84. Switzer, Director's Letter Number 63–66, October 11, 1962, folder 1, box 13 and Summary of the Meeting of the Women's Committee of the President's Committee on Employment of the Handicapped, September 11 and 12, 1962, folder 6, box 17, both in Gilbreth papers.
85. Elizabeth Eckhardt May, "Consider the 'Labor Force' in the Home," flyer prepared for the Women's Committee, President's

Committee on Employment of the Handicapped, May 1962, folder 1, box 52, Gilbreth papers.

86. May to "Friends Far and Near," December 31, 1965, folder 1, box 13, Gilbreth papers.
87. Summary of Women's Committee Meeting, The President's Committee on Employment of the Handicapped, November 15–16, 1966, folder 1, box 39Agenda, Homemaker Group—Women's Committee, November 16, 1966, folder 1, box 52, both in Gilbreth papers.
88. Women's Division, Institute of Life Insurance, "What's a Homemaker Worth?" flyer prepared for the Women's Committee, President's Committee on Employment of the Handicapped," April 1966, folder 1, box 52, Gilbreth papers. Statistics regarding the salaries of these categories of female workers are drawn from U.S. Bureau of the Census, *Statistical Abstract of the United States: 1966*, 87th ed. (Washington, DC: Government Printing Office, 1966), 235.
89. For other examples, see Annegret S. Ogden, *The Great American Housewife: From Helpmeet to Wage Earner, 1776–1986* (Westport, CT: Greenwood Press, 1986), 212.
90. Mary E. Switzer, "Introduction," in *Homemaking for the Handicapped*, ed. May, Waggoner, and Boettke, xiii.
91. See, for example, Chava Willig Levy, *A People's History of the Independent Living Movement* (Lawrence, KS: The Research and Training Center on Independent Living, University of Kansas, 1988), who suggests that the independent living movement can be traced to the appointment of Mary Switzer to the director of the OVR in 1950.

CHAPTER 5

Rethinking the American Dream Home: The Disability Rights Movement and the Cultural Politics of Accessible Housing in the United States

Andrew Marcum

The 2013 digital exhibition *Everybody: An Artifact History of Disability in America* curated by the Smithsonian Institution's National Museum of American History features an image in a section of the exhibit addressing "Place" that illustrates the tension between disability, access and equity, and cultural perceptions and spatial arrangements of the American "dream" home. Framed by curators under the title "Removal," the photo dates from the 1970s and depicts a quiet, middle-class neighborhood. Detached, single-family houses situated on carefully trimmed lawns define the background. A car makes its way around a cul-de-sac and toward a sign in the foreground that reads "NO WHEELCHAIRS BEYOND THIS POINT."[1] As the curators note, this neighborhood street sign "captures both the depth and absurdity of public concern about people with disabilities."[2] The image also suggests the ways in which built environments—

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and residential spaces in particular—can represent, reify, and reproduce dominant cultural ideologies about who belongs and who does not. As professor of architecture Korydon H. Smith observes, "Housing, in its physical, material form, is both representational and authoritative."[3] Smith suggests that this dual imperative operates because the physical constructs of houses reveal "underlying ideological constructs."[4]

This chapter reflects on the "underlying ideological constructs" of housing, "home," and disability in the contemporary USA and explores the dialectical relationship between an ongoing movement for disability rights and the built environment through a consideration of the cultural politics of accessible, community-based housing for people with disabilities. It utilizes artifacts and images from the disability rights movement in the USA, as well as accounts of "home," domesticity, and the built environment offered by disability studies scholars, activists, architects, and former residents of institutions. These archives—many of which are now publicly available online—document continuing struggles for disability rights, deinstitutionalization, and community integration in the USA. They also suggest some of the cultural meanings that get attached to "home" and domestic spaces—including ideas about disability, sex, gender, and the American "dream home" itself—all of which construct "home" as a heteronormative nondisabled space.

Such ableist, heteronormative conceptions of home actively condition the built environments we occupy in ways that isolate people with disabilities and underwrite a political economy of institutionalization that works against community integration. Despite evolving attitudes and shifting demographics, ableist cultural perceptions and social constructions of "home" and domesticity continue to limit access, integration, and quality of life for disabled people. Detached single-family housing often purposely built in remote areas far from public transportation remains the most common and culturally acceptable form of housing throughout the USA. As architects, theorists, and practitioners of accessible housing design such as Smith and Jennifer Webb have pointed out, homes like those featured in the Smithsonian exhibition's photograph were designed and built to meet the needs of young, white, nondisabled, middle-class families with children, "not for the aging, dwindling middle-class, single-parent, and ethnically diverse population of today."[5] Yet, accessible and affordable housing is essential to people with disabilities living outside of institutional settings in the community. Such housing must not only provide physical access within the home, but also facilitate access to services and opportunities for employment, education, social interaction, and community formation that people with disabilities need to thrive in the community.

This is a pivotal historical moment for disabled people struggling to live outside of institutions in inaccessible communities that currently do not support their diverse lives, needs, and aspirations. The US Supreme Court's 1999 decision in *Olmstead Vs. L.C.* established that forced institutionalization of people with disabilities is a violation of the Americans with Disabilities Act (ADA) and that people with disabilities have a right to live outside of institutions in the community whenever possible. The ruling also requires states to provide funding in support of home and community-based services for people with disabilities. The federal government and some states have responded by accelerating efforts to deinstitutionalize disabled people and place them in residential settings in the community. But there is a dearth of accessible housing in the USA. Ironically, in an effort to increase community-based housing options, some disability advocates, parents, and care providers have joined with businesses and housing providers to argue that segregated domestic settings such as farmsteads, residential "campuses," gated communities, and other forms of "intentional community" should continue to be a state-supported housing option, especially for those disabled people most severely "afflicted" by intellectual impairment, self-injury, and "disruptive behavior."[6] They argue that these settings provide a sense of community and support not available to people with disabilities in "mainstream" American society and highlight the extreme shortage of accessible housing as a reason to support the continuation of large-scale congregate living facilities.

Self-advocates, independent living activists, and state and federal officials have argued in turn that integration, and not segregation, is the best way to reduce the risks of injury, abuse, neglect, and isolation for disabled people and ensure that people with disabilities are not denied the chance to contribute to, enrich, and be enriched by the larger community. They contend that home and community-based care alone is not enough to achieve a "genuine community feeling" and that communities themselves must become more accessible to people with disabilities.[7] The persistent failure of built environments of "home" and "community" to meet the needs of people with disabilities is at the heart of these struggles. If deinstitutionalization is to succeed, then the segregating built environments of America's homes and neighborhoods must be challenged and changed. The political economy of institutionalization, as well as prevailing assumptions about disability and "home" that have long been used to justify segregating people with disabilities and denying them access to homes outside of institutions, need to be confronted in order to encourage new ways of thinking about, and building houses that cultivate, rather than stifle, access to home and community for people with disabilities.

Connecting Disability History and the Built Environment of "Home"

The visual and material artifacts and cultural critiques in this chapter demonstrate the significance of the disability rights movement to the housing debate by showing how it challenged not only architectural barriers, but also "attitudinal barriers" that gave rise to inaccessible environments. Examples of disabled people's efforts to create a "home" and live in the community also show how past struggles over social inclusion and community integration are linked to present-day struggles over accessible housing. Most importantly, stories from disabled people themselves illustrate the need to contest built environments in ways that encourage housing that integrates, rather than isolates, people with disabilities, especially the poor, the elderly, and people of color who are disproportionately affected, not only by disability, but also by a corresponding lack of affordable, accessible housing in the community.

Numerous works in American Studies and related fields have established how the construction of urban and suburban residential spaces in the USA has been a racialized, classed, and gendered project that has excluded large segments of the population from the "American dream" of home ownership, social and political integration, and economic independence.[8] The disability rights movement, and the scholarship that continues to emerge from the movement, has likewise argued that practices of spatial segregation work systematically to devalue and marginalize people with disabilities. Disability studies scholarship has also developed a recognition that experiences of living with disabilities in the community vary widely according to one's impairment and social position. This is because—as geographers, architectural theorists, and disability scholars have suggested—the built environment is not merely a physical space, but a social, cultural, political, and psychological space as well.[9] Lived experiences of disability in the built environment, as well as artifacts from the disability rights movement, provide a rich understanding of the ways in which people with disabilities have historically challenged both institutional and social segregation. These archives are essential, both to sustain the movement's ongoing efforts to achieve accessible housing in the community, and to extend and enhance the disability rights movement's capacity to establish a more just, equitable, and accessible community. Insights from movement participants, everyday experiences, and various scholars including theorists and designers of the built environment suggest that the specific and pervasive influence of ableist ideologies on the formation of modern American communities needs to be explored further. This is especially true at a moment when the "feasibility" of community integration for people with disabilities continues to be called into question.

The notion that historical artifacts, images, and personal narratives can help scholars, activists, and the public collaboratively rethink and productively alter notions of domesticity and disability that shape—and are shaped by—the built environment is not without risks. Historian and Smithsonian curator Katherine Ott, who specializes in the material culture of disability, notes that questions of objectification and exploitation, as well as questions about who owns history and who has the authority to tell and interpret histories, lay at the heart of efforts by scholars to mine individual stories, artifacts, and images for insights into how disability's past connects to its present. Humanities scholars, scientists, and medical professionals, as well as design experts, are all tasked, in part, with developing theories to explain disability and its influence in the world around us. Theories of how the built environment connects to disability, for instance, can productively draw our attention to the politics of the built environment and people's interactions with it. At the same time, such theories can serve as "the handmaiden of power by creating categories, circumscribing possibilities, and imposing the will of the theorist."[10] As Ott explains, the application of theory and analysis to images, artifacts, or narratives "can be a method of containment" that "can directly or indirectly kill diversity, creativity of expression, and wildness."[11] Scholars must approach this important archive with considerable care and reflectivity.

These concerns are especially resonant for those who have historically been spoken for and about, but who have rarely been given the opportunity to speak for, or represent, themselves. Indeed, as Ott points out, one of the lasting contributions of the disability rights movement has been to establish that people with disabilities "have a claim on the legitimacy of what is said about them and how such statements are used."[12] This means that disability studies scholars who engage with the lived experiences of others—both past and present—must recognize that scholarly authority is, as historian and digital humanities scholar Michael Frisch suggests, a “shared authority” between scholars and the larger disability community.[13] This requires scholars to make their theoretical perspectives and scholarly agendas as transparent as possible while being cautious not to occlude the perspectives and experiences of others. Sharing cultural and historical authority also entails an obligation to do scholarship that has both academic and community goals. This chapter thus not only attempts to account for the complex meanings of “home” that emerge when domestic spaces are considered from a disability perspective, but also, to engage in a critical consideration of the politics of accessible housing that advance community integration for people with disabilities.

Segregation

Institutions to house those with disabilities first emerged in the USA in the early nineteenth century in an effort to provide people with a wide range of physical, cognitive, and psychiatric disabilities with holistic, humane treatment and care. These institutions were deeply influenced by social reformers such as Samuel Gridley Howe and Dorothea Dix, who documented the deplorable conditions people with disabilities often faced. Disabled people were frequently abandoned by their families, becoming wards of the state; kept in prison or in almshouses, or, as oral historian of the disability rights movement Fred Pelka has observed, “farmed out to those willing to provide for their care at the lowest possible costs to the taxpayer.”[14] Dix and others recorded the consequences of family abandonment, community neglect, and craven exploitation of disabled people, including examples of being chained to barn walls, locked in basements or attics, and caged in outdoor holding pens. State and private institutions for disabled adults, as well as segregated schools for children, were intended to remedy these conditions and offer people with disabilities at least a minimum of safety, security, and comfort, as well as education and cure.

Many facilities became overcrowded, contributing to a massive expansion of institutions around the turn of the twentieth century. Feeling the pressures of overcrowding and influenced by eugenics, social reformers, institution administrators, and medical experts argued that people with disabilities (including, and especially, the so-called feeble-minded and moral imbeciles) were inherently anti-social, sexually depraved, and bound to produce more of their “own kind.” Increasing urbanization and the diversification of American society compounded the perceived threat posed by disabled people. Segregation from society, sometimes from birth, became the norm. The result was that, by the mid-twentieth century, institutions had become, in Pelka's words, "an insular and extensive disability gulag" complete with a massive physical infrastructure and a formidable professional lobby of nondisabled workers who actively impeded the development of community-based services and integrated public education for people with disabilities.[15] Those not housed in state institutions or private psychiatric facilities were often relegated to nursing homes or hospitals. As Pelka points out, all of these forms of housing were cut off from the outside world and most, if not all of them, violated daily "the civil and human rights of their residents."[16]

In the late 1960s and early 1970s, a broad, cross-disability movement emerged to challenge the "disability gulag" described by Pelka. The nascent disability rights movement built upon, and diverged from, longstanding efforts to expose and curtail the abuse and seclusion of disabled people within institutions in order to advocate for an end to institutionalization itself.[19] Led by people with disabilities, the movement focused on, among other things, something it called independent living, as well as self-advocacy. It issued an expansive critique of the inaccessibility of a built environment that had long prevented people with disabilities from being able to live, learn, and work in the community. Disabled activists and scholars joined professionals in the design fields—many of whom had disabilities themselves—to argue that the built environment reified strident, ableist notions of embodiment in ways that stigmatized and isolated people with disabilities and systematically denied them access to education, employment, transportation, recreation, and housing. At the same time, years of congressional investigations and scathing media reports detailing abuses in institutions led to the passage of several key pieces of legislation (including the 1963 Community Mental Health Centers Construction Act, section 504 of the 1973 Rehabilitation Act, and the Civil Rights of Institutionalized Persons Act of 1980) that significantly bolstered serious efforts to move people out of the "gulag" into a variety of domestic settings in the community. The passage of the ADA in 1990 further codified the right of people with disabilities to live and work in mainstream American society. In 2007, eight years after the US Supreme Court's *Olmstead* verdict, Medicaid began issuing waivers to facilitate the home and community-based services needed for people with disabilities to live outside of institutions. Finally, in 2014, the federal government issued new guidelines to help states determine what forms of housing and types of domestic arrangements comprised institutional settings, so that they might avoid creating these environments. As one of the interview subjects in Grace Chang's chapter in this volume indicates, deinstitutionalization and community living had become national and international trends that showed no signs of abating.

Integration: Defining Community

The deinstitutionalization movement hinges upon competing understandings of community and domesticity. In the USA, the movement of disabled people out of institutions has occurred alongside the precipitous growth of suburbs. Although both suburbs and notions of the American "dream home" first emerged in the nineteenth century, just as institutionalization was increasing, mid-twentieth-century developments such as the creation of the interstate highway system, federal subsidies to support single-family housing, and persistent declines in investment in public transportation and city services worked further to entrench the "dream home" as a domestic space of refuge far from city centers. This abliest construction (both discursive and material) of home and domesticity has led to debates about what it means to live in the community. Although nuances abound, generally the debate over disabled housing in the USA can be divided between those who support the letter of the *Olmstead* decision and advocate for smaller housing options for people with disabilities, and those who vigorously oppose such a move.

The Supreme Court's 1999 ruling has paradoxically led to calls for the reemergence of large-scale institutions. A recent article in *The Atlantic* magazine by Philadelphia-based writer and disability advocate Amy S.F. Lutz elucidates this reality and points to the need to critique and challenge both institutional and suburban models of "home." In the article, Lutz chronicles the experiences of people with disabilities and their families as they search for accessible housing and a sense of home that balances the need for privacy and independence with the need for community and care. She argues that recently emerging strategies to deinstitutionalize people with disabilities, which follow dominant postwar ideas about the suburban "good life," risk further limiting housing options for a vulnerable group of Americans who are already facing a growing housing crisis. According to Lutz, attempts by the courts and some activists and advocates to limit the number of people with disabilities who can live in a home and still qualify for housing waivers could spell the permanent end of large-scale, usually privately run alternatives to institutionalization such as farmsteads, “intentional communities,” and group homes with more than four or five residents—all of which remain appealing options for some families living with disability.[17]

Lutz contends that placing limits on what counts as a “community setting” prevents people with disabilities and their families from choosing housing options that work for them. She offers a large-scale residential facility located in Chicago named Misericordia to illustrate her point. Misericordia has 600 residents and over 400 families on its waiting list.[18] Lutz presents Misericordia as an ideal community for people with disabilities. She notes, in terms that will seem eerily familiar to historians of early-twentieth-century institutions, that the facility “offers an extensive array of therapeutic services, including occupational, physical, and speech therapy” and that its 31-acre campus has a greenhouse, a gym, a bowling alley, computer labs, and a swimming pool where the Special Olympics team practices. “Residents,” Lutz points out, “can work in the bakery, the horticultural center, the recycling program, the commercial laundry, or the restaurant.” Readers are also assured that Misericordia provides opportunities for residents to interact with people “off campus,” including employment at local businesses and participation in community and recreational groups, such as a dance troupe that performs throughout Chicago.[19] Although Misericordia is defined as an institution for financial purposes, Lutz suggests that it functions as a community and that, indeed, it provides a community for many who would not otherwise find inclusion in communities elsewhere. As one parent of a Misericordia resident told Lutz: “Misericordia is very much a community. The campus atmosphere is like a college, there’s a collegiate, small-town community feeling.”[20]

Lutz suggests that federal and state officials, as well as disability activists, need to expand their notions of what counts as a “community” in order to accommodate a diverse range of needs and living arrangements for people with disabilities. She argues that people with disabilities ought to be allowed to forge and define their own communities. She concludes that:

> The larger problem is the limited way “community” is being defined as exclusively the neurotypical community…We are all part of many communities, and the government is generally not in the business of legitimizing some over others. The push for fully integrated housing comes from a desire to avoid discrimination. But it may be another form of discrimination to suppose that I/DD adults can’t thrive in a community of their own making.[21]

Lutz correctly identifies the primary problem related to housing shortages as “the limited way ‘community’ is being defined” in exclusively ableist terms. Her analysis, however, might sound alarming to those activists and advocates who take a longer view of history and oppose any living arrangement that reminds them of the institutions they fought hard to close. As the Autistic Self-Advocacy Network notes, any domestic setting (regardless of location or size) that promotes segregation and isolation from the community is not an integrated home (and thus in violation of the *Olmstead* decision).[22] The assertion that “we are all part of many communities” elides the reality that environmental access to, and inclusion in, the communities we inhabit is often contingent upon social and class position as well as physical and cognitive ability. The claim that regulations designed to curtail the proliferation of “institutions” for disabled people constitute a form of discrimination assumes that people with disabilities currently have unrestricted choices about where to live and that they are free to pursue “a community of their own making” without interference or influence from parents, medical professionals, or care providers.

In a rather unexpected turn away from dominant thinking, Lutz emphasizes the structural failures of the status quo in order to urge (rather than discourage or alter) continued federal funding for large-scale “congregate” settings for people with disabilities. Her reasoning is based on the assumption that certain disabled people, especially those living with I/DD, are simply unable to live “independently” in the community, and that they continue to suffer many of the same abuses they experienced under the old system. Lutz observes that abuse of disabled people occurs in home-based, as well as institutional, settings and argues, rightly, that community-based care currently does not meet the needs of many people with disabilities. Qualifications for home care positions frequently end at a GED and a driver’s license. “And,” as Lutz points out, “these jobs are very poorly compensated: 45 percent of workers live below the poverty line. Unsurprisingly, given these factors, the field has a 70-percent turnover rate.”[23] To reenforce her argument that community-integrated housing may not be all it is cracked up to be, Lutz documents the failures of several community-based domestic settings:

> In 2011, *The New York Times* reported that more than 1200 developmentally disabled individuals had died of “unnatural or unknown causes” in

> New York group homes alone over the previous decade. In Georgia in 2013, 10 percent of those who had been moved to community settings died following their relocation.[24]

Much of the statistical data marshaled by Lutz establishes only a speculative link between community-based housing and the death of disabled people. It is not clear, for instance, whether 10% of those in Georgia moved into community settings in 2013 actually died as result of being relocated to "community settings." Nor is it clear that the group homes Lutz critiques actually constitute integrated community settings. As advocates for community living have noted: "A large congregate care facility is not a home in the community. If a half dozen or more people live in a provider-owned group home, it is almost never controlled by the people who live there."[25] Indeed, these figures could be seen as an argument for, rather than against, the federal government's efforts to limit the numbers of people living in group homes. To Lutz's critics, the use of the enduring scarcity of accessible housing to justify the continuation of segregated housing for disabled people illustrates a lack of political will to challenge and change the inaccessible built environments of most homes and confirms an unwillingness or an inability to confront longstanding cultural assumptions about the incapacity of people with disabilities to live in the community.

A central insight of the disability rights movement and disability studies has been to show how physical locations can, and do, shape lived experiences. Medical humanities scholar, feminist, and historian of accessible design Aimi Hamrie underscores the significance of the built environment when she writes:

> [T]he design of the built environment actively conditions and shapes the assumptions that the designers, architects, and planners of these value-laden contexts hold with respect to who will (and should) inhabit the world. In short, built environments serve as litmus tests of broader social exclusions.[26]

Hamrie's analysis supports the notion that both "home" and institutional settings produce social exclusions. As Hamrie and other scholars have argued, the built environment "actively conditions and shapes" assumptions about who will, and who should, live in the community. Inaccessible environments give rise to the assumption that disabled people do not belong in the community and that they cannot function in "mainstream" society or live in the built environments that currently exist within society. Exemplifying the phenomenon described by Hamrie, Lutz highlights the challenges of integrating people with disabilities into the community primarily by focusing on how people with significant impairments and cognitive differences (including those living on the autism spectrum) fail to adapt to existing environments and suggests that institutional "communities" designed for disabled people can address this problem. She cites numerous examples of frustrated parents whose children could not live in their communities (because of conflicts with neighbors, isolation, loneliness, or a lack of access to friends, family, and support services), but who eventually found a sense of home and community in settings defined by federal and state guidelines as institutions.

When his daughter Emily was unable to integrate successfully into two different residential neighborhoods in Ohio, Dennis Rogers founded Safe Haven Farms, an "intentional community" for people with autism and intellectual and developmental disabilities. Although the built environment of the farm is acknowledged as playing a pivotal role in enabling his daughter and others like her to thrive, Rogers tells Lutz, "We learned that the human community is all that matters, not the physical community."[27] Micki Edelsohn, the mother of a developmentally disabled son and the founder of 26 homes for disabled people in Delaware including several completely integrated, community-based apartments, told Lutz that "[c] ommunity integration is a myth."[28] As Eldelsohn explained to Lutz, "My homes are in nice neighborhoods—do you think the neighbors are asking the residents over for barbecues or to go to the movies? Of course not. There has been no real interaction between the neighbors and the people living in the homes besides the occasional wave."[29] Eldelsohn tells Lutz that, before she dies, she wants her developmentally disabled son Robert to move to an "intentional community" for people with disabilities—a built environment more like Misericordia or Safe Haven Farms than the accessible apartments in "nice neighborhoods" she runs.

Although many participants in contemporary housing debates cannot move beyond the opposite poles of "intentional communities," like Misericordia, and small-scale "integrated" housing, they have opened up room for more radical positions. Lutz herself subtly points to the ways in which "the physical community" does indeed shape the "human community" when she writes: "In an era when 50 percent of Americans don't even know their own neighbors, living in a small home can be especially isolating for a person with I/DD."[30] While this critique situates disabled people's isolation in postwar suburban sprawl, it stops short of recognizing that the problem is not simply one of disablism or an inability of people with disabilities to live up to nondisabled expectations of who counts as a desirable neighbor. The problem is that we live in an ableist society. Neighborhoods and communities, which really are not designed or structured to encourage community for anyone, especially exclude and alienate people with disabilities.

Ableism and the American "Dream Home"

As we have already begun to see, bringing disability studies perspectives to the built environments of the home enhances the debate around accessible housing that Lutz, and millions of other Americans, are now participating in by showing how the failure of people to integrate into the community is not primarily the result of their disabilities or the prejudices against them, but of structures that reify, reinforce, and in some cases produce those prejudices. There is no discussion in Lutz' article, for instance, of how homes could be designed to mitigate the environmental challenges that people on the autism spectrum and others with disabilities she profiles, face. Clearly defining transitions between spaces and reducing lighting, noise, and other distractions are just some of things designers have begun to consider when building homes and classrooms for people on the autism spectrum.[31] Neither is there any discussion of how suburbanization and isolation both from and within the periphery restrict the integration of people with disabilities into the community. Architectural theorists and design professionals like Smith and Webb, for example, argue that, in order to achieve accessible housing for disabled people, the "American dream" itself must be redefined in opposition to homogeneity and exclusion and that prevailing models of housing development characterized by standardization, racial and class stratification, and isolation from community must be challenged.[32] These social and cultural dynamics shape, and are in turn shaped by, the built environment.

Professional community planning strategies and design practices, as well as federal housing policies, have contributed to a separation of suburban and urban communities in ways that perpetuate the exclusion of people with disabilities. The separation of the American "dream home" from urban communities has made it difficult for those with disabilities seeking—or forced into—housing on the periphery of cities to access employment and educational opportunities, as well as healthcare, transportation, and social amenities that may only be available within the city. Historian of American suburbia and urban development Kenneth T. Jackson has demonstrated how distance from urban centers emerged as a defining feature of the American "dream home" in the twentieth century and how processes of spatial segregation have subsequently shaped the development of urban and suburban communities. Jackson's landmark work *Crabgrass Frontier: The Suburbanization of the United States* (1985) reveals how federal subsidies favoring suburban development, zoning practices delineating commercial and residential spaces, and a lack of access to the economic and social capital needed for the poor, the elderly, and racial minorities to obtain access to better housing in the suburbs decisively contributed to the decline of diverse, interconnected urban communities.

Yet home design is influenced by much more than housing regulations, building codes, economic constraints, and professional practices. Postwar housing policies, for example, were animated by an emergent ideology of domesticity that defined privacy, safety, social and cultural homogeneity, and the health of the heterosexual nuclear family as the cornerstones of the "American dream" of homeownership and "the American way of life." As Jackson shows, the American "dream home" did not include racial or ethnic minorities, the poor, or the elderly. These exclusions from home and community were accomplished by the isolation of the nuclear family, the decline of public transportation, and by the economic disinvestment in, and subsequent deterioration of, urban neighborhoods.[33] Although Jackson makes no mention of disability, it is clear that the creation of suburban housing he describes has had, and continues to have, significant consequences for people with disabilities, especially in terms of creating built environments that deny, rather than facilitate their access to community. The creation of housing for disabled people is deeply affected by valorized notions of what counts as a home in the first place, including where a home should be built and who should live in it. Although, as Jackson and other scholars have suggested, the homogeneity of suburbia "violates the American Dream of a balanced community," the suburbs, and especially the American "dream home," have historically excluded by promoting a version of the "American dream" where disability and difference are not considered in most design projects, and in fact are regarded as threats to the health, safety, and stability of the community.[34] Community resistance to group homes for developmentally disabled residents evidences this kind of bias and helps to sustain ways of thinking about "home" and community that systematically exclude people with disabilities.[35]

Crip/queer disability studies scholar Allison Kafer confirms the analysis of Smith and Webb, Jackson, and others, when she observes that "institutionalization remains a common response to disabled people, particularly those with 'severe' disabilities," and that, despite the Supreme Court's *Olmstead* decision, many states continue to prioritize funding for institutions over funding for home and community-based care. As Kafer notes:

> State governments across the country are responding to budget crises with cuts to healthcare and disability services, especially in-home attendant care; given that many people with disabilities require such services in order to live independently, disability rights activists and health advocates note that even more disabled people, especially disabled people of color and low-income people, are being forced into nursing homes or out onto the street.[36]

Referencing historical practices of eugenics and sexual regulation aimed at people with disabilities, Kafer goes on to note how institutionalization is often "touted as necessary for preserving the future health of the state and the nation."[37] Kafer thus links the dogmata of race, class, and ability and state-supported practices of institutionalization and the containment of disabled bodies. Leading disability historian Paul Longmore argues such practices constitute "a separate economy of disability" dominated by private care providers, hospitals, and nursing homes (as well the medical device industry) that profit from a "medical model" of disability that understands people with disabilities and their bodies as stigmatized, "sick," and in need of correction.[38] Since government data suggest that funding home and community-based care is far more cost-effective than institutionalization, the political economy of disability documented by Longmore can be seen as of a piece with the systematic denial of what queer disability studies scholar Robert McRuer has called a "disabled domesticity" that would allow for more flexible arrangements of home and family commiserate with the lives and needs of disabled people.[39]

The reluctance of the state to fund the supports necessary for people with disabilities to live in the community signals a continued investment in making the American "dream home," as well as its concomitant attachment to heteronormative domesticity, available only to the nondisabled. As Kafer, McRuer, and other scholars such as historian Sarah Chinn have suggested, an incapacity even to imagine home and domesticity outside of an ableist context pervades public policy around accessible housing and in-home care. The result is that housing designed for “the disabled” often presumes, a priori, that people with disabilities will not marry or that they will not, and indeed should not, have children. In addition, those with disabilities who choose to marry, or whom the sate deems “able” to form families with children, have sometimes been denied funding to support in-home care based on the assumption that their families, spouses, or domestic partners—and not the state—will assume the “burden” of their care. Meanwhile, as Chinn has pointed out, cultural and historical figures such as Helen Keller are frequently imagined—and sometimes eroticized—as “queer,” “lesbian,” or “gay” simply because they lived their lives in homes with members of the same sex whom they relied upon for care, support, and community. Chinn suggests that we should understand Keller as queer not because she lived with women, but because her life and living arrangements defied heteronormative constructions of gender, disability, and domesticity.[40]

Normative ideas about disability and domesticity, as well as the exclusionary features of home these ideas help to create pervade American culture. Some parents of children with disabilities mourn that their children will never marry or have children, attend prom, or drive a car. Such concerns not only imply that these activities are requisite to leading a full and desirable life, they also reveal how heteronormative structures of courtship, marriage, family, and consumption are defined by ableism and linked directly to central features of the built environment, such as the automobile and the single-family home on the periphery that the automobile helped exponentially to expand. Such lines of reasoning also point to an investment in middle-class expectations of a “good life” premised on material wealth, social conformity, and independence from others. As disability attorney and theorist Robert Funk points out, the failure on the part of disabled people to meet these expectations has historically served as “proof” of their inability to live and work in the community. Funk states: “Most people assume that disabled children are excluded from school or segregated from nondisabled peers because they cannot learn or because they need special protection. So, too, the absence of disabled coworkers serves as confirmation of the obvious fact that disabled people cannot work.” Consequently, Funk explains, “Historically, the inferior economic and social status of disabled people has been viewed as the inevitable consequence of the physical and mental differences imposed by disability.”[41]

Rather than root disabled peoples perceived inability to participate in community in their bodies, we must begin to look elsewhere, namely the American "dream home" and the culture it engenders.

In the remainder of this chapter, I examine the consequences of the proliferation of dominant understandings of the American "dream home" for people with disabilities through a consideration of artifacts from the disability rights movement and the lived experiences of disabled people who have struggled to define a sense of "home" amid an "American dream" premised upon their erasure from US society. I show how these artifacts and testimonials foreground the importance of the built environment in experiences of disability and community, and argue for an intersectional understanding of disability that accounts for overlapping structures of race, class, gender, and sexuality as integral to questions of community and access.

Disabling Domesticity

Cultural artifacts documenting the history and consequences of institutionalization in the USA provide powerful evidence of how people with disabilities, as well as mad, gay, lesbian, and transgendered people, have been systematically sequestered from their communities, subjected to torturous forms of medical testing and technological intervention, and then abandoned and forgotten. The Smithsonian's *Everybody* exhibition, which includes items such as a straightjacket, electroshock equipment, thorazine suppositories, a set of lobotomy knives, and several unmarked headstones belonging to former residents of institutions for the developmentally disabled, shows how the stigmatization, segregation, and eradication of difference has been central to defining "community" in America.[42] At the same time, the exhibition highlights how people with disabilities often forged a sense of community within deeply segregated spaces. Under the banner "Community" curators state that: "Experiences inside institutions varied widely. Bonds formed around shared routines. People might learn a trade or a language, receive an education, and make lifelong friendships. At other times, there might be forced treatment, punishment, substandard care, and abuse."[43]

This nuanced portrait of institutional life suggests that, while community can be a profoundly normalizing force that works to exclude and regulate difference, differences can also challenge and expand normative notions of "community," since people within institutions did, and do, find a sense of home and community amid difficult circumstances. Together, however, the artifacts of institutionalization presented in the exhibition suggest the limits of institutional communities and demonstrate that institutionalization of disabled people is ultimately defined by segregation from the larger community. Two iconic images from the disability rights movement in the Smithsonian's National Museum of American History collection now available online illustrate the challenges of community integration for disabled people and demonstrate the need to take an intersectional approach to questions of disability, the built environment, and the American "dream home." The first is a photograph depicting a 1994 ADAPT rally. Once known as Americans Disabled for Accessible Public Transit and now called Americans Disabled for Attendant Programs Today, about 50 ADAPT demonstrators are shown protesting with signs that read "Freedom Now" and "No More Pity."[44] The back of one man's wheelchair features a cardboard sign, which is partially obscured but the words "nursing homes" and "jail" are clearly visible. Two large American flags with stars arranged in the shape of the international symbol for disability access are the focal point of this black and white photo.[45] While the photograph conjures patriotic iconographies of democratic public activism in the service of civil rights, it also suggests the ways in which social and institutional practices of containment, such as nursing homes and jails, render civil rights unrealizable for segments of the population not easily assimilated to the "American dream." The appropriation of the American flag by activists depicted in this image, and the displacement of state stars intended to emblematize national cohesion in favor of an international symbol for disability access, at once mocks ideas of national unity that the "American dream" attempts to index and suggests how such ideas are premised, not only on the elision of geographical, cultural, and historical differences, but also on the exclusion of physical, cognitive, and psychiatric differences.

The second image depicts a 1989 ADAPT protest in which protestors are blocking two MCI New Jersey transit buses. The photo's central image is of a man in a wheelchair. The back of the wheelchair features a handmade sign that reads, "I can't even get to the back of the bus."[46] Both this image, and the image discussed above, feature captions and audio descriptions that note that the protestors are wearing blue jeans, T-shirts, baseball caps, and sneakers.[47] These descriptions of clothing do more than create a mise-en-scène for visually impaired visitors to the Smithsonian. They also suggest the social and class positions of the protestors. In so doing, they disclose how questions of access are also questions inflected by economic and social status. The sign "I can't even get to the back of the bus" at once recalls pre-civil rights strategies of racial subordination and class stratification *and* exposes the limits of civil rights and minority rights discourses within the disability rights movement. The phrase "I can't even get to the back of the bus" suggests that being in the back of the bus is, or was, somehow a privilege, a gesture that posits the notion that people with disabilities are, in some sense, worse off than black folks struggling against segregation. This discursive maneuver not only erases the activism for black civil rights done by African Americans with disabilities, but also, exposes how attempts to construct and forge a disability rights movement premised on identity can easily privilege "disability identity" over and against black people and other historically marginalized groups. Indeed, as Korydon Smith shows in a statistical analysis of race and accessible housing in the American South, African Americans have not only been historically excluded from home ownership but also continue to experience higher rates of poverty and disability than do whites.[48] Despite this reality, many in the disability rights movement have yet to draw a connection between disability, racial oppression, and nondisabled, white supremacists' ideals of "fitness," "health," and "family" that have excluded both black and disabled people from "home" and from communities structured around home. As one disabled activist in Arkansas told Smith, "It costs less to seat a black guy at a dinner counter than it does to modify the door, or restroom for someone in a power wheelchair."[49] Although the civil rights and disability rights movements shared a concern for spatial access as a prerequisite to social and political equality, the uncritical contrasts drawn here between civil rights and disability rights must be challenged in order to show how structures of racial and disability oppression work together to shape access.

Moreover, while the photo discussed above pleads for an intersectional analysis of disability that accounts for multiple and overlapping systems of oppression, it also reveals how profound inequities are literally *built into* American society. The inability of protestors to get to the back of the bus implies that disability rights requires radical structural and environmental remedies never considered by previous civil rights protestors. The recognition that oppression is configured by and through the built environment compels us to think beyond the politics of social inclusion in order to consider—and challenge—the ways in which the terms of inclusion in American life are forged in an ableist culture and naturalized through the built environment. The fight for accessible housing is an important way in which the disability rights movement can challenge corresponding structures of oppression and ableism by showing how public policy around housing in the USA has worked systematically to exclude entire segments of the American population from the American "dream home" by establishing the white, middle-class family with children as the benchmark for residential design while incarcerating those with disabilities within institutional settings, that is, "nursing homes = jail."

In his autobiographical account of the social, cultural, and architectural forces that shape the lives, experiences, and political consciousness of people with disabilities, pioneering disability studies scholar Irving Kenneth Zola underscores how white middle-class, heteronormative notions of home, domesticity, and community reinforce the disablism that people with disabilities must confront on a daily basis. Upon his arrival in the Dutch community of Het Dorp (The Village), Zola was struck by the accessibility of the built environment around him and by the ease with which residents appeared to live and work in an environment intentionally designed to foster a sense of community and integration for those with disabilities. An anti-institutional ethos seemed to pervade Het Dorp. He was scolded by village administrators for calling its inhabitants "patients" rather than residents and for referring to the village's domestic spaces as "rooms" rather than homes. Built in the early 1960s, Het Dorp was an internationally renowned model of accessible design that at first glance appeared to exemplify community integration for people with disabilities. Het Dorp provided on-site opportunities for employment and recreation for residents and designers emphasized how the campus not only mimicked the feel of a "real community," but also how it was physically and socially connected to the adjoining community. Zola soon realized, however, that there was something amiss in this differently constructed utopia. Expressing a mix of exhilaration and unease as he contemplated the lived experiences of residents, Zola reflected:

> Then I recalled their homes and a sense of privacy absent in most institutions. 'Does the fact that they have their own homes provide some relief?' 'For some,' was the reply. 'But still others say they are more lonely here than before.' 'God what an irony,' I burst out, 'that this whole idea of privacy, each person having his own home, may be so out-of-whack with his experience, that it mutes its very intention.'[50]

Zola's observations underscore that, although environmental access is a necessary prerequisite for achieving a sense of home, community, and dignity for people with disabilities, accessible design is not enough. Rather, the cultural assumptions, social expectations, and "attitudinal barriers" that shape both the built environment and lived experiences in that environment must be accounted for, confronted, and challenged.

For instance, when Zola visits a married couple in the village, he notices that the couple (long-time residents of Het Dorp) had to knock down walls and rearrange their home to accommodate familial and domestic arrangements seen as incompatible with disability. Designers of the village originally saw no need for constructing family housing since those with disabilities were not expected to marry or have children. Zola himself was greeted with surprise when residents learned he was a father and was offended when he was repeatedly asked whether his divorce was the result of his disabilities. When he decided to abandon his cane and leg braces for a wheelchair in order to achieve a more "authentic" experience of village life, Zola was treated with patronizing condescension and a presumption of incompetence by the very staff that had at first welcomed him as a distinguished professor and accomplished, able scholar. Moreover, although Het Dorp was touted as being integrated with the neighboring village, Zola discovered that it remained an enclave of environmental accessibility where residents were subtly reminded of their "difference" from their neighbors outside of Het Dorp.

Zola's experiences reveal a cultural politics of the built environment that exposes key aspects of the complex relationship between disability and domesticity. His interactions and observations show how "specialized" housing designed "for disabled people only" can perpetuate stigma and isolation from community and further instantiate able-bodied assumptions about the built environment. For Zola, and others at Het Dorp, "home" was about more than ramps and needed accessible features; it was also about family, friendship, work, and integration in the larger community outside of Het Dorp. Zola noticed, for example, that the recreational, crafts, and workplace facilities provided for residents were rarely utilized and that, given the opportunity, residents preferred to work outside The Village. There was also a tension between disabled adult residents and the nondisabled administrators "charged" with their "care," who frequently treated the residents with patronizing condescension. For instance, after admitting that he sometimes wished he could get the most disabled residents "out of my sight," one administrator expressed frustration at having to teach residents skills "they never knew before," like keeping a regular schedule. He then told Zola, "We have to force them in some way to come to work but it's good for them. Just like we have to force them to get out of their rooms but it's good for them."[51]

This conversation becomes a moment of political consciousness for Zola. He tells readers he "gagged" at these remarks, adding, "All of the feelings of infantilization I had been experiencing had some basis! Suddenly I felt no different from the other residents of whom he spoke so patronizingly."[52] Zola's experiences suggest how uniquely accessible environments such as Het Dorp have frequently served as what social historian Lindsey Patterson calls "points of access" where people with disabilities find community and become politicized by segregated "home" environments that render transparent the inaccessibility of the world beyond.[53] It is significant that Zola's encounters with disability and housing occurred as an American overseas at the cultural high-water mark of American suburbanization and at the beginning of modern, broad-based movements for disability rights and deinstitutionalization in the USA. The conventional cultural conceptions of home, family, and domesticity Zola confronted disclose how prevailing normative notions of home and family often lay at the core of struggles for accessible environments and help to reveal the ways in which disability, and the experiences of those with disabilities, challenge and disrupt hegemonic, normative constructions of home as a place of "sanctuary, independence, privacy, and well-being."[54]

In yet another example, activists and advocates for the disabled, as well as disability theorists such as Tobin Siebers and Michael Gill, have documented how institutional "homes" for people with disabilities systematically deny residents the privacy, independence, sexual autonomy, and affirming sense of self essential to modern conceptions of "home." Seibers, for example, catalogs how—despite the fact residents may pay rent for their rooms—group homes, nursing homes, and long-term care facilities "purposefully destroy opportunities for disabled people to find sexual partners or to express their sexuality."[55] Staff typically do not allow residents to be alone in their rooms with anyone who might be of sexual interest. Many facilities segregate men and women. Other facilities do not allow any two persons, regardless of sex or gender, to sit together alone in the same room. Residents are frequently subject to intense surveillance with their activities monitored and recorded daily. Doors are left open and rooms are often shared with roommates carefully selected by staff. Medical and institutional authorities often control residents' access to erotic literature, masturbation, and sexual partners.[56]

Gill's recent study of sexuality and intellectual disability suggests how, even in residential settings where disabled people's sexuality is acknowledged, the spatial politics of the built environment can combine with accepted assumptions about sexual propriety and the limits of disabled people's sexuality to severely constrain sexual options for them. Since the 1970s, many residential facilities for the disabled have embraced masturbation as a means to achieve institutional objectives such as controlling sexual urges, producing a more docile and compliant "clientele," and confining sexual expression to nonreproductive, "safe" methods.[57] Gill makes clear the limits of this approach in facilities and residential settings where no functional privacy exists. Although professionals have increasingly understood masturbation as commonplace and pleasurable even for those with disabilities, this activity is strictly policed and restricted to meet institutional aims, rather than the needs and desires of residents. Moreover, as Gill points out, masturbation, alone and in private, is presented as the only appropriate manifestation of sexuality for people with disabilities regardless of their gender. This supposition presumes an ability to masturbate without assistance, something that is not always possible for people with disabilities. It also presumes that people with disabilities have the privacy needed to masturbate alone and that if they do not already possess a "normal" desire to avoid masturbating with, or in front of, others, then they must be instructed in this desire due to their mental and social deficiencies.[58]

The sexual exploitation, rape, and abuse of people with disabilities living in institutions are often touted as a reason to monitor residents' interactions with others and limit sexual activities to masturbation. While such fears are indeed well-founded, Gill's analysis suggests that the surveillance prompted by these fears not only forecloses the possibility of "respectable" sexual expression in private, it is also predicated on the assumption that disabled people (particularly those with intellectual disabilities) are always already incapable of giving consent. This assumption denies sexual agency to people with disabilities and, in so doing, renders them as nonsexual, arguably making them even more vulnerable to sexual abuse while also establishing a presumption of exploitation and abuse where none may exist. The built environment of institutional settings thus works with gendered notions of domesticity and sexuality to define the limits of "appropriate" sexuality for many disabled people. Resistance by disabled people to inaccessible home environments, as well as to the confining spaces of institutions, can therefore be seen as simultaneously confronting architectural practices that construe "home" as a nondisabled space and challenging the cultural assumptions that define institutional and non-institutional residential settings as regulating and maintaining normative sexuality. For example, in their chapter in this volume, Gallo-Silver, Bimbi, and Rembis argue that LGBTQ people with disabilities who live at home or in institutions may face the double bind of homophobia and what Gill has termed "sexual ableism" and are likely to have even fewer opportunities to meet and engage with other LGBTQ adults.[59]

In his study of disability, the built environment, and the meaning of home, Geographer Rob Imrie reveals how people with disabilities have had to redesign and adapt their homes in order to achieve the sense of dignity and independence often associated with "home."[60] The spatial policing of disabled sexuality discussed above extends and complicates Imrie's work by showing that efforts by disabled people to establish a sense of "home" disrupt more than architectural practices. Such challenges expose the heteronormative cultural politics of home and domesticity in the USA during the era of deinstitutionalization. Newspaper clippings and flyers featured in a section of the Smithsonian Institution's 2000 exhibition on the disability rights movement further illustrate the need to confront both the built environment of home and the heteronormative ableist standards it enshrines. A flyer featured in the exhibit warns "Keep Your Neighborhood Safe. Keep Your Neighborhood Peaceful. Keep Your Neighborhood Healthy. Keep the Mentally Retarded Away from City Streets. Keep the Mentally Retarded Away from Your Children. Keep the Mentally Retarded Away from Your Home."[61] The flyer presents the developmentally disabled as a threat to safety, peace, health, and children, fears also historically ascribed to gay men and lesbians. Dominant heteropatriarchal notions of sex, gender, and ability thus structure the production and reception of images of disability. Failure to adhere to ableist notions of cognitive ability is presented as a danger to families, children, and communities.

The lived experiences of institutionalization and deinstitutionalization offered by people with disabilities in Western New York and recorded by the Center for Disability Studies and Center for Inclusive Design and Environmental Access at the University at Buffalo also show how nondisabled conceptions of disability and domesticity become embedded in the struggles of people with disabilities to find and secure "home." These narratives further suggest that struggles over housing and the cultural politics of "home" represent especially rich archives from which to rethink, reconsider, and rehistoricize both the American "dream home" and the disability rights movement by highlighting the potential of disability—and histories of the disability rights movement—to forge a more nuanced and complex cultural politics of home and family. Former residents of The West Seneca Developmental Center in Western New York, for instance, express a feeling of deep, poignant, ambivalence when describing life in the institution that offered them a home and sense of community with others like themselves and, at the same time, took them away from homes and families in order to place them in a built environment where they could be "treated," surveilled, and sometimes subjected to dehumanizing psychological and physical abuse by staff and caretakers. Residents describe the indignity of a built environment that offered little or no privacy, where they sometimes shared rooms with many other residents and used open showers and toilets with no closing doors. Returning to their original family homes after life in the institution presented new challenges. Residents relate feeling confined and restricted in family homes that were often inaccessible. One former resident of the West Seneca Center explains how, after moving back home, he missed the institution's large spaces, which allowed him to play practical jokes on staff members while evading their detection.[62] Other residents describe the abuse they suffered while living in West Seneca and the challenges they faced living in inaccessible communities after leaving West Seneca. One resident describes West Seneca as a prison where the doors were always locked so that she could never go outside. She recalls a cousin who was raped while in the institution and remembers doing unpaid work to help staff, who encouraged her to "smack around" residents who would not listen, and once gave her permission to "beat up" a blind resident. She suffered similar abuses in group homes after leaving the Center. When she was finally able to move into her own apartment, it was in a poor neighborhood with an absentee landlord. She was robbed and taken advantage of by neighbors. A lack of access to public transportation meant she rarely left her apartment.[63]

Experiences like these suggest that a history of the disability rights movement focused on how the movement liberated disabled people from institutional settings must account for the ideological underpinnings of "home," domesticity, and community in the USA. They reveal how "home" is not always where one's family resides and that home, in order to be a home, must be accessible and safe. As architects Jennifer Web and Nancy Miller argue, "person–environment fit" is essential to home. A home in which a person must crawl on the floor to access their own bathroom is not a home at all. But neither does an accessible bathroom guarantee a sense of "home"—though it may indeed be integral to it. Echoing long-standing critiques of institutionalization and the nursing home industry advanced by disability rights activists and disability studies scholars, Webb and Miller observe:

> Ironically, the term home has also been used to refer to residential care options for persons with varying levels of functioning and has been applied to housing facilities of all scales, inhabited by a number of persons that are not related, and controlled by a roster of employees (e.g., nursing home). The simple use of the word home for such a facility does not make it so.[64]

Webb and Miller argue that the implementation of policies and practices that allow people to remain independent and stay in their homes for as long as possible is far more cost-effective and socially desirable than subsidizing institutional care.[65] At the same time, they imply that housing "inhabited by a number of persons that are not related" undermines a sense of "home" for people with disabilities, a notion central to heteronormative, able-bodied constructions of home that is directly contradicted by the experiences of people with disabilities who testify that "person–environment fit" is sometimes more easily found in institutions and that the ability to live independently outside of those institutions often depends on support from paid staff or other nonfamily members. These experiences at once recall the well-intentioned efforts of advocates like Amy Lutz to promote a reconsideration of institutional settings as a viable "home" for disabled people and complicate those efforts by grounding disability oppression, not in their inability to adjust to the built environment, but in the built environment itself.

The architect Ron Mace recounted his earliest experiences of home in a 1992 interview with Prof. Edward Steinfeld of the University at Buffalo Center for Inclusive Design and Environmental Access. Mace recalled: "I lived in houses that were badly built and especially after I had polio I kept thinking why people make things this way? I wouldn't have done it this way. From a little kid I was thinking I could do a better job than this. You know I didn't know why you had to go through every room in the house to get to the room you want to go to… things like that."[66] The experience of alienation from the built environment Mace describes extended beyond his own home. Mace recalls, for instance, how school was also a place he was repeatedly told by administrators and teachers he did not belong and how the built environment of the school reenforced this message. He remembers that when he had to go to the bathroom, a family member would have to come and check him out of school, take him home, and then bring him back if there was time left in the school day. Mace recounts being carried up and down steps by an older brother, a process, he tells us, that "sometimes worked and sometimes didn't."[67] For Mace and his contemporaries, prevailing ableist, heteronormative assumptions about one's "place" in a community were reflected both in the built environment and, not surprisingly, in the architectural training necessary for creating built environments.

Disability rights activist and architect Marilyn Golden remembers being discouraged from entering the architectural profession not only because of her disability, but also, because of her gender. An academic advisor discouraged her from signing up for a drafting class by telling her "The only girls who take drafting classes are the ones who want the boys to look up their skirts."[68] Such comments reflected a double bind for women with disabilities like Golden. On the one hand, they suggest a "woman's place" rests firmly in the domestic sphere of home and family and not at the drafting table. The expectation was that Golden would find a boy, marry, and not pursue a meaningful career outside the home. On the other hand, Golden's disability called into question her eligibility for marriage, home, and family.

As an activist, Golden saw connections between movements for women's rights, civil rights, and disability rights, and recalled how these earlier movements provided a "back door" to the disability rights movement and influenced her engagement with that movement following a spinal cord injury in the mid-1970s. "I find a lot of times that people in the disability movement are not that connected to other political issues and don't see the links between disability rights and other issues and I think those links are really important. … and so I like the idea that I came in the backdoor."[69] Golden's use of the "backdoor" metaphor here spotlights how the built environment structures the social isolation of people with disabilities; a reality that she suggests has had profound implications for the politics of the disability rights movement itself. "I think any constituency that you're in, I mean what group it is, affects the way the politics goes and I think people with disabilities are so isolated and segregated by society that it's not a surprise that the disability movement sometimes occurs in isolation from other issues."[70] Examining the disability rights movement and the politics of accessible housing in the USA shows how questions of accessible housing and design are indeed connected to other struggles for equality. Early forms of resistance to suburbanization and the American "dream home" demonstrate that many Americans have long viewed the cultural vision of tranquil, heteronormative domesticity in isolated households with suspicion. Nineteenth- and early-twentieth-century feminists and socialists, for instance, called for a "grand domestic revolution" that would transform America's homes and cities and end sexual exploitation by, among other things, building kitchenless houses and multifamily dwellings.[71] It is time we consider yet another grand domestic revolution that will enable people of varying abilities and body types to create a place they can call home.

Conclusion

This chapter has argued that historical artifacts, images, and narratives documenting the experiences of disabled people with the built environment of "home" can help us challenge and rethink the segregating environments of both community and institutional settings. The accessibility of these archives in digital form encourages the cultivation of new historical perspectives on the disability rights movement and the cultural politics of the American "dream home." Connecting the experiences of people with disabilities in the built environment with the larger historical struggle for disability rights is necessary for challenging entrenched assumptions within, and about, the built environment. An uncritical embrace of access to "home" and community for people with disabilities in institutional, rather than community settings risks leaving intact the cultural norms, spatial practices, and multivalent structures of race, class, sex, and oppression that have excluded people with disabilities from the "dream home." What is needed is to rethink home and domesticity not only in terms of environmental access and community integration, but also, in terms of meeting a variety of human needs not premised on inclusion in heteronormative, nondisabled forms of domesticity or the exclusion and segregation of people with disabilities from the community. The lived experiences of people with disabilities, along with scholarship on disability from across the humanities and the ongoing efforts of activists and architects to achieve accessible housing, show that another American "dream home" is possible and that the exclusion of people with disabilities from the residential landscape depicted in the Smithsonian exhibition's photograph is neither inevitable nor unalterable.

NOTES

1. The Smithsonian Institution National Museum of American History, *Everybody: An Artifact History of Disability in America*, "Places/Outside/Removal" July 2013, http://everybody.si.edu/place/removal (accessed August 20, 2015).
2. Ibid.
3. Korydon H. Smith, "Drawing the Line: Just Housing," in *Just Below the Line: Disability, Housing, and Equity in the South.* Korydon H. Smith, Jennifer Webb, and Brent T. Williams, eds. (Fayetteville, AR: University of Arkansas Press, 2010), 231.
4. Ibid., 232.
5. Brent T. Williams, Korydon H. Smith, and Jennifer Web "Redefining Policy and Practice," in Smith, Webb, and Williams, *Just Below the Line*, 223.
6. See Amy S.F. Lutz. 2015. "Who Decides Where Autistic Adults Live." *The Atlantic* May 26. http://www.theatlantic.com/health/archive/2015/05/who-decides-where-autistic-adults--live/393455/ (accessed August 17, 2015). Dominic A, Sisti, Andrea G. Segal, and Ezekiel J. Emanuel, "Improving Long-Term Psychiatric Care: Bring Back the Asylum," *JAMA*. 313, no. 3 (2015): 243–244.
7. See Max Barrows, George Braddock Allies, Paula C. Durbin-Westby, et al. 2011. *Keeping the Promise: Self Advocates Defining the Meaning of Community Living*. March, 6 https://www.acf.hhs.gov/sites/default/files/aidd/keepingthepromiseofcommunit_abe.pdf (accessed August 17, 2015). Participants in the summit were of leaders from the Autistic Self-Advocacy Network, the National Youth Leadership Network, Self-Advocates Becoming Empowered, and allies.
8. For more on the history and cultural politics of suburban and urban spaces and neighborhoods in the USA, see Lisa McGirr, *Suburban Warriors: The Origins of the New American Right* (Princeton, NJ: Princeton University Press, 2002); George Lipsitz, "The Racialization of Space and the Spatialization of Race: Theorizing the Hidden Architecture of Landscape," *Landscape Journal* 26, no. 1 (2007): 10–23; Raùal Villa, *Barrio Logos: Space and Place in Urban Chicano Literature and Culture*

(Austin: University of Texas Press, 2000); Nicholas Lemann, *Promised Land: The Great Black Migration and How It Changed America* (New York: Vintage Books, 1992); Craig E. Barton, *Cites of Memory: Perspectives on Architecture and Race* (New York: Princeton Architectural Press, 2001); Delany, Samuel R. *Times Square Red, Times Square Blue.* (New York: New York University Press, 1999); Amy Gluckman and Betsy Reed. *Homo Economics: Capitalism, Community, and Lesbian and Gay Life* (New York: Routledge, 1997); Christina B. Hanhardt. *Safe Space: Gay Neighborhood History and the Politics of Violence.* (Durham, NC: Duke University Press, 2013).

9. For more on the development of disability geography as subfield, see Chouinard, Vera, Edward Hall, and Robert Wilton, eds. *Towards Enabling Geographies Disabled Bodies and Minds in Society and Space* (Farnham: Ashgate, 2010); Brendan Gleeson, *Geographies of Disablity.* (New York: Routledge, 1999).
10. Kathrine Ott, “Disability Things: Material Culture and American Disability History: 1700–2010” in Susan Burch and Michael Rembis, eds. *Disability Histories* (Urbana, IL: University of Illinois Press, 2014), 125.
11. Ibid.
12. Ibid.
13. Michael Frisch, *A Shared Authority: Essays on the Craft and Meaning of Oral and Public History.* (Albany, NY: State University of New York Press, 1990).
14. Fred Pelka. *What We Have Done: On Oral History of the Disability Rights Movement* (Amherst, MA: University of Massachusetts Press): 48.
15. Ibid.
16. Pelka, *What We Have Done*, 49.
17. Lutz, “Who Decides…”.
18. Ibid., B.
19. Ibid.
20. Ibid.
21. Lutz, “Who Decides…” N.
22. See Burrows, et al., *Keeping the Promise.*
23. Lutz, “Who Decides…” A.
24. Ibid.
25. Burrows, et al., *Keeping the Promise*, 7.

26. Aimi Hamraie, “Designing Collective Access: A Feminist Disability Theory of Universal Design,” *Disability Studies Quarterly* 33, no. 4 (2013) http://dsq-sds.org/article/view/3871/3411 (accessed August 18, 2015).
27. Lutz, “Who Decides…” B.
28. Ibid.
29. Ibid.
30. Ibid.
31. See, for example, Sherry Ahrentzen and Kimberly Steele. 2009. *Advancing Full Spectrum Housing: Designing for Adults with Autism Spectrum Disorders.* Arizona State University, The Herberger Institute School of Architecture and Landscape Architecture, Tempe, AZ, The Stardust Center for Affordable Homes and the Family, Phoenix, AZ.

    https://stardust.asu.edu/docs/stardust/advancing-full-spectrum-housing/full-report.pdf (accessed August 18, 2015).
32. Korydon H. Smith and Jennifer Webb “Defining Policy and Practice,” in Smith, Webb, and Williams, *Just Below the Line*, 109.
33. Kenneth T. Jackson, *Crabgrass Frontier: The Suburbanization of the United States* (New York: Oxford University Press, 1985), 245.
34. Smith and Webb site sociologist Herbert Gans in their description of the “American dream” as saying that suburbia “violates the American Dream of a balanced community.” in Smith, Webb, and Williams, *Just Below the Line*, 109.
35. For examples of this, see Clifford May, “Homes Serving Mentally Disabled Meet Resistance,” *New York Times*, March 24, 1986; Robert Keating, “The War Against the Mentally Retarded,” *New York*, September 17, 1979, 88.
36. Allison Kafer, *Feminist, Queer, Crip* (Bloomington, IN: Indiana University Press, 2013): 30.
37. Ibid.
38. According to Longmore people with disabilities have been segregated into a “separate economy of disability.” “That economy,” states Longmore, “is dominated by nondisabled interests: vendors of overpriced products and services; practitioners who drill disabled people in imitating the ‘able-bodied’ and deaf people into mimicking the hearing; a nursing home industry that reaps enormous revenues from incarcerating people with disabilities.” Paul

K. Longmore, *Why I Burned My Book and Other Essays on Disability* (Philadelphia: Temple University Press, 2003), 220.

39. Robert McRuer, *Crip Theory: Cultural Signs of Queerness and Disability* (New York: New York University Press, 2006), 89.
40. Sarah E. Chinn, "Gender, Sex, and Disability from Helen Keller to Tiny Tim," *Radical History Review* Winter (2006): 240–248. Chinn suggests we should understand Keller as queer not because she lived with women but because her disability, life, and domestic arrangements exposed and defied heteronormative expectations of gender and domesticity.
41. Joseph P. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* (New York: Three Rivers Press, 1994), 143.
42. The Smithsonian Institution National Museum of American History, *Everybody: An Artifact History of Disability in America*, "Places/Inside/Identity/Community/Autonomy" July 2013, http://everybody.si.edu/place/removal (Accessed August 20, 2015).
43. Ibid.
44. The Smithsonian Institution National Museum of American History, *The Disability Rights Movement*, "The Movement," July 2000, http://americanhistory.si.edu/disabilityrights/exhibit_page1.html (accessed August 20, 2015).
45. Ibid.
46. Ibid.
47. Ibid.
48. Korydon H. Smith, "Defining Equity," in Smith, Webb, and Williams, *Just Below the Line*, 51–53.
49. Ibid, 76.
50. Irving K. Zola, *Missing Pieces: A Chronicle of Living with a Disability* (Philadelphia: Temple University Press, 1982), 44.
51. Ibid, 69.
52. Ibid.
53. Lindsey Patterson, "Points of Access: Rehabilitation Centers, Summer Camps, and Student Life in the Making of Disability Activism, 1960–1973," *Journal of Social History* Winter (November 2012): 1–27.
54. Vera Chouinard, Edward Hall, and Robert Wilton, eds. *Towards Enabling Geographies Disabled Bodies and Minds in Society and Space* (Farnham: Ashgate, 2010), 8.

55. Tobin Siebers, "A Sexual Culture for Disabled People," in Robert McRuer and Anna Mallow, eds., *Sex and Disability* (Durham, NC: Duke University Press, 2012): 45.
56. Ibid.
57. Michael Gill, *Already Doing It: Intellectual Disability and Sexual Agency* (Minneapolis, MN: University of Minnesota Press, 2015): 86.
58. Ibid., 93–94.
59. Ibid., 3–4.
60. Rob Imrie, "Disability, Embodiment, and the Meaning of the Home," in *Towards Enabling Geographies Disabled Bodies and Minds in Society and Space*. Vera Chouinard, Edward Hall, and Robert Wilton, eds. (Farnham: Ashgate, 2010), 23–44.
61. The Smithsonian Institution National Museum of American History, *The Disability Right Movement*, "The Struggle for Autonomy and Self-Definition," July 2000 (Accessed July 3, 2015 http://americanhistory.si.edu/disabilityrights/exhibit_self_definition1_full2.html).
62. Larry Jordan, interview by Michael Rembis, Buffalo, NY, July 26, 2013.
63. Laura Nicholson, interview by Kathryn Lawton, April 22, 2015.
64. Jennifer Webb and Nancy G. Miller "Defining Home," in Smith, Webb, and Williams, *Just Below the Line*, 23.
65. Smith, Webb, and Williams, *Just Below the Line*, XV.
66. Ron Mace, interview by Edward Steinfeld, 1992.
67. Ibid.
68. Marilyn Golden, interview by Edward Steinfeld, Oakland, CA, October 5, 1992.
69. Ibid.
70. Ibid.
71. Jackson, *Crabgrass Frontier*, 51.

PART II

Care

CHAPTER 6

A Feminist Technoscientific Approach to Disability and Caregiving in the Family

Laura Mauldin

In modern capitalist societies, domestic space is associated with notions of the "private sphere," family, and care, and as such, often rhetorically positioned in opposition to labor, work, and industry. That is, the concepts of labor, industrialization, and technologization are often absent in analyses of home and family. Within domestic spaces, however, there is still work that is done, labor that this performed, and done so with particular tools. There are many forms of domestic labor, such as cleaning or managing a household. This chapter focuses specifically on caregiving in the context of a disabled family member. The goal is to draw together feminist disability studies with science and technology studies (STS) in order to offer up a conceptual starting point for thinking about care and caregiving in this realm in a way that accounts for the role of technologies in the process.

Any discussion of caregiving should be approached with the understanding that it can take many forms. Family caregiving patterns in relation to disability can include spousal or partner caregiving, sibling caregiving, caring for an aging parent, or parenting a child with a disability. And people with disabilities can be those who provide as well as receive care. Certainly, caregiving occurs in many ways regardless of the disability status

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of those in relation to one another. For example, the care work involved in raising a child with a disability blurs the lines of care involved in raising any child. Similarly, caring for a spouse or partner with a disability blurs the lines of providing emotional support and care for any partner. In short, disability is but one variable and one characteristic of some humans, but all humans need care, and care is central to all relationships regardless of disability status. In this chapter, I focus on the context of disability precisely because it is often accompanied by care work infused with practices based on scientific (specifically medical or health-related) knowledge and may be executed using particular technological artifacts. Expanding disability studies into this realm and explicitly merging it with STS allows for an examination of caregiving in relation to how technological changes shape, co-construct, and constantly redefine what disability is, what caregiving looks like, and what the meaning of good care for those with disabilities is constructed as in the first place. Rather than being an endorsement of seeing disability strictly in the context of health or medical knowledge/technologies, this chapter asks: How do scientific thinking and health-related technologies infuse the intimate labor of caregiving? How does this affect all people's lives, including both disabled and nondisabled providers and recipients of care?

Technological artifacts are not neutral tools. In the field of STS, the term technoscience is used to highlight how social and political elements are embedded into and intertwined with material or technological artifacts. As such, science, technology, and society are co-constructive. In disability studies, the disabled body is politicized and disabled at least in part by social meanings and interactions with the environment. Ideology permeates both the bodies providing and receiving care *and* the tools used in the name of that care. Thus, the development of technologies and constructs of disability are in a dynamic, reciprocal feedback loop. One might look then at care practices as a way to understand the relationship between medical technologies and disability and the meaning-making that gets done in this relationship.

There are a number of reasons why a feminist technoscientific approach is useful in studying disability and care. For one, a feminist science studies or STS approach makes the role of gender explicit. This is important because the domestic sphere and caregiving have traditionally been relegated to women, women have long used technologies in domestic and caregiving practices, and yet their roles as technological users and innovators are often ignored.[1] A feminist science studies approach also offers up the opportunity for an intersectional analysis that takes all social categories—race, class, gender, and disability status—into account when examining configurations of care and the utilization of technoscientific artifacts. In this way, it stands ready to dialogue with feminist disability studies (as I will elaborate on later in this chapter). But it also brings important critique; as disability studies scholar Aimi Hamraie aptly points out in her review of recent work in feminist science studies, "Even when race does not appear intelligible as a factor in feminist technoscience… whiteness nevertheless circulates to produce privilege, access, and self-determination for white US feminists and to deny epistemic and political agency to women of color, both domestically and internationally."[2] My call for a feminist technoscientific approach not only serves to highlight the role of gender in caregiving, but also asks that future work in this area take a broader, intersectional approach and interrogate the privilege of white, middle- and upper-class individuals in the literature thus far.

In this chapter, I specifically focus on medical or health technologies. Medical sociology has long been concerned with the rapid expansion of medicine and medical technologies on contemporary life. Disability studies scholars Gregor Wolbring and Bonnie Lashweicz have also taken this into consideration and argue that "[h]ome care, consisting of provision of health support and resources within a person's private residence, is an increasingly preferred model of care for older people and people with disabilities who are in constant need of some form of health intervention… Health technologies continually reshape what is possible in home care and the creation of home environments."[3] In a greater effort to understand the effects of "medicalization," which is a sociological concept describing how we understand bodies through medical language, medical thinking, or medical frameworks, this chapter presents ideas for a critical analysis of caregiving practices from a feminist disability studies lens, specifically as it intersects with STS.[4] There are many different kinds and degrees of disabilities. This chapter is intended to start a dialogue about care as it relates to disability, broadly defined. However, the intent is not to conduct an exhaustive review of the topic of care, but rather to begin a conversation through some broad theoretical strokes about how disability studies might expand its scope and engage more deeply with home and family life. One way to do this is to account for aspects of care and caregiving more creatively, specifically in relation to science, medicine, and technology (and in particular, medical technologies).

Shifting Sites of Caregiving and "Care Coordination"

The importance of including the topic of care in this volume is demonstrated in a variety of evidence. Hogan reports that today "more than one-eighth of all families with children in the United States include at least one child under age eighteen who has been diagnosed as having a disability. Nearly all of those children live with their families."[5] It has also been established that rates of disability increase with age: 11 % of adults aged 25 to 44 have a disability, whereas by age 75 to 79, 53.6 % of adults have a disability.[6] Not only are children with disabilities living at home and life spans increasing, but rates of disability in the general population and in families also continue to rise. Through various statistical analyses, Altman and Blackwell have determined that households with disabled children aged 0 to 17 increased from 10.4 % in 2000 to 13.0 % in 2010. At the same time, households with disabled adults aged 18 to 64 also increased from 15.9 % in 2000 to 17.4 % in 2010. In total, 25.6 % of all households during that time had at least one person with a disability. Altman and Blackwell also point out that as rates of disability rise, they are doing so predominantly in the context of a home and that families continue to provide care and support regardless of the location of their disabled family member: "Families traditionally have been the dominant form of support for persons with disabilities, whether the person with a disability lives in the same residence, in the same community, or in nearby communities."[7] Although dominant sites of caregiving have shifted in North America over time, "family" in one form or another has remained at the center of most disabled people's lives.

Current research reflects the sheer magnitude of caregiving done by family members in the USA today. The development and advancement of medical treatments and technologies that facilitate individuals living longer than before (across the lifespan) also contributes significantly to increased caregiving in the home. The National Caregiver Alliance and the American Association of Retired Persons report that overall, "65.7 million caregivers make up 29 % of the U.S. adult population providing care to someone who is ill, disabled or aged."[8] An important reason to consider care work through a feminist lens is that it is gendered. The same report also showed that "[m]ore women than men are caregivers… Men may be sharing in caregiving tasks more than in the past, but women still shoulder the major burden of care." In addition to gender, intersectional analysis might also consider the disparities in caregiving by race and ethnicity; the same report states that caregiving rates are lowest among Asian Americans (20 %), highest among Hispanics (36.1 %), with African American families reporting 33.6 % and white families at 30.5 %. Overall, 66 % of caregivers are women, and of those women, 34 % are caring for more than one person.[9] Furthermore, numerous studies have also shown that daughters are far more likely to provide caregiving to aging parents than sons.[10] As feminist scholars have shown, taking gender into account can be a rich site for further understanding the caregiving experience, although analyses need not be solely focused on women. For example, one of the most referenced accounts of caregiving within disability studies is Michael Berube's astute rendering of his experiences of his son's disability and caring for him.[11]

Taken together, the rising number of people with disabilities, and the centrality of the home in care work, requires many families to engage in "care coordination." Care coordination "includes coordination across medical providers and also among medical and long term, rehabilitation, and other care providers."[12] It involves not only direct care work, but also the development of relationships with providers and navigation across a number of institutions and bureaucracies. As both the prevalence of disability and medical intervention increases, it is not just the demands of care giving that increase, but also its complexity. Interventions have become increasingly more technoscientifically complex and portable, used beyond the walls of a clinic and extending into daily routines within the home. For example, individuals with multiple chronic conditions may utilize a variety of health technologies in the home on a daily basis, which range from telemetry devices to home infusions, to ventilators, to an infinite number of other medical or adaptive devices that cannot be captured in their entirety here. Specific studies of technologies or conditions would help to illuminate these patterns. The point, however, is that care work being performed by caregivers is increasingly medically complex, ongoing, and intertwined with and using knowledge and tools associated with science, technology, and medicine.[13]

It is important to note again that this complexity and technoscientific turn is highly dependent upon having access to health care. While I am arguing here to examine intersections between disability, technology and care, it is important to point out that such an entanglement depends on having access to these technologies, the social and cultural capital required for care coordination, and the time and resources to provide such care. It is easy for analyses like I suggest to privilege primarily white, middle-class families with the resources to perform and coordinate such labor.[14] What about those who are located outside the USA, or those within the USA who are poor or unable to access such resources? How do nonwhite families negotiate care work? There is much more to investigate regarding how, for example, healthcare policies and health resources in the USA are unevenly distributed, as well how global capitalism commodifies—and colonizes—intimate labor like caregiving.[15] Race, class, gender, and geographic location all stratify access and thus shape the care work that is done.

Care in Feminist Scholarship and Disability Studies

Care and caregiving have received much attention in feminist sociological scholarship. Research has consistently shown that care, framed as a kind of labor that occurs within the home or domestic sphere, is an informal labor system that is persistently gendered and culturally devalued. It is also well documented that childcare duties have historically been the responsibility of women.[16] Indeed, the gendered patterns found in care are no different when it comes to parenting children with disabilities; it is most likely the mother who will be expected to provide therapeutic care mandated by medical professionals and who are consistently held responsible for that care. As sociologist and disability studies scholar Allison Carey showed in her review of parent memoirs, there was a tension between the feminist movement's criticisms of the medical profession and mothers of children with disabilities finally gaining access to services and therapies. She writes that the concept of intensive mothering emerged, where "professionals expected them to serve as extensions of the medical/therapeutic professions and to transform their homes into sites of therapeutic practice."[17] Feminist endeavors in the fields of bioethics and philosophy have also sought to theorize care, and in particular scholars like Eva Feder Kittay have long worked at attending to the issues of care at the intersection of disability studies and feminist philosophy and ethics.[18]

Clearly, care is a gendered process and of interest in feminist scholarship, but there are tensions between feminist scholarship and disability studies, where care is approached with some hesitancy. There are a variety of historical and political reasons for this hesitancy. One is the male-dominated disability rights movement. Another, and perhaps more fundamental, reason is found in the political history of the "two models" of disability, namely, the medical model and the social model.[19] In the medical model, a person's disability is an individual pathology, socially undesirable, and in need of cure or mitigation using medical intervention. The social model, however, distinguishes between "impairment" (the physical condition of the body) and "disability" (the social attitudes and physical barriers that prevent certain bodies from participating fully in society). Thus, by talking about care, the body and its impairments or limitations are brought front and center—and because disability has historically and predominantly been seen as *only* about the state of disabled people's bodies, it can seem dangerous to draw further attention to this. However, there are critiques of these bifurcated models.[20] Feminist scholar Susan Wendell, writing at the intersection of feminist theory, the body, and disability, has long pointed out that the body is both a cultural *and* a material entity.[21] It is time that disability studies scholars embrace a more nuanced and sustained analysis of care. It is another important point of tension between feminist scholarship and disability studies that can be mined.[22]

Disability Studies' uneasiness with both care and family—as a social system and a domestic sphere—often extends beyond its purported violations of the social model's tenets. Among certain scholars, the family in disability studies has represented a fraught site of dominant ideologies about disability as an individual pathology to be overcome by fixing the person's body. Parents may mourn the discovery of a child's disability, engage in curative techniques to fix their children—the discussion of the outrage over the Ashley X treatment that appeared in Kim Hall's *Feminist Disability Studies* is a good example of this—and women may abort a fetus if prenatal testing finds disability to be present.[23] Thus, the families and the care they engage in are often conceptualized as conduits of medicalization, as complicit enactors of institutional violence in the name of medicine, cure, or benevolence, and therefore an obstacle to the disability rights movement. This is especially true for scholarship in disability studies related to mothers of children with disabilities.[24] Critiques of how mothers and families engage in medical interventions and practice care are not undue, but they often do not attend to the multiple complexities that constitute care work, which often is embedded in a culture that prizes technologies and scientific thinking. I would argue these are reasons *for* delving deeply into the realm of care through a disability studies lens rather than reasons to exclude or avoid it.

Turning an analytic eye to care in the domestic sphere can productively disrupt the tensions and overlaps in feminist and disability studies scholarship. A feminist disability studies approach allows us to encounter moments for complicating our understandings of caregiving within the family. As Garland-Thomson writes, “A feminist disability theory should illuminate and explain, not become ideological policing or set orthodoxy.”[25] Garland-Thomson suggests that feminist disability studies complicates previous theories of care through its attention to the gendered and relational nature of care, and also by taking seriously the materiality of bodies and the meanings we attach to them. In the next section, I build on such an approach, by examining care work done within the home and the family through an STS lens. The histories and practices of technologies co-construct and shape the kind of care work we do, and thus the way we experience disability and caregiving, and the way we understand or explain the bodies that are both receiving and shaping care. By focusing on care in the family, embodiment is no longer denied and longstanding issues of gender and family can be further explored. This enterprise also recategorizes technoscientific and medical processes that are enacted in the name of care and shifts consideration of them squarely into the realm of the social. That science, medicine, and technology are social is a central tenet of STS, which I will now delve into further.

Technologization and Medicalization of Care in the Domestic Sphere

Even though we often consider the domestic sphere in opposition to labor and industrialization, Ruth Schwartz Cowan pointed out in her classic book, *More Work for Mother*, that work done in domestic spaces is also transformed by industrialization and technologization. She argues that labor in the domestic sphere must be seen within its larger social context and in relation to technology: “Industrialization has occurred just as rapidly within our homes as outside them.” She then provides a history of how the household sphere and housework were transformed by technology. Yet she distinguishes housework from that of childcare, categorizing care as a different form of work. Cowan describes childcare as a kind of “work process,” or a series of definable tasks. She also shows how the time spent on childcare increased over time and the guiding ideology of it became increasingly medicalized. As scientific thinking and medical knowledge assumed a tighter grip on the popular imaginary in the twentieth-century USA, infant care became much more complex. As Cowan argues, “In an effort to combat infant mortality… mothers were watching meticulously over their children’s diets, weighing them several times a day, and repeatedly carrying them to a physician's office for check ups."[26] While childcare is not the focus of Cowan's book, she does situate it as part of the labor system in the domestic sphere and within the larger pattern of industrialization in society. Others, such as sociologist Jacquelyn Litt, looked at the increasing role of medicalization in mothering for African American and Jewish mothers in an important book that examines gender, mothering, care, and race.[27] Because of the long-standing gender gap in domestic work and childcare, it is no accident that scholarship in this realm focuses on mothers. Mothering is indeed one form of care work, but I would argue that families and households are infused with multiple vectors of care, each of which is substantially influenced by scientific and medical knowledge.

Using Cowan's definition of care as a series of definable tasks, we can also consider that care enacted in relation to disability is a series of definable tasks. I am less interested in drawing strict lines around what is care related to disability and what is not than I am in understanding the role of technologies and medical thinking in shaping ongoing care work. And because of the medicalization of disability, care related to disability may be especially technological and driven by medical and scientific knowledge and tools. This is further reason to turn to STS to examine how the care work process occurs within a social and technological system—indeed a sociotechnical system—where particular tools are implemented in particular ways. These tools and the thinking that accompanies them are, just like bodies, saturated with ideology, politics, and meaning.[28]

With the advent of neoliberalism and the movement to deinstitutionalize disabled people, care for those people with disabilities has taken on increased significance within individual families in the USA. This shift has overlapped with something scholars in STS call biomedicalization. Irving Zola's original conceptualization of medicalization has been expanded within STS. Clarke and colleagues, for example, argue that because of the proliferation of technologies, medicalization has been transformed into the more complicated process of biomedicalization.[29] Traditionally, sociologists associate medicalization with control over disease processes, while biomedicalization thinks in new ways about transformation—of the body or the creation of types of bodies at the molecular or genetic level, that is, transformation of life itself—through technoscientific means.[30] As Clarke and colleagues argue, one feature of biomedicalization is that "the key site of responsibility shifts from the professional physician/provider to include collaboration with or reliance upon the individual patient/user/

consumer."[31] Using a feminist disability studies approach, we can explore how caregiving that occurs in the intimacy of the home has been biomedicalized, how it has been radically transformed by increased medicalization, and the proliferation and integration of technologies, as well as the moral demands put on individuals to engage in these activities. Although I have previously mentioned studies of motherhood, we can look beyond motherhood for signs of this shift to biomedicalization in processes of caregiving: assistive technologies, telemedicine, quantified self technologies, the establishment of clinical practices centered on particular interventions that rely on various technologies, deployment of medical equipment and technologies in home settings, insurance coverage of various technologies and therapies requiring medical technologies at home and the industries supporting them, the vast reach and demand of healthcare systems into homes, the encouragement of clinical and scientific thinking in everyday life, and the neoliberal shift toward individual medical intervention at the expense of creating larger social or structural changes—in the way we consume food, for example—all contribute to these shifts. We can use the insights of STS and disability studies to examine how caregiving is structured or co-constructed by specific tools and how scientific or biomedical thinking shapes the tools we take up in the first place (or even what we deem to be good care in the first place), the extent to which we use them, and how they are integrated into daily lives.

In this biopolitical era of biomedicalization, care and disability are intricately entangled and intermeshed in family life. The development of technologies changes not only the care work we do, but also the very definition of "good care"—often what is labeled as "good" care shifts in relation to technology and medicine. Given the history of medicalization in disability studies and its connection to normalization, it is important and provocative to note (and critique) that using tools of biomedicalization is deemed "care." Sometimes these tools of medicine are bound up in normalization projects, and sometimes they are enthusiastically adopted by all parties in efforts to provide relief or aid in functionality.[32] Thus, using the tools of science and medicine in caregiving practices can be ambivalent. Rather than passing judgment to determine whether a particular type or process of care is indicative of normalization or creating synchronicity between a body and its environment in a productive and liberating way, we should explore how caregivers are socialized into understanding what good care looks like vis-à-vis medical thinking and medical technologies. Additionally, we must learn how these dynamics are enacted in the intimacy of the home and the consequence of this integration for all involved. For example, how do people with disabilities experience this? Who has access to these technologies? What structures or processes dictate how people integrate them? Feminist disability studies scholar Alison Kafer aptly captures my sentiment in describing her political/relational model of disability:

> By my reckoning, the political/relational model neither opposes nor valorizes medical intervention; rather than simply take such intervention for granted, it recognizes instead that medical representations, diagnoses, and treatments of bodily variation are imbued with ideological biases about what constitutes normalcy and deviance. In so doing, it recognizes the possibility of simultaneously desiring to be cured of chronic pain and to be identified and allied with disabled people. [33]

In sum, the results of greater medical intervention mentioned earlier (such as a longer life span, living longer with a chronic illness or disability, etc.), the rise of biomedicalization, and the fact that people with disabilities are largely cared for by family members mean that the overall picture of family caregiving has been transformed by the expanding use of technologies.

All of these changes create novel demands on family members to develop new skills and integrate new knowledge into care work, calling into question the very notion of "expertise." Another fruitful opportunity to draw STS and disability studies together emerges when we begin to think critically about expert knowledge. As Cowan stated in her historical study of technology and domestic work, "Tools organize our work for us in ways that we may not have anticipated."[34] The biomedicalization of home care creates informal "experts" in the home in addition to altering care work processes. STS scholars have questioned who is an expert and how expert knowledge is made, circulated, and received both by its immediate objects and more generally. As Evans and Collins point out, "expert knowledge remains an important input to decision-making but… experts might be found anywhere."[35] Looking for experts in our homes can be a productive way for disability studies scholars to interrogate and disable domesticity.

There are so many questions to ask as a result of changes in technological capabilities and the expansion of medicalization: How do caregivers and people with disabilities experience their knowledge of medical technologies? Do they identify as "experts"? Does their knowledge count?[36] Is their expertise sufficiently integrated into the design and implementation of such technologies? What result does increased technoscientific demands and coordination with healthcare systems have on the caregiving experience? Furthermore, the availability of these scientific or medical tools is mediated by larger health-related institutions (healthcare policy, agencies, technological industries, insurance companies, etc.) as well as race, class, and geographic location. Who gets access? How do they get it? Who has the cultural capital to navigate these systems? How does this get promoted to those who are disenfranchised? By attending to care work and the tools available to use in care work, we can investigate the co-construction of disability in contemporary society through technological artifacts and technoscientific industries like health and health care.[37] Now I shall turn to some more specific examples of how we might enact a feminist disability studies approach that includes a feminist STS lens to studying care.

Specific Sites for Analysis: Motherhood and Beyond

As I mentioned above, mothering, by far, is the most widely studied form of caregiving and a vast literature exists on medicalization and motherhood.[38] Thus, I will elaborate further on motherhood and caring for a child with a disability as an example of how examining caregiving through an STS and feminist disability studies lens could be beneficial. However, I long for scholarship beyond the scope of motherhood and hope that others expand into other sites for analysis. There are so many other intimate configurations of care to consider through a feminist disability studies and STS lens that are needed in the larger body of research on caregiving patterns—such as sibling care, partner care, caring for one's aging parent, and so on. There are many other ways that the materiality of bodies, the merging of technoscience with the body and care, and the politics of disability come together in the home.

Mothering and the modern technologies associated with it are deeply imbricated in disability studies literature that generally sees care in the home as a site of oppression for disabled people. As Sara Ryan and Katherine Runswick-Cole contend: "Traditionally, research focusing upon the experiences of mothers of disabled children has been dominated by a medical model of disability and there has, correspondingly, been a steady stream of research which focuses upon the burden and stress of having a disabled child."[39] Mothers are often held up as normalizers in the disability studies literature, because of their deployment of medicalization in caring for their child. Ryan and Runswick-Cole warn that critiquing the normalizing role of contemporary mothering practices may not adequately situate mothers' experiences within the larger environment, which is ableist and highly demanding as it socializes women into medicalized mothering. I would argue that indeed critiquing mothers' actions is unproductive; we should be critiquing the systems which socialize women into the idea that disability must be normalized and done so in particular ways of mothering. One way to do this is to situate mothers' actions—and indeed all caregivers' actions—by using STS and feminist disability studies to investigate how the ethos of the broader social context of biomedicalization shapes caregiving actions, which will enable scholars to account for women's (and any caregiver's) experiences in new ways, while also attending to the ways in which bodies are co-constructed via technological processes.

There is certainly already scholarship that draws together the history and social aspects of science and medicalization and motherhood in order to offer a better account of motherhood, disability, and childcare. Rima Apple's "Constructing Mothers," for example, looks at the history of medicalization and the rise of scientific thinking to conceptualize what she calls "scientific motherhood," or "the belief [and the insistence] that women require expert scientific and medical advice to raise their children healthfully."[40] Apple provides a historical account of how this belief developed and the ways it was propagated. In the nineteenth century, women were expected to seek out information for themselves and were seen as generally capable of raising children on their own. By the twentieth century, mothers began to be seen as incapable on their own and in need of doctors and other experts, as well as popularized forms of scientific knowledge in order to become a "modern mother."[41] Again Allison Carey's review of memoirs traces this unfolding and how mothers began to "work with" their children in medically or therapeutically sanctioned ways, rather than spending time with them. However, she also importantly emphasizes that "[t]hese dilemmas must be situated in the context of privilege."[42]

In my own research, I have found there are patterns and features with regard to biomedicalization, motherhood, and disability. In the case of mothers of deaf children, the path toward a technoscientific intervention (cochlear implantation) is set for them in a variety of highly formalized and institutionalized ways that depend on cooperations across multiple industries. A series of care work processes that depend on technologies are laid out as "common sense" and thus disability is depoliticized and the process of adopting such intervention is effectively rendered a "nondecision." The process of socializing parents into the biomedicalized script of deafness is highly structured and purposeful, and draws on broader cultural conceptualizations of disability as an undesirable state. Furthermore, the very availability of the technology of cochlear implants restructures the work that gets done in caring for a deaf child, how deafness is defined in the first place, and ultimately what constitutes good care for a deaf child.[43]

New medical technologies change care work in unanticipated ways and restructure any associated work processes. Returning to Cowan's conceptualization of care work as a work process with particular steps involved, we might begin to examine—on a larger scale—the socialization of mothers and any caregivers into technoscientific and biomedicalized thinking and tools. This predominantly happens through healthcare institutions, although this kind of scientific thinking has seeped into the broader cultural ethos. One study by Leiter, "Dilemmas in Sharing Care," for example, characterizes the ethos threading through Early Intervention Programs in particular as a "therapeutic imperative." This imperative is the expectation and obligation created for mothers to engage in therapeutic care work (as determined by programs like Early Intervention) and to do so at all times, exceeding the amount of work in which professionals engage. This is one example of scholarship that examines specific aspects of caregivers' experiences and how clinical practice and medical knowledge structures them. We could also investigate the process of noticing and labeling "the problem," the process of diagnosis, the years of follow-up care vis-à-vis agencies and health institutions, ongoing clinical relationships, management of care work in the home, and learning and mastering the available tools and technologies and care practices in day-to-day home life. Furthermore, demographics and types of disabilities will affect these experiences, and we must engage in more intersectional analyses.

In using a feminist disability studies/STS approach, the collaboration between technoscientific objects and industries with larger demands on women, caregivers, and expectations of how to respond to disability is emphasized. The moral demands to engage in such care—such as the way parents are increasingly taking on a collapsed parent/caregiver/informal expert role in efforts to care for their disabled child—are also situated within larger cultural values pertaining to scientific motherhood (or I would argue, scientific care in general by any caregiver). These are only a small sampling of the ways in which a feminist disability studies/STS analysis can be deployed at the site of disability and care. A number of questions remain unanswered and unexplored, such as: How do various devices get incorporated and integrated into daily life? How do bodies work in tandem with these technologies? How do gender, class, and race influence the use of technology and care giving outside of the context of mothers and motherhood? How does access to resources and "expert advice" influence the use of technologies in the home? Or alternatively, how do larger structural forces influence and in some cases dictate the use of technologies in the home?

Conclusion

In this chapter, I focused on further illuminating the social sphere of the home and the informal care labor being done in relation to disability. Rather than seeking to undermine the social and political aspects of disability, this is intended further to expand the scope of disability studies and further expand the realms captured in a disability studies analysis. Specifically, this chapter articulated the need for a feminist disability studies technoscientific analysis of care work done in the domestic sphere in order to analyze medicalization, technologies, and concepts of care.

I have argued for a better understanding of care labor in the intimacy of the home, as it relates to the themes of scientific thinking, medical intervention, and the use of technologies. We know that this care work is gendered, and thus exploring the importance of gender is meant not only to validate what has been traditionally devalued as "women's work," but also to draw attention to the ways in which technoscience intersects with disability and other social categories like race and class. One aim of this chapter has been to highlight the tensions between feminism and disability studies in relation to care, and attempt to draw together feminist disability studies with STS in order to offer up a conceptual starting point for thinking about care in this realm. The goal of this perceived collaboration between disciplines is to begin to think about how we might approach studying, theorizing, and analyzing the circumstances of care that occur on a daily basis in the homes of families in the USA and beyond its borders. Although US or North American theories of and approaches to disability, technoscientific intervention, and biomedicalization cannot simply be transposed onto other geographic locations, my hope is that this chapter offers an initial gateway into more localized studies and discussions.

In a biomedicalized context, healthcare systems mediate the flow and availability of medical technologies. Meanwhile, interconnected sets of agencies and intervention programs have shifted to "parent-centered" approaches, creating what disability studies scholar Valerie Leiter has called the "therapeutic imperative." I suggest we see this imperative through a technological systems/work process lens and expand beyond mothers to examine how medical technologies are being integrated into care practices in everyday life, giving rise to a whole new set of questions: How does this generate new work processes? What do we need to take into account if we want to understand them? How does the process of biomedicalization intersect with caring for a family member with a disability? How have technologies enabled people with disabilities to become care providers and assume greater levels of care over their own body? In what ways are caregivers socialized into norms around medical intervention and how does this shape what care labor they undertake? In what ways do technologies and interventions shape the experience of disability and a care of the self?

In drawing together these literatures on gender, technology, and disability, I propose that we might undertake new ways of critically analyzing care. These intimate interactions are technologically mediated, sophisticated, and embodied. Thus, we cannot begin to understand care without understanding the medicalized, biotechnological context in which it is taking place. Additionally, the work of caring and what is deemed "good care" in the first place is constructed between people and the tools that are available to them. For all of these reasons, I have argued it is crucial to understand care through these relationships because they contribute to the meanings that get made around disability, raising a child with a disability, caring for a parent, a partner, and so on. In short, new technologies create new sociotechnical arrangements, novel care demands, and co-construct the meanings and experiences of disability and caregiving along the way.

Notes

1. Judy Wajcman, *TechnoFeminism* (Cambridge ; Malden, MA: Polity, 2004).
2. Aimi Hamraie, "Cripping Feminist Technoscience," *Hypatia* 30, no. 1 (February 1, 2015): 307–313.
3. Gregor Wolbring and Bonnie Lashewicz, "Home Care Technology Through an Ability Expectation Lens," *Journal of Medical Internet Research* 16, no. 6 (June 20, 2014).
4. Irving K. Zola, "Medicine as an Institution of Social Control," *The Sociological Review* 20, no. 4 (November 1972): 487–504; Peter Conrad, "Medicalization and Social Control," *Annual Review of*

Sociology 18, no. 1 (1992): 209–232; Peter Conrad, *The Medicalization of Society: On the Transformation of Human Conditions into Treatable Disorders* (Baltimore: Johns Hopkins University Press, 2007).

5. Dennis P. Hogan, *Family Consequences of Children's Disabilities* (New York: Russell Sage Foundation, 2012).
6. Matthew Brault, "Americans With Disabilities: 2010," Current Population Reports (Washington, DC: US Census Bureau, 2012).
7. Barbara M. Altman and Debra L. Blackwell, "Disability in U.S. Households, 2000–2010: Findings from the National Health Interview Survey: Disability in U.S. Households," *Family Relations* 63, no. 1 (February 2014): 20–38.
8. National Alliance for Caregiving and the American Association of Retired Persons, "Caregiving in the US: 2009" (Washington, D.C, 2009).
9. Ibid.
10. There are a number of studies that have demonstrated this pattern. See, for example, Jane Aronson, "Women's Sense of Responsibility for the Care of Old People: 'But Who Else Is Going to Do It?,'" *Gender & Society* 6, no. 1 (March 1, 1992): 8–29; Angelina Grigoryeva, "When Gender Trumps Everything: The Division of Parent Care Among Siblings" (American Sociological Association Annual Meeting, Hilton San Francisco Union Square and Parc 55 Wyndham San Francisco, San Francisco, CA, August 15, 2014); Merril Silverstein, Daphna Gans, and Frances M. Yang, "Intergenerational Support to Aging Parents the Role of Norms and Needs," *Journal of Family Issues* 27, no. 8 (August 1, 2006): 1068–1084.
11. Michael Berube, *Life as We Know It: A Father, a Family, and an Exceptional Child* (New York: Vintage, 1998).
12. Gerard Anderson and Jane Horvath, "The Growing Burden of Chronic Disease in America," *Public Health Reports* 119, no. 3 (2004): 263–270.
13. There are many studies and memoirs about such phenomena. For examples of memoirs, see Jane Bernstein, *Loving Rachel: A Family's Journey from Grief* (Urbana: University of Illinois Press, 2007); Rachel Adams, *Raising Henry: A Memoir of Motherhood, Disability, and Discovery* (New Haven: Yale University Press, 2014); Kerry Cohen, *Seeing Ezra: A Mother's Story of Autism, Unconditional Love,*

and the Meaning of Normal (Berkeley, CA: Seal Press, 2011). Marion Cohen, *Dirty Details* (Philadelphia: Temple University Press, 1996). For an example of some studies that primarily focus on motherhood, see Valerie Leiter, "Dilemmas in Sharing Care: Maternal Provision of Professionally Driven Therapy for Children with Disabilities," *Social Science & Medicine (1982)* 58, no. 4 (February 2004): 837–849; Gail Landsman, *Reconstructing Motherhood and Disability in the Age of "Perfect" Babies*, 1 edition (New York: Routledge, 2008); Rayna Rapp, "Chasing Science: Children's Brains, Scientific Inquiries, and Family Labors," *Science, Technology & Human Values* 36, no. 5 (December 28, 2010): 662–684.

14. My own work—which is sociological—has reflected this as well. Part of this is logistical; when beginning from a clinical research site, often the families that are consistently present in the clinic are white, middle-class families who are deemed by professionals as highly compliant. What gets lost here are the stories of families who do not have the resources or have other definitions of what good care looks like. These populations are much more clinically hidden and thus less understood. There are important implications here that new sites of research and new methodologies are needed to pursue a deeper understanding of the nexus of medicine, technology, and caregiving that goes beyond white, middle-class families. While resolving these issues is beyond the scope or capability of this chapter, these are important areas for future investigation and a point of legitimate critique here.
15. Rhacel Parreñas and Eileen Boris, *Intimate Labors: Cultures, Technologies, and the Politics of Care* (Stanford, Calif: Stanford Social Sciences, 2010).
16. Emily Abel, "A Historical Perspective on Care," in *Care Work: Gender, Labor, and the Welfare State*, ed. Madonna Harrington Meyer (New York: Routledge, 2000), 8–14; Arlie Hochschild and Anne Machung, *The Second Shift: Working Families and the Revolution at Home*, Revised edition (New York, NY: Penguin Books, 2012); P. Herd and M. H. Meyer, "Care Work: Invisible Civic Engagement," *Gender & Society* 16, no. 5 (October 1, 2002): 665–688.
17. Allison Carey, "Parents and Professionals: Parents' Reflections on Professionals, the Support System, and the Family in the

Twentieth-Century United States," in *Disability Histories*, ed. Susan Burch and Michael Rembis (Chicago: University of Illinois Press, 2014).

18. For examples, including Kittay's work, see Carol Gilligan, *In a Different Voice: Psychological Theory and Women's Development*, Reissue edition (Cambridge, Mass: Harvard University Press, 1993); Nel Noddings, *Caring: A Feminine Approach to Ethics and Moral Education, Second Edition, with a New Preface*, Second Edition, With a New Preface edition (Berkeley: University of California Press, 2003); Eva Feder Kittay, *Love's Labor: Essays on Women, Equality and Dependency* (Routledge, 1998); Eva Feder Kittay, "The Ethics of Care, Dependence, and Disability," *Ratio Juris* 24, no. 1 (March 2011): 49–58.
19. Len Barton, *Disability and Society: Emerging Issues and Insights* (New York: Longman, 1996); Mairian Corker and Sally French, *Disability Discourse* (Buckingham: Open University Press, 1999); Lennard J. Davis, *The Disability Studies Reader*, 4 edition (New York, NY: Routledge, 2013).
20. Tom Shakespeare and Nicholas Watson, "The Social Model of Disability: An Outdated Ideology?," *Research in Social Science and Disability* 2 (June 20, 2001): 9–28; Tom Shakespeare, *Disability Rights and Wrongs*, 1 edition (New York: Routledge, 2006); Tobin Anthony Siebers, *Disability Theory* (Ann Arbor: University of Michigan Press, 2008); Alison Kafer, *Feminist, Queer, Crip*, 1 edition (Bloomington, Indiana: Indiana University Press, 2013).
21. This chapter is in dialogue with these and other feminist disability studies texts. Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability*, 1 edition (New York: Routledge, 1997); Kim Q. Hall, *Feminist Disability Studies* (Bloomington: Indiana University Press, 2011); Kafer, *Feminist, Queer, Crip*; Cynthia Lewiecki-Wilson, *Disability and Mothering: Liminal Spaces of Embodied Knowledge*, 1st Ed, 1st Pr 2011 edition (Syracuse, N.Y: Syracuse University Press, 2011); Simi Linton, *My Body Politic: A Memoir* (Ann Arbor: University of Michigan Press, 2007); Harilyn Rousso, *Don't Call Me Inspirational: A Disabled Feminist Talks Back* (Philadelphia: Temple University Press, 2013); Jenny Morris, "Impairment and Disability: Constructing an Ethics of Care That Promotes Human Rights," *Hypatia* 16, no. 4 (November 1, 2001):

1–16; Jenny Morris, *Pride Against Prejudice: A Personal Politics of Disability* (London: Womens Pr Ltd, 1999).

22. There is literature on how feminists often claim to be working toward eliminating discrimination based on bodily difference, but often exclude women with disabilities. Secondly, some of the following texts also show how debates over selective abortion create conflicts between feminism's advocacy of reproductive choice and disability activism that advocates for the value of disabled lives. Anita Silvers, "Women and Disability," in *Blackwell Companion to Feminist Philosophy*, ed. A. Jaggar and I.M. Young (Oxford: Basil Blackwell Limited, 1998), 330–340; Michelle Fine and Adrienne Asch, *Women with Disabilities: Essays in Psychology, Culture, and Politics* (Temple University Press, 2009). Marsha Saxton, "Why Members of the Disability Community Oppose Prenatal Diagnosis and Selective Abortion," in *Prenatal Testing and Disability Rights*, ed. Erik Parens and Adrienne Asch (Washington D.C.: Georgetown University Press, 2000); Erik Parens and Adrienne Asch, eds., *Prenatal Testing and Disability Rights*, 1st ed. (Georgetown University Press, 2000); Marsha Saxton, "Disability Rights and Selective Abortion," in *The Disability Studies Reader*, ed. Lennard J. Davis, 4th ed. (New York: Routledge, 2013), 87–99.
23. See Hall, *Feminist Disability Studies.*
24. For a literature review and discussion of the state of mothers in disability studies, see Sara Ryan and Katherine Runswick-Cole, "Repositioning Mothers: Mothers, Disabled Children and Disability Studies," *Disability & Society* 23, no. 3 (2008): 199–210.
25. Rosemarie Garland-Thomson, "Integrating Disability, Transforming Feminist Theory," in *Feminist Disability Studies*, ed. Kim Q. Hall (Bloomington: Indiana University Press, 2011), 13–47.
26. Cowan, *More Work for Mother.*
27. Jacquelyn S. Litt, *Medicalized Motherhood: Perspectives from the Lives of African-American and Jewish Women*, 1 edition (New Brunswick, NJ: Rutgers University Press, 2000).
28. In the now classic essay, Langdon Winner articulates how technological objects are embedded and imbued with social meanings: Langdon Winner, "Do Artifacts Have Politics?," *Daedalus* 109, no. 1 (January 1, 1980): 121–136. Actor-network theory (ANT) is also an important theory in STS, which is the idea that technological objects are part of the social network and should be considered

equally alongside social actors. For more on this theoretical tool, see Bruno Latour, *Reassembling the Social: An Introduction to Actor-Network-Theory* (Oxford; New York: Oxford University Press, 2007).

29. Adele E. Clarke et al., *Biomedicalization: Technoscience, Health, and Illness in the U.S.*, 1 edition (Durham, NC: Duke University Press Books, 2010).
30. Nikolas Rose, *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century* (Princeton, NJ: Princeton University Press, 2006); Adele E. Clarke and Janet Shim, "Medicalization and Biomedicalization Revisited: Technoscience and Transformations of Health, Illness and American Medicine," in *Handbook of the Sociology of Health, Illness, and Healing*, ed. Bernice A. Pescosolido et al., Handbooks of Sociology and Social Research (Springer New York, 2011), 173–199.
31. Clarke et al., *Biomedicalization.*
32. Sumi Colligan, "Why the Intersexed Shouldn't Be Fixed: Insights from Queer Theory and Disability Studies," in *Gendering Disability*, ed. Smith, Bonnie and Hutchinson, Beth (New Brunswick: Rutgers University Press, 2004); Ingunn Moser, "Against Normalisation: Subverting Norms of Ability and Disability," *Science as Culture* 9, no. 2 (June 2000): 201–240; Ingunn Moser, "Making Voices': New Media Technologies, Disabilities, and Articulation," in *Digital Media Revisited: Theoretical and Conceptual Innovation in Digital Domains*, ed. Gunnar Liestøl, Andrew Morrison, and Terje Rasmussen (Cambridge, MA: MIT Press, 2003), 491–520; Ingunn Moser, "Disability and the Promises of Technology: Technology, Subjectivity and Embodiment within an Order of the Normal," *Information, Communication & Society* 9, no. 3 (June 1, 2006): 373–395.
33. Kafer, *Feminist, Queer, Crip.*
34. Cowan, *More Work for Mother.*
35. Robert Evans and Harry Collins, "Expertise: From Attribute to Attribution and Back Again," in *The Handbook of Science and Technology Studies*, ed. Edward J. Hackett et al., 3rd ed. (Cambridge, MA: MIT Press, 2008), 609–630.
36. I ask this question in the spirit of Donna Haraway's classic feminist science studies piece articulating the all-important and driving question: Whose knowledge counts? See Donna Haraway, "Situated

Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective," *Feminist Studies* 14, no. 3 (1988): 575.

37. See Margrit Shildrick, "'Why Should Our Bodies End at the Skin?': Embodiment, Boundaries, and Somatechnics," *Hypatia* 30, no. 1 (February 1, 2015): 13–29.
38. See, for example: Rima D. Apple, "Constructing Mothers: Scientific Motherhood in the Nineteenth and Twentieth Centuries," *Social History of Medicine* 8, no. 2 (August 1, 1995): 161–178; Linda M. Blum, "Mother-Blame in the Prozac Nation Raising Kids with Invisible Disabilities," *Gender & Society* 21, no. 2 (April 1, 2007): 202–226; Donald B. Bailey et al., "Family Relations in the Genomic Era: Communicating about Intergenerational Transmission of Risk for Disability: Family Relations in the Genomic Era," *Family Relations* 63, no. 1 (February 2014): 85–100; Linda M. Blum, *Raising Generation Rx: Mothering Kids with Invisible Disabilities in an Age of Inequality* (New York: NYU Press, 2015); Ara Francis, "Stigma in an Era of Medicalisation and Anxious Parenting: How Proximity and Culpability Shape Middle-Class Parents' Experiences of Disgrace," *Sociology of Health & Illness* 34, no. 6 (July 2012): 927–942; Landsman, *Reconstructing Motherhood and Disability in the Age of "Perfect" Babies*; Jacquelyn S. Litt, *Medicalized Motherhood: Perspectives from the Lives of African-American and Jewish Women*, 1 edition (New Brunswick, N.J: Rutgers University Press, 2000); Parens and Asch, *Prenatal Testing and Disability Rights*; Rapp, "Chasing Science"; Rothman, *The Tentative Pregnancy*; Allison Carey, "Parents and Professionals: Parents' Reflections on Professionals, the Support System, and the Family in the Twentieth-Century United States," in *Disability Histories*, ed. Susan Burch and Michael Rembis (Chicago: University of Illinois Press, 2014); Huber et al., "How In-Home Technologies Mediate Caregiving Relationships In Later Life," *International Journal of Human-Computer Interaction* 29, no. 7 (2013): 441–455; Scott S. Hall et al., "Implications of Smart Wear Technology for Family Caregiving Relationships: Focus Group Perceptions," *Social Work in Health Care* 53, no. 9 (October 2014): 994–1014.
39. Ryan and Runswick-Cole, "Repositioning Mothers."
40. Apple, "Constructing Mothers."
41. There is also a recent collection edited by Lewiecki-Wilson and Cellio *Disability and Mothering: Liminal Spaces of Embodied*

Knowledge, 1st Ed, 1st Pr 2011 edition (Syracuse, N.Y: Syracuse University Press, 2011), which focuses on mothering and disability and includes essays on the intersections of technoscience, disability, and mothering.

42. Carey, "Parents and Professionals."
43. Laura Mauldin, *Made to Hear* (Minneapolis: University Of Minnesota Press, 2016); Laura Mauldin, "Precarious Plasticity Neuropolitics, Cochlear Implants, and the Redefinition of Deafness," *Science, Technology & Human Values* 39, no. 1 (January 1, 2014): 130–153.

CHAPTER 7

Inevitable Intersections: Care, Work, and Citizenship

Grace Chang

It has become a truism that US society, like many wealthy societies globally, is facing a “crisis of care,” with a direct care work force of only about 3 million workers currently, and nearly 30 million people projected to need direct care by the year 2040.[1] Thus, there will be a profound gap between those needing care and the workforce that can provide that care, presenting what the National Domestic Workers Alliance calls “a social crisis of immense proportions.”[2] But what constitutes the crisis, beyond the trend that America’s needs for elder care and support services for people with disabilities have surpassed and will continue to outpace the number of workers available to provide this care?[3]

From a labor perspective, we see that poor immigrant women of color predominate in this work that is typically underpaid and hazardous on many levels, with worker abuses common.[4] Yet we also see the abuse of people with disabilities, as consumers and receivers of these care services, as well as their “legalized” exploitation as workers in a variety of sub-minimum wage employment contexts. These settings operate ostensibly to offer “care” or “employment and training” services for people with disabilities, yet often provide neither. They have largely escaped public awareness or criticism

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because of ableism, a lack of other options, and joint corporate and state interests that render people with disabilities vulnerable to abuse and neglect both in and outside the home, under the guise of "care."

At a panel on domestic work and inequalities of race, class, gender, and citizenship, scholar Eva Kittay has observed that caregivers are as vulnerable as those they care for, in the contexts of both unpaid and paid care work.[5] This points to the inverse conclusion that those receiving care services are as vulnerable as those who are caring for them. The lives, struggles, and vulnerabilities of care workers, and the people they provide care services for, are intimately connected in ways that could serve to ally these groups in strength, but often place them both at a disadvantage and at odds with each other instead. While in theory the interests of care workers and care clients should be aligned, in reality in struggles for better wages and conditions, the interests of care workers, who are already disenfranchised as poor, immigrant women of color, can potentially be pitted against the rights of people with disabilities, who also face poverty, social discrimination, and economic exploitation as both workers and consumer citizens.[6]

This dilemma demands that we not only acknowledge such tensions, but also address and transcend them by finding bases of alliance across these communities and movements. Clearly, we must approach discussions of a "crisis of care" from these understandings of the intersections of care, work, and citizenship—encompassing race, class, gender, disability, and immigration status—and how they inform connections between some of the most vulnerable members of society: immigrant women of color and people with disabilities. These groups, as workers and consumers, share exploitative labor conditions and precarious life conditions, linking them in broader social justice struggles that they could potentially wage together. As they organize against the multiple forms of social discrimination and economic exploitation they face daily, we must confront how these groups' interests can align or collide.

These intersections present a number of questions that I argue are at the heart of what I would identify as the true crises of care in our society: (1) How are immigrant women of color and people with disabilities marginalized in society and exploited as workers under similar ideologies, policies, and structures? (2) How are these common vulnerabilities used to pit these groups against each other? (3) What potential alliances could immigrant women of color and people with disabilities engage to resist these divisions and organize for rights, protections, and entitlements from the state in the arenas of care, work, and citizenship?

Crises of Care

"[These cuts] will push us, in our already vulnerable situation, over the edge … I will have to find a job outside of the house and cut back the time spent caring for M.R … Already, I am stretched thin and am living on the margin … I cannot provide more care for no pay when already there are insufficient funds to keep our household afloat."[7]

These were the words of one mother after the governor of Washington State ordered drastic social service budget cuts in 2010, potentially making it impossible for her to continue caring for her adult disabled daughter at home. M.R. was the lead named plaintiff in the case of *M.R. v. Dreyfus*, in which 12 people with disabilities sued Susan Dreyfus, head of the Department of Social and Human Services (DSHS), requesting an injunction on these draconian cuts. Several local organizations partnered with the individuals, arguing the cuts would lead to reduced hours for personal care assistants to provide services such as bathing, toileting, eating, and going to doctor's appointments.[8] The loss of these critical supports would jeopardize not only the health and well-being of people with disabilities, but also their personal autonomy and freedom to live in their own homes. Disability rights advocates across the country proclaimed these cuts could mean the difference between life and liberty at home and a slow death in an institution.

M.R. was described in a declaration on her behalf as a 37-year-old woman with "severe mental retardation [*sic*], daily grand and petite mal seizures, scoliosis, cerebral palsy, hypothyroidism, and mood disorder."[9] She lived with her mother, a registered nurse who assisted her with basic activities of daily life such as eating, toileting, bathing, dressing, medication management, and moving from place to place. M.R.'s mother also gave her medications through a feeding tube and food through it when she refused to eat. While M.R.'s Medicaid waiver made her eligible for full-time institutional care, her mother chose to care for her at home "because her extensive personal care and medical needs are best served [here]."[10] By law, M.R. was entitled to 236 hours per month of in-home personal care services, but M.R.'s mother provided many more unpaid hours of care, as is often the case for family providers.[11]

Even before the budget cuts reduced M.R.'s authorized hours by 9 %, a DSHS assessment had concluded that M.R.'s household was in "crisis mode" and at "serious risk of failure."[12] M.R.'s mother added, "[i]f M.R.'s hours are reduced from their present levels, I will have no other option but to take another job, which will require moving M.R. into an institutional facility. I cannot afford to continue giving services at the rate that I have[.] I have to get an outside job, and I know of no other individual, Adult Family Home or Personal Care Provider who can take care of M.R. due to her medical and behavioral issues."[13] Furthermore, if M.R.'s mother were forced to take another paid job, M.R. would lose not only the original compensated hours of care services, but also the countless (and indeed unaccounted for) unpaid hours that her mother was previously able (albeit perhaps forced) to provide.

The declaration on behalf of M.R. stated that she would likely suffer in an institutional setting, because she has difficulty communicating, is "disruptive and aggressive," "makes unwanted physical contact with others … by trying to hug them or assault them" and thus was previously expelled from two Adult Day Health facilities.[14] In response to M.R.'s declaration, a DSHS program manager who had never met M.R. relied exclusively on the assessment of M.R.'s case manager's statement that they "[did] not believe that the decrease in hours would significantly increase the risk of injury, health deterioration or institutionalization."[15] The Western district court, which ruled against the plaintiffs, ironically stated it was "unable to determine whether the alleged threat of institutionalization [was] the result of the State's reduction in personal care service hours or the deterioration in medical condition" of many of the plaintiffs.[16] Fortunately, the Ninth Circuit Court of Appeals disagreed and found that the plaintiffs need only showed that the reduced care hours could potentially exacerbate the risk of institutionalization, and need not be the exclusive cause.[17] Moreover, the Court of Appeals found that "An ADA plaintiff need not show that institutionalization is 'inevitable' or that [she] has 'no choice' but to submit to institutional care, in order to state a violation of the [ADA]."[18]

The Ninth Circuit Court of Appeals ordered a preliminary injunction to stop implementation of the cuts, a decision the governor threatened to appeal to the US Supreme Court.[19] This alarmed many who feared an erosion of hard-won disability rights gains if the case were to be heard by the much more conservative US Supreme Court.[20] At risk was the "integration mandate," established under the 1990 Americans with Disabilities

Act (ADA) and later reaffirmed in the landmark US Supreme Court case, *Olmstead v. L.C.* (1999), that people with disabilities have the right to services enabling them to live in the "most integrated" community setting possible, instead of institutional living. Disability rights organizers and advocates from around the nation rallied forces to pressure the governor, through calls, letters, op-eds, and protests at the state capitol, not to appeal the decision.[21] In a resounding victory for the disability rights community across the country, the governor announced in October 2012 she would not challenge the lower court's decision in *M.R. v. Dreyfus*.[22]

The significance of *M.R. v. Dreyfus* was more than just the potential disaster averted for the plaintiffs and future users of personal care services in Washington State. The case illustrated how much was at stake for both communities—care workers (whether hired from "outside" or family providers) and people with disabilities receiving care services—who stood to lose or gain much ground together. The proposed budget cuts posed a threat not only to the quality of life and livelihoods of both care providers and care receivers, but also to the entire principle of people with disabilities living integrated in society, made possible by the labor of home care workers and family providers. While the victory in *M.R. v. Dreyfus* may have appeared only to stave off cuts and maintain the status quo, it could have been a drastic lose-lose proposition for both care workers and disabled clients alike, with the greatest and disproportionate impacts on people of color.

One report at the time detailed the disproportionate impacts of the Washington State social service budget cuts on communities of color living in the state, including proposals to cut programs that only served immigrants and refugees.[23] State long-term care (LTC) services had been slashed by 9 %, with particularly deep cuts to home care, which translated into reduced services for over 50,000 people. Of those receiving services, people of color were reportedly 58 % more likely to rely on LTC services than their white counterparts. LTC providers, who are disproportionately people of color, also suffered serious cuts to their work hours, health benefits, and training standards, putting both workers' and consumers' safety at risk.[24] Clearly, cuts to LTC severely jeopardized the quality of life of more than 50,000 people living with a disability or chronic illness, and the livelihoods of thousands of workers whose jobs were at risk and threatened to become even more onerous and hazardous.

Nationwide, the patterns of inequity in terms of gender, race, class, and citizenship are parallel to those in Washington State's home care workforce or even more pronounced, with the home care industry comprised of roughly 2 million workers, the vast majority of whom are women and disproportionately poor, immigrants, and of color.[25] Thus, it is not surprising that home care workers have been effectively excluded from Fair Labor Standards Act (FLSA) protections for more than 40 years through an exemption for so-called companionship workers.[26] While the Labor Department had attempted to right this historic inequity through new federal regulations granting home care workers minimum wage and overtime, Judge Richard Leon of the US District Court for Washington, D.C., ruled to block them just as federal reforms were about to take effect in January 2015. Judge Leon ruled that the Labor Department's revised regulations, by defining companionship too narrowly, were "inconsistent" with the intent of Congress. The Labor Department's rationale was that, through the exemption, Congress had only meant to exclude casual workers performing "elder sitter" services, literally providing not much more than companionship, rather than the kinds of labor that home care workers actually perform in personal care, household, and paramedical services. The court, however, asserted that Congress wrote the exemption with a broader view, motivated by "concern with the ability of their constituents to pay for in-home care on a regular basis."[27] In other words, Judge Leon argued that while Congress may have recognized the value of the services provided by these workers, keeping wages low for these services was of greater concern.[28] This was insult added to injury for home care workers who routinely perform much more strenuous, complex, and often hazardous labor than the label "sitting" or companionship implies, and deserve the commensurate wages and protections they have been excluded from for decades.[29]

These exclusions undoubtedly stem from prevailing public views that such care work, typically done by women, is "unskilled" work that should be offered freely as a "labor of love" in the household, or cheaply by poor women of color typically employed in this work "outside" the home.[30] Many care workers do indeed act out of genuine care, love, and compassion on the job to support the quality of life and independence of their senior and disabled clients. Yet they should not be expected to make sacrifices and provide this care literally at their own expense. I argue that workers may effectively "pay to work" for someone else's care under some conditions, as the following home care workers' testimony reveals:

> I work hard at a demanding job, seven days a week. I save taxpayers money and bring comfort and dignity to a person with a severe disability, yet my family is living in poverty. I work at a for-profit home care company. After five years, I make just $9.15 an hour, with no sick leave and no vacation. It used to be $9 an hour but then the agency told us a raise was coming. It turned out to be 15 cents, which was just humiliating…I love my job. But I am the sole supporter of my family and I'm paid so little that we can't cover our expenses. It's just wrong.[31]

A report by the Paraprofessional Healthcare Institute (PHI), documents that more than half of home care workers earn poverty wages, requiring them to rely on public benefits to supplement their earnings.[32] Two million workers earn average wages of just $9.61 per hour or $1652.92 per month, clearly insufficient to cover rent in many areas of the country, not including utilities, or food, health, and child care expenses.[33] Based on several studies, PHI proposes that raising wages for home care workers could lift millions of poor families out of poverty, reduce public benefit expenditures by billions of dollars, and help to address problems of high turnover rate.[34]

Indeed, scholars and advocates, activists and organizers, have long promoted the notion that improving work conditions and wages for care workers will enhance care for their clients, ultimately benefiting everyone. The ideal is certainly morally appealing, but is often fraught with tensions that pose enduring obstacles for improved quality of life for either care workers or clients. For example, some disability rights advocates argue that if wages for home care workers are raised such that the cost of community-based care exceeds that for institutional care, then the hard-won rights of people with disabilities for independent, community-based living may be threatened. Historically the change from institutionalization to community-based care was largely predicated on an economic rationale of "cost-efficiency," rather than a moral imperative, as journalist Deborah Sontag observes:

> Deinstitutionalization was the result of a struggle to end protracted and unnecessary confinement. It was also a way for states to offload considerable expense to the federal government…Indeed…cost-shifting has been "the major driving force" behind deinstitutionalization, "with the philosophy a tag-on."[35]

While Sontag exposes the mercenary motives behind deinstitutionalization, she perhaps neglects other dimensions of this cost-shifting, not only to the federal government, but to the people who typically provide care in the community and at home. It is often assumed (and the case) that savings captured with the shift to community and home-based care can be achieved by paying immigrant women of color care workers low wages, or absorbed by women caring for family members at home for no wages, as was amply demonstrated in *M.R. v. Dreyfus*. But if these costs have already been shifted to the backs of care workers and family providers, and budget cuts threaten to push people even further to the edge—or over it, as M.R.'s mother said—then complex conflicts and bitter struggles may emerge.

Uneasy Alliances

Joelle Brouner, a long-time disability rights organizer, served as Executive Director of the Washington State Rehabilitation Council in Seattle at the time of *M.R. v. Dreyfus*.[36] As she explains, she has seen from experience that when coalitions are ostensibly built around the concept that better wages and conditions for care workers leads to better quality of care—or what she calls the "trickle-down theory of care"—they often result instead in fraught alliances.[37] Moreover, Brouner says that when Service Employees International Union (SEIU) organized home care workers, and sought to establish wages that she feared might put the price of home care out of the reach of most people with disabilities, or at a level where institutionalization would cost less than in-home care, "it promoted a mentality that we should just go back to institutionalization—and that's a problem, because I choose homecare because it is a matter of my freedom."[38]

David Rolf, President of SEIU Local 775, the home care workers union in Seattle, says that the threat of such a return to institutionalization is very unlikely, adding: "In fact, if you talk to Medicaid directors in all fifty states, they are all measuring their progress by how quickly they are reversing institutionalization."[39] Instead, he says, "It is a far more real threat to figure out how to pay for long-term care and community-based services, which is the model this country and the world are heading towards."[40] He urges: "Ultimately, home care needs to be more expensive than it is in order for people not to be making poverty wages… I don't think it's a secret that there are those, including in the disability community, who want people to continue receiving low wages, with no background checks, and with secret employment situations, etc. because they see it as an issue of their independence and autonomy."[41] On the other hand, Rolf acknowledges that in the past, unions did fight to keep the state mental health institutions of the day open, “to serve their immediate members, and to preserve well-paid existing jobs, versus what were then very low-wage jobs in the community” and suggests, “this is part of where the historical distrust comes from between the disability community and unions.”[42]

These tensions and mistrust often continue to this day, but are not insurmountable, as Bill Hennings, Executive Director of the Boston Center for Independent Living, attests from 30 years of experience as a disability rights activist and manager of human services for people with disabilities.[43] He has worked with a number of unions to close down institutions, including SEIU 1199, a local union of personal care attendants and hospital workers in the Northeast, who not only did not resist them, but also supported their efforts. He says that many people organizing alongside them for disability rights have embraced the idea that it is cheaper to support people in the community than in institutions, and “while true in general, it is predicated on low wages for workers in some settings.”[44] He cautions, however, that promoting this rationale is “dangerous because if the economics don’t play out, then you’ve surrendered the human rights grounds already.”[45]

Hennings also points to several scenarios where people with disabilities face a real threat of institutionalization. For example, he says, younger people with disabilities are being institutionalized at higher rates because there is no affordable housing in Boston, so “if you become disabled, lose your unit, and you have no place to go, that’s where you see institutionalization happen—for people without subsidies, it’s de facto.” Hennings says the average person on SSI would have to pay 120 % of that income just to get reasonably decent housing. In addition, he addresses the potential danger of a “tipping point,” that could occur “when you suddenly up the wages of workers who were formerly paid through Medicaid…and if the government would then start cutting funding to those services, over time we might see an increase in institutionalization.”[46] Hennings adds, “While I haven’t seen it around here, there’s a worry that if they extend the Fair Labor Standards Act (FLSA) provisions for overtime to home care workers, many workers may lose their hours from their regular employers.”[47]

Lydia Edwards, campaign coordinator for the Massachusetts Coalition for Domestic Workers and domestic worker rights attorney, concurs with Hennings that a loss of hours is perhaps the most significant threat to home care workers currently.[48] Edwards has worked hard to build a bridge to the disability rights community, culminating in four independent living centers signing on to the Massachusetts Domestic Worker bill of rights. Edwards suggests that even when better wages or overtime pay has been instituted, workers are often "choosing" to work a longer week, "opting" to forego the overtime because they are afraid they will have their hours cut otherwise. Evidence shows these fears are not irrational: when workers do not "choose" to forego overtime pay they could claim, they often do lose hours. According to a National Employment Law Project (NELP) report, "Home care employers that are required or have voluntarily elected to begin paying overtime have typically found ways to reduce overtime usage."[49]

Stephanie Woodward, Advocacy Director at the Center for Disability Rights in New York, says that this is exactly how people with disabilities living in the community could lose hours of care services and be forced into institutions. Serving as counsel for the National Council on Independent Living (NCIL) and American Disabled for Attendant Programs Today (ADAPT), Woodward authored an Amici Curiae brief supporting the injunction by Judge Leon against the new Department of Labor (DOL) rule.[50] She asserts that when it proposed the new rule, the DOL was well aware that without the funding necessary to pay for these changes, states and home care agencies would cut or cap hours of care available to clients.[51] Thus, while the rule was ostensibly intended to attract and support more attendants in the industry, she argues that it would have the opposite effect by imposing these unfunded costs on state Medicaid programs. She explains that if the rule is implemented, attendant services can be defunded outright by the state or de facto: "The costs associated with this rule have led states to impose caps either actively, by explicitly limiting attendants' hours, or passively, by refusing to reimburse agencies for the additional costs of overtime."[52]

Woodward says that the DOL itself "illustrated how states could contain these costs by capping hours so that attendants could not earn overtime," noting that states and agencies have already indicated plans to follow this advice if the rule is implemented.[53] She suggests "it exposes that there is no real commitment to trying to expand overtime for workers, if they are looking at all these loopholes to avoid paying it."[54] In other words, Woodward argues that the DOL was fully aware when it was attempting to institute these changes that, without the funding to make them viable, there would be grave impacts for both disabled consumers and workers. If Woodward is correct, then the DOL's rule is disingenuous and ineffective policymaking, or benevolent neglect at best. She warns, "The new rule will have the effect of making home and community based services, and with them, the rights of people with disabilities to live in freedom, an option, not a right."[55]

Woodward outlines how certain groups of workers and clients would be most severely affected by the rule, such as Consumer Directed Personal Assistance attendants, because most states currently do not require or allocate state Medicaid funding for overtime pay for CDPA attendants.[56] She highlights that the DOL anticipated and acknowledged these possible impacts, without suggesting viable remedies. For example, the DOL recognized that "a significant overtime compensation issue…associated with 24-hour care" will mean that the effect of the rule will fall most severely on "attendants of those with the most significant need for services."[57] While the DOL proposes agencies can "mitigate these overtime costs by rebalancing workloads or hiring additional attendants," Woodward explains that splitting shifts among several workers leaves "orphan" hours beyond 40 hours that workers generally do not want, especially for clients who need high-level services.[58]

Woodward says, "Nowhere in [the DOL's suggestions] are the needs of consumers for consistent, quality service, and minimal disruption addressed."[59] Gaps in care caused by having to find new attendants can lead to potentially life-threatening conditions such as infections, skin breakdowns, and pneumonia. Moreover, she urges that the ability of disabled people to participate equally in economic and social life "relies on their ability to control the most intimate aspects of their lives, including who sees and touches their naked bodies, who assists them in preparing for sexual activity, and who touches their genitals in the shower and after toileting."[60] People who have developed strong and arguably irreplaceable relationships with attendants who have provided intimate care services for them long term can suffer devastating impacts from disruptions or loss of these services and these relationships.

For example, Shelly, a 50-year-old woman with cerebral palsy impairing her mobility, speech, and ability to perform many daily activities, has worked with the same attendant, Hope, for ten years. Hope works 72 hours per week assisting Shelly with tasks such as transferring in and out of bed, showering, toileting, dressing, eating, and interpreting Shelly's speech. In a declaration on Shelly's behalf, Woodward states "Hope and Shelly have grown so close that they spend holidays together as a family" and Shelly considers Hope a "trusted attendant and friend" who knows her needs, body, and speech.[61] Thus, if Hope's hours were capped, Shelly would have to hire a new attendant, if she can find one, who will not immediately understand Shelly's speech, and she will have to train them how to assist her with these critical and intimate tasks.[62] Also, before securing attendant services enabling her to live in the community, for many years Shelly was institutionalized, where a worker repeatedly physically and sexually assaulted her at age 11. As a sexual violence survivor, she has posttraumatic fears of being alone with men she does not know.[63] This compounds the burden she would face if forced to find a new attendant who could meet her complex needs skillfully and knowledgeably.

The case of Dominick, a disabled transgender man, who has employed the same attendant, Christy, for 13 years, illustrates the importance of trust, safety, and continuity in these relationships to ensure the personal autonomy and bodily integrity of disabled consumers. Christy assists Dominick with tasks such as dressing, showering, toileting, and feeding for 80 hours a week. In a declaration on Dominick's behalf, Woodward states, "Christy and Dominick have grown so close that they are now roommates." If Christy's income were reduced because she was limited to working 40 hours, they could not afford their rent and Dominick would have to find another attendant. Having to seek another attendant to assist him with these intimate daily tasks would force Dominick to reveal his transgender identity to applicants and his private body parts and scars to anyone newly hired. The brief explains: "Hiring a new attendant means allowing a stranger, who does not know him, his needs, or his body, to touch him."[64] Dominick has had the same attendant for 13 years because he knows it may be difficult to find attendants that he feels safe with, since many people are not accepting of transgender people. These concerns are particularly acute in the context that transgender people and people with disabilities are at high risk of violence, often at the hands of caregivers.[65]

Shelly's and Dominick's cases demonstrate the importance of long, sometimes continuous hours of services provided by a consistent attendant, from the perspective of the client. From the standpoint of workers as well, there is a documented need for more hours of work, as the following testimony represents:

> I care for an energetic 87-year-old woman with Alzheimer's disease…It takes love, patience, and understanding to do this job well. It requires organizational skills and a lot of physical strength and hard work. I make $10 an hour, just a dollar over the state minimum wage. No matter how hard

> I try I can never get anywhere near full-time hours, and that still wouldn't be enough…None of us are looking to get rich—we just want to be able to live and support our families like everyone else.[66]

This worker's words attest to the physically, mentally, and emotionally demanding nature of her work, and suggest that she stays in this intensive work in part out of love, care, and compassion, despite the fact that she cannot earn enough to support her own family on these wages or hours. More than half of home care aides work less than full-time, and while workers may have more than one client, it is difficult to string together full-time work.[67] As the PHI reports, half of the home care workforce turns over each year, suggesting "workers leave because they cannot afford to stay."[68] In my view, it seems that the workers can neither afford to stay nor leave, but whether they stay under these poor conditions, or are forced to leave in search of better situations, both they and their clients undoubtedly suffer.

Taken together the perspectives of disabled consumers and home care workers presented here reflect that their interests are actually aligned on the issue of hours. Both groups express the need for more compensated or reimbursed hours to enable attendants to have consistent work and clients to have continuity of care. From a labor perspective, however, accounts of 72- and 80-hour weeks performed by attendants are alarming. Yet the clients, workers, and organizers I interviewed responded collectively to explain how these hours are not only acceptable, but desirable and critical to the intimate services performed and the close ties formed between clients and attendants. Bruce Darling, Executive Director of the Center for Disability Rights and ADAPT member, explained:

> The work isn't like an assembly line job, and we're not talking about post-acute home health care either, which is a highly demanding job on a continuous basis. Our opponents like to mix everything together, but when you are working in LTC and support services, it includes times when the person is sleeping and you might also be sleeping. It's more like a partnership. You spend a lot of time together, you see them naked, you may be preparing them to get ready to have sex.[69]

Darling said we should not view or "pretend this is a detached, professional relationship like any other job because it is much closer than that."[70]

I asked why such explanations are not simply the same rhetoric that employers often invoke to justify paying their domestic workers and nannies so little—insisting "we're really friends" or "they are just like family" to rationalize their exploitation on the basis of close relationships and sentiments they imagine to be mutual.[71] Darling responded persuasively: "The fundamental difference here is the power dynamic—in those cases, the domestic worker has no power in the relationship. Between an attendant service user and an attendant, the power dynamic is entirely different because the consumer is vulnerable and that vulnerability comes into the relationship and levels it." Darling said that the close bonds and genuine mutual concern between care worker and client are real and signify "a different kind of symbiotic relationship."[72]

I witnessed this kind of relationship when I interviewed Jensen Caraballo, disability rights organizer, and Wilfredo Rodriguez, his lifelong friend and attendant for the past three years, while they were traveling and working in Washington, D.C., Caraballo told me, "The reason I'm even here is that Will is here with me. If they cut his hours, I would no longer be able to fight for my rights." Caraballo lived in a nursing home from the age of 15 to 21 and said, "I had to fight really hard to get my attendant services to get out." The county assessed his needs and hours and kept telling him they believed he could not direct his own services so he was repeatedly denied the services enabling him to leave—a damning circular "logic." Caraballo says, "Now I live in my own home, have a job, and can do a whole bunch of things with my attendant services. Without them I would be right back in a nursing home."[73]

Caraballo's friend and attendant Will Rodriguez, said "I've known Jensen my whole life…and became an attendant when he needed me" after leaving the nursing home. "If my hours were capped at 40, he might have to look for another attendant and find someone else even though he is comfortable with me and I know everything he likes." Rodriguez emphasized, "I'm used to 48 hour shifts, and it's hard enough to live on [earnings from those hours] as it is."[74] Caraballo is social media coordinator for the Center for Disability Rights. When he travels for work, it is made possible by his friend and attendant traveling with him. "Any time I go out of town, Will does 72 hours. I rely on him to support my independence," Caraballo said.[75] Currently Rodriguez can be paid through Medicaid to work up to 16 hours a day, or 72 hours a week (up to four 16-hour days and one 8-hour day). So when Caraballo travels for work, he can travel for five days at a time with an attendant, but if those hours are capped at 40, he will only have up to two

16-hour days and 8 hours of services and he cannot bring multiple attendants. If the DOL rule takes effect, Caraballo's ability to travel for work will be extremely limited, especially when traveling to the West Coast, because he will have one day to travel there and one day back, leaving only a half day to actually work there.[76]

At the close of the interview, Caraballo emphasized that his friend and attendant Rodriguez is "also an activist for disability rights," beyond providing the services that support Caraballo to live and work, at home or on the road. Caraballo and Rodriguez traveled to D.C. to attend NCIL's celebration of the 25th anniversary of the ADA and stage a rally at the capital with hundreds of other attendees to urge their congress people to support the Community Integration Act (CIA), a bill requiring any provider of LTC services to provide it in the community. The federal law would address existing loopholes under the ADA and *Olmstead*, mandating that people have an absolute right for community living, regardless of funding streams.[77] In the past, disability rights groups such as Caraballo's staged a takeover of the governor's office in New York, demanding and securing five million dollars as "bridge" funding to pay workers overtime until Judge Leon blocked the DOL rule that would have taken effect in January 2015.[78]

Relationships like Caraballo's and Rodriguez's seem to be at the core of the ethic and practice of groups like ADAPT and NCIL, whose members include both disabled people and attendant workers. Speaking to Caraballo and Rodriguez together convinced me that their unique relationship genuinely embodies the kind of alliance between disabled people and care workers that many have envisioned, called for, or claimed. This shows how the potential for these alliances has been realized both within these groups and individual relationships, and in the kind of radical organizing enabled by them, at work and at home.

But if these examples offer a model, then why have we not seen other alliances like these flourish between care worker unions and disability rights organizations? I argue that disabled consumers and low-wage care workers need to forge coalitions targeting the federal government to demand guaranteed Medicaid funding for better wages and overtime for home care workers. The overtime issue seems to have emerged as a testing ground for these kinds of alliances, but they have not proven sustainable thus far.[79] Clearly, the "win-win" situation envisioned—with coalitions formed around the idea that better wages lead to quality care and better lives for all—has not yet materialized.

Bruce Darling has observed that no one has won during the tumultuous period while overtime protections were instituted through the new DOL rule, then blocked by the courts, and repeatedly subjected to appeal. Instead, he has watched while the lives of care workers and disabled clients have been repeatedly disrupted and thrown into turmoil. He has found that everyone, including workers, consumers, and fiscal intermediaries (such as home care agencies), has been "opting out" of overtime hours of work or services amid this chaos, because of valid fears of losing them long term otherwise.[80] Darling is quick to clarify: "We were fighting for better wages, before this whole overtime [struggle] began. We have always said that attendants need to get the best wages possible—that is a core value to us. The issue is that we must recognize the realities of politics and funding streams, and the negative impacts of these unfunded changes on people with disabilities and on attendants."[81] Darling says that progressives of all stripes have avoided this contentious issue, but "we must contend with it and have these difficult conversations."[82]

Likewise, Lydia Edwards, domestic worker rights attorney and organizer says these are conversations the disability rights community and care workers need to continue. She questions whether "[t]here were other approaches we could have considered, such as making overtime defined so that it kicked in at 45 hours—similar to the New York and Oregon Bill of Rights for domestic workers—or assuring that spouses, family members, etc. doing continuous care had access to state funding. But when you are pitted against each other, you can't have that conversation."[83] Edwards has not given up on these conversations, as she continues to facilitate dialogues between these groups, stressing that these are not theoretical debates on either side: "For people with disabilities, these questions pose a threat to their independence, and that is everything. That is why people are so adamantly fearful of institutionalization—because it is a slow death. If that's the only option, wouldn't you choose to stay at home and give up the overtime [hours of care services]? What would you choose?"[84]

From every angle of this critical question, my discussions with both labor and disability rights organizers come back to the central principle that this should not need to be the "choice," that the human needs, rights, and dignity of care workers should not be pitted against those of the people for whom they provide care services. It is important to emphasize that while the interests of these two groups are not inherently in conflict, they are subject to divide and conquer tactics, precisely because they both occupy vulnerable places in society and precarious places in the labor market. Thus, I will not present a litany of horror stories of abused workers or abused clients within care work or employment situations, although these certainly abound. Instead, I want to highlight the parallel constructions that make poor immigrant women of color and people with disabilities vulnerable to exploitation in similar and interconnected ways.

Myths of the Beneficent State, Magnanimous Employers, and "Nonworkers"

There are glaring similarities in the ways that immigrant women of color and people with disabilities are constructed as those who do not labor or who do not really work. Our society has cast both groups as nonworkers, and arguably noncitizens, in order to exclude them from labor protections historically. I argue that these communities could forge alliances, on the basis of these shared constructions, to fight for these rights and protections as both workers and consumers. Elsewhere, I have discussed the ways in which the labor of immigrant women, prisoners, and workfare workers is not seen as labor but as an opportunity for them to repay imagined debts to society and mitigate the burdens they are presumed to impose on the state.[85] These include welfare and social services that immigrants allegedly steal from "real" citizens; the costs of incarcerating prisoners, though they earn pennies an hour to pay for toiletries, medications, calls, or library use; and the hefty workfare grants that welfare recipients are believed to be getting from the toil of hardworking, tax-paying Americans. The work performed by these groups and their labor conditions are remarkably similar: invisible, unsanitary, hazardous, low or unpaid service or manufacturing work—whether in sweatshops or prisons, cleaning private homes or public buses and parks.

The prevailing ideology is that these workers need not be compensated fairly or at all, since they are not providing labor but receiving charity and redemption. Thus, the state and private employers construct fantastic narratives of providing merciful and magnanimous opportunities to immigrant, prisoner, or workfare workers to justify reaping tremendous profits or savings from the toil of these "nonworkers."[86] This rhetoric also serves to deny these classes of workers standard labor rights and protections enjoyed by other workers, particularly those doing certain kinds of labor, such as domestic work and agriculture. Historically, the exclusion of workers in these industries from labor protections stemmed from the demand by former slave-owners for cheap workers to replace their slaves after emancipation.[87]

Domestic workers, agricultural workers, prisoners, and people with disabilities have all been excluded or "exempted" from the FLSA and other labor protections at one time or currently.[88] Because of these exclusions, people with disabilities have been employed in various settings at sub-minimum wages for decades with measurable benefits for the state and employers, and few benefits if not outright harms to workers.[89] Their exploitation is justified by casting the work they perform as "charity," or "opportunities" offered by magnanimous employers or the beneficent state. They are viewed as learning skills, receiving job training, or just doing something to occupy their time while the state and/or employer is presumably offering the "gifts" of assimilating, or "rehabilitating" them. Thus, as with immigrant women of color, poor people, and prisoners, defining people with disabilities as nonworkers and sub-citizens has enabled their exclusion from labor protections of all kinds, relegating them to a reserve army of labor, alongside these other groups.[90]

An extensive study by the National Disability Rights Network (NDRN) exposes a widespread system of employing people with disabilities at sub-minimum wage, sometimes in "segregated" and "sheltered" workshop settings bearing a striking resemblance to sweatshop, prison, and workfare labor contexts.[91] This segregation facilitates the exploitation of people with disabilities, creating an underclass much like undocumented immigrants—identified as noncitizens, subhuman, and super-exploitable workers, and kept out of sight to hide this neglect and abuse. The "legal" payment of sub-minimum wages under the FLSA exemption effectively condemns them to a life of poverty. Employers pay as little as 10 % of the minimum wage, with most workers earning only 50 %.[92] Wages are set "based on their measured productivity when compared to non-disabled workers performing similar work."[93] In a poignant commentary, one observer provides a damning expose of how immigrant women of color are pitted against disabled people in the wage-setting process. The writer describes how an extraordinarily fast, nondisabled, immigrant woman of color who appeared to be a veteran sweatshop worker was used to inflate the standard:

> I have worked in [a] sheltered workshop. I have seen the very fast Hmong woman without a disability hauled out for every time setting activity. On my best day I couldn't have kept up with her and my fine or gross motor skills are intact. She was the standard all were measured against. It was obvious to us that this artificially lowered client earnings.[94]

The NDRN report dispels the myth that sheltered workshops serve as "job training programs" that teach skills or prepare people to work in competitive, traditional jobs: "They spend their time in day-wasting activities, often practicing assembly skills which will be taken apart by the line supervisor or their peers in order to keep everyone busy…[These] skills are sometimes not even transferable to traditional work because most sheltered workshops do not have modern tools or machinery.[95] Just as with workfare programs, the training ostensibly being provided does not offer real marketable skills.[96] Not surprisingly, then, there are still three people working in segregated day programs for every person working in a competitive employment site, which translates into an economic vulnerability that often affects relations between people with disabilities and their caregivers.[97]

People with disabilities are kept in noncompetitive settings for many years at a time, with staff often evaluating them as not "job ready."[98] As NDRN suggests, since nonprofit agencies under federal contracts are exempt from paying employees the prevailing wage, such contracts create incentives to keep people segregated at these worksites.[99] Staff are motivated to guarantee their own jobs by keeping people with disabilities in these programs, never deeming them ready for competitive employment, and rationalizing this as need for further "training."[100] Employers depend on government funding to subsidize their businesses, profiting or staying in business largely from funds that should benefit people with disabilities directly.[101] Clearly, sheltered workshops are not self-sustaining, but kept afloat by hefty government subsidies, supplementing their minimal contract income by providing government-funded ancillary services, such as "daily living skills training," case management, housing, transportation, and "job-related services."[102] One sheltered workshop generated an annual income of over $11 million, including $6 million from business contracts and $4 million from government funds.[103] NDRN reports, perhaps most outrageously that "the federal Medicaid program heavily funds sheltered work. Ironically, funding largely comes from a program where Congressional intent was to enable individuals with disabilities to access services in community-based instead of segregated settings."[104] Clearly, if we need to cut some programs to fund Medicaid coverage of overtime for home health workers, we might look no further than these sheltered workshop subsidies.

Dependence on Dependency and Profitable Nonprofit

In light of the harms of these programs or, at best, limited benefits to people with disabilities, why are they still so widely in use? Besides obvious benefits to nonprofit and for-profit employers and government agencies, what accounts for their acceptance, if not outright public support? I argue that they are legitimized by long-standing dominant US ideologies about citizenship, work, and independence, deeply embedded in US welfare and disability policy. For example, Congress established the ADA ostensibly on the principle that "unnecessary discrimination" denied people with disabilities "opportunities" for promoting independence, productivity, integration, and inclusion in the community, costing "billions of dollars in unnecessary expenses resulting from *dependency and non-productivity.*"[105] Thus, a primary if not paramount concern was not to end "unnecessary discrimination" against people with disabilities but the "unnecessary expenses" resulting from their presumed subsequent lack of productivity and dependency on the state. Later legislation affirmed that work should be in integrated settings to "allow individuals with disabilities to seek the services necessary *to obtain and retain employment and reduce their dependency on cash benefit programs.*"[106] Thus, the state's vested interest in integrating people with disabilities as full "citizens"—as defined by their workforce participation and productivity—is primarily to reduce their presumed dependence on public benefits.

This rhetoric belies the interests of both government and employers to keep people with disabilities in situations of segregation and "dependency," allowing them to reap savings and profits on the backs of these workers, who are indeed productive by any measure, generating ample rewards for all but themselves. More importantly, the deep entrenchment of these ideologies and the public's belief that these programs promote self-determination, productivity, and independence (or reduced dependence on the state) enables the state to justify subsidizing this exploitation of disabled workers, while failing to provide entitlements or services for them as clients. Indeed, the "clients" (aka workers) in these settings are neither receiving care services, nor being acknowledged as the extremely low-wage workers they are. Meanwhile, the programs theoretically providing care to "clients" are generating income from multiple sources: through government subsidies, through contracts with what we might identify as the true clients—companies employing group home residents or people with disabilities in day programs as contract workers—and finally through fees paid by families who place family members in their "care" as residents or participants. Yet while these programs are promoted as providing "care," they do little more than warehouse people with disabilities and occupy their time generating profits for corporations and nonprofits, and savings for government, as one observer captures perfectly:

> It would be a cold day in hell when I would allow my son or daughter to be financially abused in this way. The workshops are paid by the company that hires them to do the work. That is revenue stream one. The sheltered workshop is a non-profit and not subject to tax as other businesses are. That's revenue stream two. The state or county pays for services to the client… That is revenue stream three. If the workshop is associated with 2nd hand sales of donated goods that's revenue stream four.

This comment demonstrates an acute awareness of the double assaults of predatory capitalism and the neglectful state on people with disabilities as workers and clients. The state fails to provide either care for people with disabilities as consumers or rights and protections for them as workers.

Despite glaring examples of the lack of real services for so-called clients, many people are quick to defend these programs. Executive Director Curtis Decker notes the glaring shortcomings in the current system in the NDRN report's introduction: "Unfortunately, sheltered workshops and the subminimum wage still exist today because of self-interested employers and systematic neglect by federal agencies, buttressed by outdated stereotypes of people with disabilities and the low expectations held by the general public, lawmakers, and, sadly, even some families and the disability rights community."[107] Recently there has been increased exposure and scrutiny of these programs, often leading to calls for their elimination.[108] Yet when federal laws proposed limiting sub-minimum wage and sheltered workshops for youth with disabilities, many people resisted. Some parents argued they were good, safe environments for their sons and daughters with disabilities to spend their days doing "meaningful" activities, earning some money, learning skills, having experiences they might otherwise not have, and getting some basic needs met, including medication, toileting, and feeding. One member of a County Board of Developmental Disabilities in Ohio insists:

> The workshops [offer] employment training and employment… It also provides people with a life. It provides people with a focus… And for families it also provides a respite from that 24-7 responsibility every day.[109]

Similarly, one man whose autistic son worked in a program where people with developmental disabilities cleaned hotel rooms, sewed table linens, assembled auto parts, or answered telephones for less than four dollars an hour, commented: "This has been a godsend."[110] After the Justice Department investigated a program in Rhode Island and ordered the state to find new "rewarding employment" situations for former clients, there was great resistance from parents. As one journalist reported:

> They argued that the workshop's established routine had provided their children with a safe place to be, among friends. 'How will you protect my son from being bullied again? How will you make sure that my daughter isn't ridiculed again?'[111]

These parents' responses to what might have been a welcome remedy to their children's exploitation reflect other competing interests, including their need for respite from caring for their children with disabilities without supports. In organizing to dismantle these programs, Joelle Brouner often encounters this kind of resistance from other disability advocates and parents alike:

> Particularly if a family member is with them all day and isn't working either, they need the respite. They see it as "safe," are assured that no one is getting hurt. And some of them can't imagine what their child or family member would be doing otherwise—so often parents support it.

In other words, the disability industry not only banks on the social service system's self-interest, but also preys on the needs of family caregivers of people with disabilities for respite or alternatives to providing that care themselves.[112] Because it can offer this relief, parents or family members of people with disabilities may be less likely to complain about or view this employment as exploitative—and less inclined to demand other services. Thus, the government capitalizes on these "employment" programs as a stand-in for "care," abdicating its duty to provide social services or entitlements that would truly serve people with disabilities or their families.

Inevitable Intersections

Many parents and advocates are neither satisfied with the "services" nor duped by "employment" programs doubling for "care" and do indeed make demands of the state to provide genuine supports. As one observer commented:

> The reality is there is a tidal wave of young adults with autism about to hit our society. We don't have enough housing for them, much less jobs and job coaches… it was convenient that the notion of honoring the civil rights of people with disabilities also let federal and state governments off the hook for the expense of disabled children. Parents have absorbed all those costs with many incurring major debt they will probably never recover from.[113]

Similarly, one mother described the continual cutbacks in services her adult daughter faced and the slow erosion of what limited resources she had been able to access:

> My daughter has received [vocational rehabilitation] services in the past. She hasn't had any in some time…She couldn't even get her caseworker to answer her phone calls, etc. They stopped paying for her transit, books to go to college… [b]ecause she had to withdraw many semesters due to hospitalizations and illness. If she relied on the government to make people do the right thing for employment and education for persons with disability [*sic*], she would never get anywhere.[114]

Ultimately, this mother lamented: "They're just waiting for the day when she stops asking for help or dies."

These comments share a sharp indictment of how the state and disability industry collude to "let government off the hook" for the welfare of people with disabilities and their families. They also bear a striking resemblance and connection to the testimonies of care workers trying to support themselves and their families, like Liliana Cordero:

> I love what I do. I don't want to go somewhere else because it pays more, considering that my passion is taking care of the elderly. People [say] "Go back to school!" Well, I've been trying to save up to get more training, but I always need the money for something [else] or for the kids. And anyway, you can't teach compassion. That's why we need a raise—so that people like me can afford to do the work we love.[115]

Similarly, Patricia Evans, projecting forward to a time when she will need care, says:

> When it comes to home care workers, you live in poverty. You work in poverty. You retire poor, hoping you will qualify for the services you have provided for so many years to others. Then, you die in poverty. That's just

> not right. We make a real difference in people's lives. We're people of worth. We make a valuable contribution to society, and it's time that our paychecks reflected that.[116]

These testimonies describe in no uncertain terms the crises of care these women face—crises that are not only looming, but already upon them and us as a society. The signs are clear that we must forge the inevitable links between feminist, labor, welfare, immigrant, and disability rights struggles that promise to free us collectively, or threaten to bind us indefinitely in a perpetual divide-and-conquer, no-win state of affairs.

In "Poverty, Welfare Reform and the Meaning of Disability," Jennifer Pokempner and Dorothy Roberts show that having one child or more with a disability is linked with greater poverty in families.[117] They draw from the work of Eva Kittay, who documents how the devaluation of women's care work in and outside the home is especially harmful to families with disabled children, making them particularly vulnerable to exploitation.[118] In *Love's Labor: Essays on Women, Equality and Dependency*, Kittay argues:

> Full social citizenship requires that if we are called upon to care [for a child, family member, or fellow citizen], we can fulfill these duties without losing our ability to care for ourselves, and that in caring for another, the full burden of support as well as care for the one dependent on us will not fall upon our shoulders alone. Without such assurance, we have not yet attained the powers and capacities to function as free and equal citizens.[119]

What would it take for people with disabilities and the immigrant women of color who typically care for them, whether as family providers or care workers in or outside the home, to achieve this free and equal citizenship Kittay envisions? Certainly, immigrant women of color are "always and already" seen as noncitizens, regardless of immigration status—just as disabled people, poor people, and prisoners are seen as sub-citizens. These groups are all viewed by society not as citizens, workers, or consumers but alternately as "charity cases" or "welfare cheats," helpless souls or dangerous menaces to society—thus deserving of only pity, punishment, or rehabilitation instead of fair wages for their "nonlabors." These common constructions bind these groups to each other in perilous ways that obstruct any path to citizenship—legal, metaphorical, or otherwise—and deprive them of freedom through detention, incarceration, institutionalization, or homelessness.

Theoretically, these groups share vulnerabilities that could connect them in common cause, fighting for liberty from these forms of imprisonment, or funding for fair wages and hours for care workers. Yet instead, these groups are susceptible to being pitted against each other, as classes of people who are failed by the state, and classes of workers whose very vulnerabilities are rendered profitable by the market. The crises at hand compel our communities and movements to work together to rally public support and secure resources for care services as guaranteed basic rights and entitlements—not charity, redemption, or respite. Likewise, we need to fight for labor regulations that ensure that care workers can both give and receive care and sustain their lives without forfeiting their own rights to basic needs and protections. Until we do so, some people will always be in jeopardy of sacrificing their own freedom and well-being in order to provide, willingly or not, for someone else's.

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Addendum Since the federal Court of Appeals ruled on August 21, 2015, to uphold the Department of Labor rule extending minimum wage and overtime to home care workers, disability rights advocates such as Stephanie Woodward have reported that "everything that the disability community predicted and feared has come true." Because the rule mandated overtime payment for home care workers without establishing the funding to pay for it, they have seen hours for personal attendant workers being capped or insufficient funding provided to cover the costs. Thus, many people face re-institutionalization when they and their attendants cannot get adequate hours of services or work past 40 hours.

ADAPT members are working to oppose this capping of hours, and have introduced the Disability Integration Act, mandating that attendants be paid competitive wages, offering an incentive for people to enter and stay in the field. For more information, contact: Stephanie Woodward at swoodward@cdrnys.org or see disabilityintegrationact.org.

NOTES

1. Student Labor Action Project, a project of Jobs with Justice, on Caring Across Generations Campaign, http://studentlabor.org/2012/01/23/caring-across-generations/
2. Ibid. and http://justiceinca.rosenbergfound.org/poo-butler.php
3. Paul K. Sonn, Catherine K. Ruckelshaus, and Sarah Leberstein, National Employment Law Project (NELP) report, "Fair Pay for Home Care Workers: Reforming the U.S. Department of Labor's Companionship Regulations Under the Fair Labor Standards Act," August 2011, p. 20.
4. Ai-jen Poo with Ariane Conrad, *The Age of Dignity: Preparing for the Elder Boom in a Changing America,* New York: New Press, 2015; Evelyn Nakano Glenn, *Forced to Care: Coercion and Caregiving in America*, Cambridge: Harvard University Press, March 2012; Eileen Boris and Jennifer Klein, Caring for America: Home Health Workers in the Shadow of the Welfare State, Oxford University Press, April 2012; Grace Chang, Disposable Domestics: Immigrant Women Workers in the Global Economy, Cambridge: South End Press, 2000.
5. National Domestic Workers Alliance Conference, "Justice in the Home: Domestic Work Past, Present, and Future," October 17, 2014, Barnard University.
6. For the purposes of this chapter, I make an artificial division between immigrants/people of color and people with disabilities, but recognize that many people occupy all of these identities at once and experience xenophobia, racism and ableism. In addition, people with disabilities who are undocumented immigrants, or family members who care for them, cannot access or benefit from programs such as In Home Support Services (IHSS) as either consumers or care workers.
7. *M.R. v. Dreyfus*, Order Amending Opinion and Denying Rehearing and Amended Opinion, June 18, 2012, Filed December 16, 2011, p. 6995.
8. ARC of Washington, SEIU 775NW; Puget Sound Alliance for Retired Americans.
9. M.R. v. Dreyfus, Order June 18, 2012, p. 6994.
10. Ibid., p. 6995.
11. Ibid.
12. Ibid.
13. Ibid., p. 6996.

14. Ibid.
15. Ibid.
16. Ibid., p. 6997.
17. Ibid., p. 7002.
18. Ibid., p. 7009.
19. Toshio Meronek, "Disability Advocates, Nursing Home Industry Battle for Health Care Dollars for Aging, Disabled," *Truthout*, April 28, 2013.
20. David Lord, "Advocate surge squelches Olmstead threat," Op Ed, *Disability Rights Washington*, 10/22/2012, http://www.disabilityrightswa.org
21. See Lord, p. 3, for organization names.
22. Meronek, Lord.
23. Jill Mangaliman, "The Color of Cuts: The Disproportionate Impact of Budget Cuts on Communities of Color in Washington State," March 5, 2011, p. 5 and 11.
24. Ibid. In Washington, 26 % of home care workers are people of color, while the overall percentage of people of color living in Washington State is 18 %. White people were the majority of SEIU 775 membership, 73 % of the home care workforce, and 82 % of the state's population.
25. Michelle Chen, "Judge Rules That Home Care Workers Are Really Just 'Companions.'" The Nation, January 16, 2015. https://www.thenation.com/blog/195273/judge-rules-home-care-workers-are-really-justcompanions
26. A 1974 amendment extended FLSA overtime and minimum wage protections to domestic workers for the first time, but in the process exempted baby sitters and those who provide "companionship services to the elderly or disabled." NELP, p. 3.
27. Ibid.
28. Ibid.
29. PHI, "Paying the Price: How Poverty Wages Undermine Home Care in America," p. 9. See also, NELP report, p. 5.
30. Eighty-nine percent of home care workers are women, and more than half are people of color, and one in four is an immigrant to the U.S., PHI, p. 9.
31. PHI, p. 2, Roxanne Trigg of Milwaukee, Wisconsin.
32. Moreover, these calculations are based on full-time work, when unpredictable and part-time hours are the norm. PHI, p. 5.

33. Ibid.
34. PHI, p. 6. In all 50 states, the living wage for a two-person household is nearly double the median wage of a home care worker [EN 5 of PHI, p. 5]. A California study showed that increasing hourly wages to $14 would save the state over $5 billion per year, "in part because workers would no longer need to supplement their incomes with public benefits." EN 7 of PHI, p.6 citing Zabin, C., Dube, A., Jacobs, K. (2004). The hidden public costs of low wage jobs in California. The State of California Labor, Vol. 4, pp. 3–44. Available at: http://escholarship.org/uc/item/9hb1k75c#page-2
35. Deborah Sontag, "A Schizophrenic, a Slain Worker, Troubling Questions," *New York Times,* June 16, 2011.
36. She is currently Director of the Division of Vocational Rehabilitation in Colorado.
37. Interview with Joelle Brouner, June 23, 2011, by telephone.
38. Ibid.
39. Interview with David Rolf, February 9, 2015, by telephone. He is also Vice President of SEIU International.
40. Ibid.
41. Ibid.
42. Ibid.
43. Interview with Bill Hennings, June 9, 2014.
44. Ibid.
45. Ibid.
46. Ibid.
47. Ibid.
48. Interview with Lydia Edwards, June 6, 2014.
49. Sonn, Ruckelshaus, Leberstein (NELP), 17.
50. BRIEF FOR ADAPT AND THE NATIONAL COUNCIL ON INDEPENDENT LIVING AS AMICI CURIAE SUPPORTING APPELLEES in HOME CARE ASSOCIATION OF AMERICA, et al., Plaintiffs-Appellees, v. DAVID WEIL, Administrator of the Wage and Hour Division, U.S. Department of Labor, et al., Defendants-Appellants. ON APPEAL FROM THE UNITED STATES DISTRICT COURT FOR THE DISTRICT OF COLUMBIA, April 6, 2015. [hereafter referred to as "Brief"].
51. Interview with Stephanie Woodward, July 19, 2015, by phone.
52. Brief, p. 8.

53. 76 Fed. Reg. 81190, 81226. Brief, p. 4; Brief, pp. 13–14.
54. Interview with Stephanie Woodward, Washington, DC, July 26, 2015.
55. Brief, p. 5.
56. Veterans and those with minority languages, and living in rural, tribal settings. Brief, pp. 19–23; CDPA programs are self-directed Medicaid services in which the disabled consumer has "employer authority" or personal choice and control over how and by whom their services are provided, through their own recruiting, hiring, training, and supervision of their attendants, p. 7 of brief; citing PHI, "Which States Provide Minimum Wage and Overtime to Home Care Workers?" (Oct. 2011).
57. 78 Fed. Reg. 60,454, 60,528.
58. Id. at 60,528–560,530; Interview July 26, 2015 and Brief, p. 18.
59. 78 Fed. Reg. 60,528–560,530. Cited p. 13.
60. Brief, P. 23.
61. Ibid., p. 17.
62. Ibid., 18.
63. Ibid., 28.
64. Ibid., 27–28.
65. Rebecca L. Stotzer, Violence Against Transgender People: A Review of United States Data (May 2009), cited in Amici Curiae brief on behalf of ADAPT and NCIL, 23–24; In 2011, women with disabilities experienced violence at three times the rate of women without disabilities and disabled men experienced violence at twice the rate of nondisabled men. Ericka Herrell, U.S. Dep't of Justice, *Crime Against Persons with Disabilities, 2009–2011—Statistical Tables* (Dec. 2012); Trish Erwin, *Intimate and Caregiver Violence Against Women with Disabilities* (July 2000); Laurie E. Powers and Mary Oschwald, *Violence and Abuse Against People with Disabilities: Experiences, Barriers and Prevention Strategies,* cited in Amici Curiae brief, 27–28.
66. PHI, p. 1, Theresa King of Los Angeles.
67. Ibid.
68. Ibid.
69. Interview with Bruce Darling, Washington, DC, July 27, 2015.
70. Ibid.
71. Chang, p. 167–168, 170–171, citing Sau-ling Wong, Mary Romero, Rosanna Hertz; see also Judith Rollins.

72. Darling, July 27, 2015.
73. Interview with Jensen Caraballo and Wilfredo Rodriguez, Washington, DC, July 26, 2015.
74. Ibid.
75. Ibid.
76. Brief, p. 26.
77. Interviews with Stephanie Woodward, July 26, 2015, and Bruce Darling, July 27, 2015.
78. Ibid.
79. Liza Kaufman Hogan, "How to Solve the Looming Care Deficit," March 12, 2015, http://www.nextavenue.org/how-solve-looming-care-deficit/ and Tim Wheat, Boulder ADAPT, "ADAPT Confronts Tom Perez and SEIU: People with disabilities are angry Labor rules will force Americans into institutions," http://www.adapt.org/freeourpeople/30years/report04.php
80. Interview with Bruce Darling, July 27, 2015.
81. Ibid.
82. Ibid.
83. Interview with Lydia Edwards, June 6, 2014.
84. Ibid.
85. Chang, 155–189.
86. Ibid.
87. My co-panelists and I discussed this history at the "Organizing in the Shadow of Slavery: Domestic Workers, Farm Workers and Low Wage Workers in the South" Workshop, US Social Forum, June 30, 2007; See Excluded Workers Congress at http://www.domesticworkers.org/news/2011/excluded-workers-congress-reimagining-right-organize and Domestic Workers United and DataCenter, "Home Is Where the Work Is: Inside New York's Domestic Work Industry," July 14, 2006; see also Kim Gilmore, "Slavery and Prison: Understanding the Connections," Social Justice: Journal of Crime, Conflict and World Order, Vol. 27 No. 3 (2000) and Chang, pp. 73–76 on denial of public assistance to black women in order to compel them to work in agriculture and domestic service.
88. The 13th amendment of the U.S. constitution abolished slavery "except as a punishment for crime." Gilmore (2000).
89. Section 14(c) of the FLSA authorizes employers, after receiving a certificate from the Wage and Hour Division, to pay "special" minimum wages, less than the Federal minimum wage, to workers with physical or mental disabilities. See http://www.dol.gov/whd/regs/compliance/whdfs39.pdf

90. Harlan Hahn cites Gough (1979: 25–26), who expands Marx's idea of the industrial reserve army to include not only the unemployed, but other "marginal groups like the disabled, the seasonally employed, those displaced from previous modes of production (like peasants), immigrants … and housewives." Harlan Hahn, "Advertising the Acceptably Employable Image: Disability and Capitalism," *Policy Studies Journal*, vol. 15, No. 3, March 1987, 551.
91. A sheltered workshop is a segregated facility employing only (or primarily) people with disabilities, usually in an institutional setting where "participants" have little or no contact with non-disabled people besides paid staff. [U.S. Department of Justice (DOJ) Report on United States' Title II ADA Investigation of Employment, Vocational, and Day Services for Persons with Intellectual and Developmental Disabilities in Rhode Island, (Washington, D.C.: January 6, 2014), 8]; National Disability Rights Network (NDRN), "Segregated and Exploited: The Failure of the Disability Service System to Provide Quality Work," Washington, D.C.: 2011.
92. NDRN, 8–9.
93. For example, when workers would usually be compensated at minimum wage of $8.00 per hour, a disabled worker in a sheltered workshop determined to be "half as productive as a non-disabled worker" would earn $4.00 per hour. [§ 214(c)(2)(A), cited in DOJ report, p. 8, footnote 11].
94. Michelle Diament, "Feds Take Aim at Sheltered Workshops," *Disability Scoop*, April 14, 2015 http://www.disabilityscoop.com/2015/04/14/feds-aim-shelteredworkshops/20216/
95. NDRN, 32, citing Alberto Migliore, et al. "Why do adults with intellectual disabilities work in sheltered workshops?" 28 Journal of Vocational Rehabilitation 29, 6, 29–40.
96. Chang, 161–163.
97. NDRN, 8.
98. Ibid., 33.
99. Ibid., 18.
100. NDRN, 33–34; see also DOJ, 26.
101. Ibid., 35, footnote 79, citing Government Accountability Office, "Special Minimum Wage Programs: Centers offer Employment and Support Services to Workers With Disabilities, But Labor Should Improve Oversight," GAO-01-886 (Sept. 2001), at 4, GAO-01-886, http://www.gao.gov/new.items/d01886.pdf
102. Ibid., 35, footnote 81, GAO.

103. Ibid., 36–38. Government funding sources include Medicaid, Vocational Rehabilitation, Social Services Block Grants and state and local taxes.
104. P. 36. Employment related services, i.e. building skills needed to become or stay employed, billed as “pre-vocational services,” are reimbursed under Medicaid through Home and Community-Based Services Waivers. PL 109–171. Section 6086, 1915c, endnote 82; Leveraging Medicaid: A Guide to Using Medicaid Financing in Supportive Housing. http://www.tacinc.org/downloads/Pubs/Medicaid-Final-July10.pdf, endnote 86.
105. 42 U.S.C. § 12101(a)(8); NDRN,15.
106. Ticket to Work and Work Incentives Improvement Act of 1999 P.L. 106–170 §2(b)(4).
107. NDRN, 3.
108. Michelle Diament, “Obama Signs Law Limiting Sheltered Workshop Eligibility,” July 22, 2014. http://www.disabilityscoop.com/2014/07/22/obama-law-limitingsheltered/19538/; see John Hrabe, “Goodwill’s Charity Racket: CEOs Earn Top Dollar, Workers Paid Less Than Minimum Wage,” *Huffington Post*, September 25, 2012.
109. Jill Riepenhoff, Far Below Minimum Wage, The Columbus Dispatch, August 1, 2011.
110. Ibid.
111. “A Couple Gaining Independence, and Finding a Bond,” Dan Barry, NYT, October 5, 2014, p. A1.
112. See Paul Longmore, *Why I Burned My book and Other Essays on Disability*, Philadelphia: Temple University Press, 2003, 220.
113. Diament, April 14, 2015.
114. Ibid.
115. PHI, p. 6.
116. Ibid., p. 18.
117. Jennifer Pokempner and Dorothy Roberts, “Poverty, Welfare Reform and the Meaning of Disability,” *Ohio State Law Journal*, Vol. 62 (2001), 20–23.
118. Eva Kittay, *Love’s Labor: Essays on Women, Equality and Dependency* (New York: Routledge, 1999), 117, cited in Pokempner and Roberts, footnote 87.
119. Ibid., 131.

CHAPTER 8

Reclaiming the Sexual Rights of LGBTQ People with Attendant Care Dependent Mobility Impairments

Les Gallo-Silver, David Bimbi, and Michael Rembis

In modern American society, sexual expression is a personal behavior often conflated with other "forbidden" subjects that involve genitals, masturbation, and nudity. Discomfort with the subject of sex and sexual activity contrasts with American consumer society's plethora of sexualized images, its eroticization of people (women and children, for example), food ("food porn"), and violence ("torture porn"), and its fetishization of consumer goods (e.g. automobiles, home appliances, and clothing). This mixture of sexual approbation and salacious voyeurism, combined with long-standing prejudice against people with disabilities, results in

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the sexual disenfranchisement of people with varied impairments that an ambivalent and often intolerant society defines as not only abnormal, but also sexually undesirable or repulsive.[1]

In this chapter, we utilize a combination of literature review and secondary data analysis to explore the sexual experiences of lesbian, gay, bisexual, transgender, or queer (LGBTQ) people with mobility impairments who rely on attendant care services in their homes, usually provided by paid staff or family members. By engaging in a close reading of a few cases, and situating those cases within the relevant literature emerging from the applied fields and disability studies, we are able to identify the salient barriers of ableist and heterosexist attitudes to the human right to sexual expression. In addition, we give voice to those LGBTQ people who have successfully negotiated interdependent sex lives facilitated by both paid and family caregivers. We must never lose sight of the multiple oppressions and daily violence experienced by LGBTQ disabled people. Yet, we also need to take the time to consider those stories in which disabled people and their caregivers interact in mostly compassionate and understanding ways, working together to achieve an interdependent way of empowering disabled people sexually.

For many people with attendant care dependent (ACD) mobility impairments due to spinal cord injury, cardiovascular accidents (CVA, stroke), cerebral palsy, spinal bifida, muscular dystrophy, multiple sclerosis, post-polio syndrome and other conditions, sexual expression and activity are aspects of meaningful living.[2] The paternalistic and often segregating social service and rehabilitation communities continue the pre-ADA sexual disenfranchisement of people with disabilities without partners who are LGBTQ, which poses significant challenges to the quality of their lives. Constraints on the sexual expression of people with mobility impairments continue to exist in many chronic care facilities, nursing homes, some group homes, and in more "traditional" familial and household settings.

Current studies estimate that there are 2.7 million noninstitutionalized users of wheeled mobility devices in the United States, of which 810,000 use powered wheelchairs. While the use of powered wheelchairs does not necessarily correlate with attendant care dependence, it may be an indicator of global mobility impairment. A recent Gallup Poll reports that 3.4 % of adults in the United States identifies as LGBT (the "queer" designation was not used). This translates into a possible population of LGBT people with ACD mobility impairment at potentially 27,540 people (of the estimated 54 million people with disabilities in United States).[3] Those

LGBTQ people with disabilities who require attendant care services usually live in home or community settings. Although they represent a fraction of the overall disabled population, the stories and experiences of LGBTQ people with disabilities are critically important to work in disability studies and in larger movements for social justice, because in some respects they are representative of the experiences of the majority disabled population, at least in Western or Global North countries. As disability studies scholar David Mitchell has argued (with Sharon Snyder) in his most recent book (2015), in many ways all "crips" are indeed "queer." Following Robert McRuer and others, Mitchell argues that a potent disability studies critique requires the formation of "crip/queer," "nonnormative positivisms" that draw their content and their theoretical and political heft from the embodied experiences of disabled people.[4] Our intent is not to discount or negate the many acts of violence visited upon the bodies of LGBTQ people by blurring those experiences into a majority "disabled experience." Rather, we explore LGBTQ experiences (as well as those of other disabled people) to build the "social fund of knowledge about disability" that Rayna Rapp and Faye Ginsburg argue is "foundational to the integration of disability into everyday life."[5] Telling the stories of the sexual experiences of LGBTQ people with disabilities opens up an important practical and theoretical space that builds on the insights of Mitchell and others by engaging in a dialectical and relational analysis of caregiving in this important context.

For many LGBTQ people living with attendant care dependent mobility impairments, simply finding a sexual partner can be difficult, many remain "partnerless." For LGBTQ people living at home, their partnerless status may be the result of prejudices among LGBTQ individuals who have the same ideas of what constitutes a beautiful and desirable body as the wider society and culture. LGBTQ people with mobility impairments, especially those who rely on attendant care, have an array of stigmas related to their disability, sexual minority status, and dependence that have a chilling effect on access to meeting partners during in-person social situations.[6] One quandary (for both the disabled person and their potential partner) may arise if their potential sexual partner is non- or less-physically disabled and needs to perform the care regularly provided by an attendant. Negotiating whether that care will take place for the most part before the couple meets to engage in sexual activity, or whether the non- or less-physically disabled sexual partner will perform that care can become problematic. Personal hygiene, bodily maintenance, and preparation for sexual activity take on heightened visibility and importance in a relationship when one is dependent upon attendant care services. If both participants are attendant care dependent, this can, in some ways, be liberating because there is, relatively speaking, no period of adjustment (to having a sexual partner with mobility impairment) required. However, it can be emotionally draining because the couple needs to discuss the roles of their respective attendants before each encounter, and they must deal with the presence of third parties in extremely intimate settings. For some lesbian-, gay-, or queer-identified people multiple sexual and facilitating participants, whatever their role, may cause little or no stress, but for others it can be stressful. Even things that people on the "dating scene" and many couples take for granted, such as eating a meal together or having a drink together, may require negotiation or the assistance of the prospective sexual partner whether non- or less-physically disabled. All of these factors may cause problems within the relationship. The places where a couple can engage in sexual activity and things as seemingly fundamental as body positioning might also be things that the prospective sexual partners would need to discuss in order to manage a successful and fulfilling encounter for both partners.[7]

Difficulty in finding a suitable sexual partner may leave many LGBTQ people with disabilities asking unspoken and unanswered questions such as: Who would want me? How can I meet people? And how do I manage my own sexual arousal? Independent living and disability rights advocates recognize that sexual activity sustains quality of life, creates feelings of well-being, diminishes fatigue and legitimates the adulthood of a population that is at risk of infantilization.[8] Yet they often have a difficult time convincing researchers and the general public to respect—and in many cases, even to recognize—the sexuality and sexual practices of people with disabilities, making it difficult for the latter to find answers to their questions. Disabled people in general, and especially LGBTQ people with ACD mobility impairments have received little attention both from society and in the literature. There are, however, some theories that have emerged concerning the (lack of) sexual experiences of people who are non- or less-physically disabled that also apply to ACD LGBTQ people. The theories have mostly been used to define "in clinical terms" people's relationship to their own sexuality and to their bodies regardless of disability. Researchers have created a category they call "sexual avoidance" and another called "sexual anorexia." Sexual avoidance states that the person fears sexual contact with others due to concerns about safety, desirability, and/or performance, but the person does continue to masturbate, suggesting the presence of sexual desires and urges. Sexual anorexia, on the other hand, states that the person does not have thoughts or fantasies about sex, his/her body is unresponsive to sexual stimulation, and the person does not masturbate. Both sexual avoidance and sexual anorexia when experienced by people with disabilities can be rooted in the profound lack of privacy experienced by people with ACD mobility impairments, something that affects all people with disabilities to varying degrees. This lack of privacy, combined with the need for basic assistance with intimate bodily functions such as toileting and bathing, may actually be the major barriers to LGBTQ people with ACD mobility impairments having more or any sex with others, not the perceived "problems" with "sexual functioning" that many researchers cite in their work.[9]

Researchers, and society more generally continue to promote an inadequate and ultimately unhealthy understanding of human sexuality that continues to focus on the functional aspects of the sexual response and less on an individual's needs for intimate connection to others.[10] Rather than an ableist focus on the mobility impairment's effect on the person's genital functioning or the linear Phases of Human Sexual Response, rehabilitation programs and professionals, as well as the general public, need to be more aware of the fact that the body is highly adaptable, and sensual.[11] Sensuality is the pleasurable response to feelings, thoughts, sensory perceptions, and physical stimuli. Sensuality focuses on warmth, texture, scent, taste, and relaxation of muscle tension, all of which can be a prelude to sexual release.[12] Any type of touch has sensual and erotic potential. Culture, life experiences, faith based beliefs, gender, and sexual orientation identify what is sensual, which parts of the body are erogenous, and in what ways excitement is acceptable. All areas of the body respond to sensual touch and have a potential for erotic pleasure, including those areas that have supposedly been "injured."

Lydia is one example of someone with a disability exploring her own sensuality. Lydia was in her thirties when a gunshot wound severed her spine. Since that time, she has lived in her own home with an attendant. Her sexual experiences are, we suspect, common among many people with disabilities, especially those who use attendant care workers. In an interview with researchers, Lydia recalled: "I was taught to use an electric toothbrush, and as luck would have it, I found out that if I could manage to hold the electric toothbrush near my clit, it felt good. I felt a familiar sensation in my lips and forehead that I associated with getting-off.

The issue for me was, getting my attendant to attach the electric toothbrush to my hand, without tooth paste and help me with positioning myself to enjoy it the most." Lydia had found a way to be sexual, now she needed to act on her desires.

Lydia decided to take control of the situation. She realized that she did not have to be explicit about why she wanted a separate electric toothbrush, her laptop with assistive technology (to use her audio enhanced Lesbian erotica e-books), or privacy for the use of both. After all, she reasoned, this was her body and her home attendant. *Lilly worked for her.* If she had privacy when having a bowel movement, why not for other reasons as well. In this way, Lydia added masturbation to her nighttime routine. The specifics of her fantasies and self-stimulation routine were not part of the negotiation with her home attendant. Rather, Lydia understood that the close relationship she and Lilly shared did not require a discussion of these details. They talked about many things, and Lydia shared stories about the women she loved and Lilly shared similar information about the men in her life. Yet the pair, tacitly or otherwise, decided to draw a distinct line between what they considered public and private knowledge. Lilly never commented on the Lesbian erotica Lydia read. There were no questions or explanations, and the lack of discussion, in this instance, was respect of Lydia's privacy to masturbate as she pleased. The interpersonal nature of caregiving/care receiving relationships, the mutual respect, and the level of emotional intimacy that develops in many of these relationships, provides an environment for reclaiming one's sexual rights without disrespecting or exploiting either person.[13]

In a world filled with stories of abuse, neglect, and confrontation, Lydia and Lilly's story reveals a counter-narrative of empowerment through interdependence and mutual respect. No doubt Lydia and Lilly's relationship is shot through with subtle slights, daily negotiations, and thinly veiled critique disguised as playful banter. And we cannot deny the social and structural embeddedness of both Lydia and Lilly. As Grace Chang's chapter in this volume reveals, people with disabilities and their attendant care workers may not and perhaps will not always agree on some fundamental issues, such as labor organizing and disability rights. Yet theirs is a relationship that can help us redefine the interconnectedness we all feel on a daily basis. Care work is both dynamic and reciprocal. We are all givers and receivers of care, often simultaneously. Being cared for and caring for others are not discrete stages that one passes through during their lifetime. Care is ongoing, a constant presence in all of our lives. Maintaining these relationships of care requires vigilance and mutual respect. In Lydia and Lilly's case, each took great care to respect one another's boundaries and support one another when needed. This mutual caring relationship in turn enabled Lydia to experience the sensual pleasures of her body in new ways.

As Lydia's story reveals, for the person with mobility impairments, many areas of the body remain responsive to touch. Any sensual experiences can be and often are eroticized, and despite what some researchers might say, the person with ACD mobility impairments has sexual thoughts, fantasies, and needs regardless of the functioning of various parts of their body. The nature of one's thoughts, fantasies, and needs whether focused on opposite sex, same sex, or intersexed partners, do not change the body's pleasurable physiological responses, which are more accurately portrayed by the cyclical understanding of the human sexual response.[14] This understanding of human sexual response recognizes the impact of emotions, connections, and relationships on the body's sexual functioning. This model helps clinicians and those working in the applied fields to describe the ways in which people with ACD mobility impairments of any sexual orientation can cultivate, retain, and rebuild a sense of themselves as sexual beings.[15]

Despite more "person-centered," holistic thinking among some professionals, there remains a serious deficit in the education and practice of sexual rehabilitation of LGBTQ people with ACD mobility impairments.[16] Any person that requires acute in-patient rehabilitation due to the severity of their impairments must rely on their own personal resources following discharge from rehabilitation facilities into the care of family or paid caregivers, or a combination of both, if they wish to educate and empower themselves sexually.[17] If they are fortunate, or more likely diligent enough, they form what Rapp and Ginsburg call "mediated kinship" networks with other disabled people and allies. Through these networks, they share their thoughts, opinions, advice, and experiences. They provide support and community—care—to their fellow kin. Yet, there remain LGBTQ people with disabilities who deny and withdraw from their sexuality and sexual needs; this is true for the majority disabled population as well. This retreat from their own sexuality can be exacerbated if family members and paid caregivers pretend to ignore due to embarrassment or confusion any glimmer of sexual responsiveness in the recipients of their care. Because of the stigma associated with disability and especially disabled sexuality, and because of the often fraught power relations within families and relations of paid caregiving, people with ACD mobility impairments can also find signs that they remain sexual beings equally embarrassing, creating a feedback loop with family and other care providers that ultimately reinforces the negation of their own sexuality.[18]

For LGBTQ people with ACD mobility impairments, signs of embarrassment and even shame may arise particularly when working with paid caregivers. If one "private pays" a caregiver or is able to recruit their own paid caregiver under public medical insurance programs for people with "multiple medical problems," then one plausibly could discuss one's sexual issues and concerns. Often though, people do not have access to these programs and they do not have the financial means to pay privately, and therefore they need to rely on the state and use home care companies that have rules and policies that may preclude, prohibit, or recommend avoiding discussions of sexuality and sexual activity. The sexual abuse of people with disabilities often is the justification for the anti-sexual expression stance of agencies supplying attendants.[19] The end result of these policies for many people with disabilities is the emergence of a powerful taboo that hangs over any discussions or expressions of their own sexuality, giving rise to feelings of shame and guilt that are difficult to dislodge once they have been internalized.

The challenge for some LGBTQ people with ACD mobility impairments without partners is exploring the sensual and sexual potentialities of their bodies with minimal assistance. Boyd, who came out to his parents when he was 14 years old, describes his journey to regain his sexual in(ter)dependence after experiencing a stroke at age 17. "I was 14 when I told my dad I was Gay. It was a relief because I was so afraid my dad would find my gay porn zines. But he was great and focused on safe sex. He left me alone when friends visited even though most of them were straight and I was not going to have sex while my dad was home anyway," Boyd recalled. At age 17, Boyd survived a massive stroke. Since the stroke and following his discharge from the rehabilitation hospital, his parents became his caregivers. Boyd, who spoke with difficulty, continued physical and occupational therapies at home, while continuing to need personal assistance with bathing and toileting. His father became his primary caregiver. Boyd remembers that, "After the stroke things changed, I was a little kid again, needing help with everything." Initially, Boyd experienced feelings of shame around his sexuality. Boyd experienced erections when being bathed and because of this became unwilling to take a bath at all. Thereafter, Boyd determined that if his bedding was twisted around his torso, he could rub himself against it to orgasm, and that if he had an orgasm, he did not have an erection when bathed. He seemed to have found the perfect solution to his sexual "problems." But where, when, and how would he find the privacy to masturbate?

By accident, his father walked in on Boyd masturbating in his bed, as Boyd had little privacy in his home. His father left Boyd's bedroom quickly. Later in the day, Boyd apologized to his father but was also very angry that he had such little privacy. The ensuing frank conversation negotiated more privacy for Boyd, as well as acceptance of his right and need for sexual release. Boyd later recalled, "He caught me one day trying to jerk off. I had a long talk with my dad and told him nothing has changed, I am still Gay and still horny. I told him that I learned that if my bed sheet twisted around me in a certain way, I could rub one out but needed help to get the sheet in the right position. He turned bright red but he did it and it became part of our routine." Following further negotiation with his dad, the two reached a mutual agreement that enabled Boyd to experience his own sexuality. The stage was set for exploration of what Boyd could enjoy rather than having to depend on the random positioning of his bedding. In addition to masturbating in bed, Boyd felt empowered to return to using his sex toys and computer to access Gay erotica. Computer technology enables some people with disabilities to participate in virtual mutual masturbation (cybersex), and identify potential face-to-face partners. For the LGBTQ person with mobility impairments who may be unable to find accessible social environments to meet potential partners or who prefers online sites as a way to meet people, the Internet diminishes social and sexual isolation, while maintaining a certain level of privacy and independence. Using a computer with assistive technology, Boyd obtained sex accessories that approximated different types of sexual activities. Some of these would need his father (as caregiver) to position them appropriately. Others, Boyd could use on his own. Soon, Boyd was having potential sexual partners visit him in his home. "Oh," Boyd recalled, "and I had to get over myself and get used to fooling around with guys with my parents at home."[20]

Boyd's experience living at home and relying on family for care in the wake of the onset of disability is not uncommon. Nor is his strong desire to reclaim his own sexuality. Questions about sex and sexuality are most often the first questions asked by newly disabled people. Privacy was paramount for Boyd. Like many other disabled people with ACD mobility impairments, Boyd was unable to explore his sexual potential due to lack of privacy. Yet, through the serendipitous twisting of bedding, and clothing, he became reacquainted with the sensual and the related sexual potential and responses of his body. Paradoxically, the privacy Boyd required—privacy which would be considered an unquestioned human right in most other situations—could only be achieved through interdependence. Instead of denying the sensual and sexual pleasure he experienced, as he had initially done during bathing, Boyd spoke out and took control of his sexual life by directing his care. He spoke directly to his father/caregiver, making his desires and his limitations known. The proactive and interdependent solutions that arose from these frank conversations focused on remedying Boyd's dilemma through assisted sexual activity where the caregiver enables a person with ACD mobility impairments to enjoy masturbation through body positioning or the use of sexual toys/accessories.[21] Though the caregiver is part of the process and often shares an intimate caregiving relationship with the disabled person, they do not necessarily participate in the sexual activity itself. The caregiver, though, assists in any needed setup, positioning, and cleanup once the sexual activity is completed.[22] Boyd successfully negotiated a caregiving relationship that empowered him sexually and respected those individuals providing his care. This is not always the case, and often LGBTQ people with attendant care dependent mobility impairments are left asking questions.

How do I meet people? How do I experiment with a variety of sensually stimulating activities? How do I obtain assistance from a caregiver, especially from one who might be either embarrassed or outraged by the notion that the object of their care is a sexual being, regardless of one's sexual orientation? How do I find a new caregiver when the need arises? How do I broach the topic of sex and sexuality with each new caregiver? And how do I negotiate my own care when I am deeply embedded in an ableist health- and home care system? These questions are further complicated by a series of LGBTQ concerns, such as: coming/being out to the attendant and attendant's supervising home care company/organization, and as an oppressed sexual minority, fears of overt and covert hostility and rejection. The result often is the disabled individual's sexual withdrawal, avoidance, and in many cases socially imposed abstinence. As the stories of Lydia and Boyd indicate, however, there are disabled people, including LGBTQ people with mobility impairments, who work to reclaim their sexual rights in proactive ways using self-advocacy along with problem-solving skills.[23] This translates into an interactive and interdependent caregiving relationship that includes soothing caregiver discomfort, establishing boundaried personal care, determining the sensations that are pleasurable, accessing erotica, sex accessories/toys, and negotiating/developing an assisted sex protocol. This relationship of care is not possible without empowering disabled people to advocate on their own behalf and solve their own problems.

Silence on the part of some people with ACD mobility impairments about their sexual needs, ensures that those needs will go unmet. While people may feel justified to enjoy sexual activity with a partner, there is considerably less entitlement to enjoy masturbation. This is a socially constructed issue with its roots in historical, cultural, faith based, and familial taboos. The taboo remains strong even though masturbation is widely practiced by the vast majority of adolescents and adults with and without partners, of any sexual orientation, gender, with or without impairments.[24] Masturbation (also referred to as self-stimulation and self-pleasuring) is the primary sexual activity for people without partners, including those with disabilities. The nature and extent of mobility impairments can be an obstacle to masturbation. Self-advocacy with family, paid caregivers, and professionals about claiming one's right to masturbate is a bold, but necessary skill for many disabled people to learn and use. Discussions about sex often are difficult but without communication, there is little likelihood of successful problem solving. While the vast majority of LGBTQ people with ACD mobility impairments have successfully negotiated sexual issues those who are not out about their sexuality may find the "Self-Advocacy and Problem-Solving Protocol" helpful.[25] The best instructors of successfully resolving issues of sexual expression are people who live the experience of negotiating with caregivers and have achieved ways to express and enjoy their sexuality, like Lydia and Boyd.

Issues that involve family caregivers are often more complex because of the specific boundary issues that affect the typical intimacy and physical interaction between family members. While parents may be accepting of their child's sexual orientation that does not mean that they are comfortable with them as sexual beings and unlike Boyd's father may believe involvement in this part of their child's life is inappropriate. Parents, that are part of a caregiver team for their adult child, emotionally tend to revert to when their child needed help with personal care in infancy and early childhood. Using this model, parents may tend to "ignore" their son's erect penis or their daughters erotic innuendoes. For some disabled men, their penis becomes erect during the catheterization process. Some men with mobility impairments can self-catheterize; others are unable to and need the process entirely or partially performed by a caregiver. Similarly, a man with ACD mobility impairments that does not directly affect the penis' functioning can experience an erection during assisted bathing. During either instance, the erection may not disappear immediately after catheterization or bathing, presenting an inopportune development, or conversely an opportunity for self-stimulation. For Boyd, one turned into the other; an inopportune development (becoming erect when being bathed) resulted in increased opportunities for self-stimulation and ultimately partnered sexual activities, but not until after frank negotiations and conversations with his family/caregivers.

Other sensual experiences arise more serendipitously and when facilitated through interdependence can become pleasurable sexual experiences. Natalya, a woman with progressive post-polio syndrome, demonstrates both the difficulties people with attendant care dependent mobility impairments face in maintaining sexual relationships, and the eventual reclamation and enjoyment of sexual pleasure that can be experienced through interdependence and mutual understanding. Natalya, who had lived "independently" using braces and canes until she reached her thirties, began to lose functioning in her arms and legs. She found that her girlfriend could not cope with her increasing needs for personal care and obtained a part time attendant. Nevertheless, her girlfriend left when it became apparent that Natalya would need a powered wheelchair. Natalya was heartbroken to be abandoned, yet she was also resilient and a survivor since first contracting polio at five years of age. Natalya obtained an attendant who bathed her using a manual shower wheelchair and massaging showerhead in her new "wet" bathroom (a tiled bathroom with a drain in the floor and a shower massage attachment). The size of the "wet" bathroom meant that there often was not a convenient place to set the showerhead, and occasionally the attendant placed it in Natalya's lap while soaping her up with a washcloth. The longer the shower massage sat in Natalya's lap, the more stimulated she became. Natalya feared but also wanted a full-on orgasm, but not with her attendant present. One day, much to Natalya's surprise, the attendant said, "You seem to really like the shower massage in your lap, maybe I could give you some privacy to enjoy it." From then on, bathing included privacy and an opportunity to masturbate with the shower massage in her lap pulsating on her pubic area. As Natalya felt more sexual, she became interested in meeting a new partner with a disability.[26]

Thus far, we have encountered people with attendant care dependent mobility impairments who have had relatively successful experiences negotiating their sexual interdependence. In many cases, conflict and confrontation are necessary for people to secure their sexual rights from the group of people with immediate power over them and a more general power over a cultures' definition of "acceptable" or "normal" behavior. LGBTQ people with ACD mobility issues have the right to know if the company that provides their home health aide or attendant provides LGBTQ sensitivity training and has overall LGBTQ affirmative policies. At age 38, Tom needed to break in another attendant. "I had many home health aides but my newest one thought homosexuality was a sin," Tom recalled. This belief was, of course, unacceptable to Tom. He was used to training new attendant care workers in accommodating his sexual needs, but this was something clearly different. As Tom put it in an interview, "I did not mind starting over to educate an attendant about the help I needed to masturbate but this new one wanted me to repent." Tom took action: "I called the agency and told them that it was against my civil rights to have an attendant tell me I am a sinner." Fortunately, for Tom, the agency listened to him and honored his request to have a new attendant care worker sent to his home; a change that turned out to be better than even Tom had expected. "They sent me someone new, who turned out to be Gay," Tom explained to his interviewer. "I am not sure the agency actually knew this. Me, and the new aide settled into a routine that was comfortable for both of us." Tom pushed the envelope and claimed parity of rights with other oppressed groups even though that was not specifically so under the law of his state at the time, as this incident predated the inclusion of sexual minorities as a protected group under federal law for programs receiving federal funding. Not all disabled people are as bold or outspoken as Tom. Self-advocacy skills can be taught or acquired through disabled kinship networks, but using them requires self-acceptance, self-love, and self-esteem, as well as the support of and extended and often mediated kinship network.[27]

For the transgendered person with ACD mobility impairment, the building of caregiver/care receiver relationships that include assistance with sexual expression can be especially difficult and require significant amounts of instruction. Sexuality and gender do not follow binary constructions. Yet paid nonfamily caregivers and some family-member caregivers steeped in dominant heteronormative culture, and trained in a medical-model of disability and sexuality that teaches that people are male or female, gay or heterosexual, assume that the objects of their care are (biological) "men" or "women," with all of the attendant cultural trappings.[28] Louisa, age 30, recalls her experience of educating caregivers to her trans identity in a matter-of-fact way. “I was born with a male body but I am a woman and lived my life as a woman since I was 18,” she conveyed to her interviewer. When she became disabled, this changed momentarily: “I was in an accident, they brought me to the hospital and I had to contend with being a sir and Mr.” She took it upon herself to educate her caregivers. “In rehab I needed to do the whole thing [educate my caregivers] over again.” Louisa’s difficulties did not end when she got home: “Finally,” she recalled, “I get home but now have to contend with the home care program, and because of my needs I get an LPN (licensed practical nurse). Actually I am considered lucky because most people don’t have medical coverage for an LPN.” Although it is difficult to discern the level of resistance, if any, on the part of the home health care agency, ultimately Louisa was successful in having her care providers recognize her trans identity. “By that time [unclear when],” she explained, “my paperwork finally describes me as trans and that my name is Louisa, not Louis. I have to be catheterized, I can’t do it myself and I did not have bottom surgery, so … Once I explained things to my nurse, she was cool with all of it and she treats me like a lady. I need a little help from her with setting up my computer so I can enjoy porn, and cybersex, she puts a condom on me but then she leaves me to it until I’m done.” In Louisa’s house, Louisa is a woman, addressed as a woman, dressed like a woman, and respected as a woman. She is not defined by having a penis.

All LGBTQ people with disabilities have sexual rights and need to be able to express themselves and enjoy themselves. The necessary environment requires respecting the person’s rights to engage in private sexual activity to improve their well-being and quality of life. For many disabled people, this often involves self-advocacy and problem solving, skills that require a certain sense of agency among LGBTQ people with ACD mobility impairments, which because of societal stigmas and other pressures many of them find difficult to cultivate. Yet agency, and sex and sexuality are crucial aspects of overall mental health and quality of life that must not only be recognized and respected, but sought after by disabled people and their caregivers. The sexual rights of people with ACD mobility impairments or any other type of impairments are part of the human/civil rights of all people. For LGBTQ people with ACD mobility impairments, confronting the multiple negative ableist and heterosexist constructions of disability and sexuality is an important component of the maintenance of self-esteem and the attainment of sexual interdependence. For many people with mobility impairments, the ultimate goal is to have a sexual partner. Sexual rehabilitation research indicates that a person becomes a more attractive sexual partner if that person is first in-touch with, aware of, and enjoying their own body. For others, masturbation is their preference rather than partnered sexual activity. Rather than explore the reasons for one choice or the other, it is more important for all LGBTQ people with ACD mobility impairments to make their own choices and be in charge of their own sexual lives. Recounting the stories of Lydia, Boyd, Natalya, Tom, and Louisa moves us one step closer to empowering all people with disabilities.

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CHAPTER 9

"Everybody Has Different Levels of Why They Are Here": Deconstructing Domestication in the Nursing Home Setting

Katie Aubrecht and Janice Keefe

This chapter examines how assumptions about dementia mediate social understandings of the nursing home and organize relations between the people who live in it. It analyzes how dementia is imagined as an opportunity to affirm the legitimacy of social orders that privilege capacity and frame the meaning of personhood from the perspective of the "rational subject." Although the analysis is guided by psychologist Tom Kitwood's theory of the person in dementia care, which promotes recognition of individuals with dementia as persons first, it questions how the normative values that shape recognition of personhood "level" the lived experience of dementia.[1] This chapter considers how this leveling is accomplished in at least two ways within the nursing home setting: by a flattening of the multiple and contested meanings and experiences of dementia and by ways of relating to dementia that treat dementia as an occasion for people

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without dementia to reflect on and reaffirm their place within the natural order of personal relations and interpersonal hierarchies. Our analysis uses a disability studies perspective to deconstruct the relationship between personhood and domestication, as this relationship has been made to appear in interviews with nursing home residents.

Dementia, a Discourse of Vulnerability

Historically, dementia has been regarded as a social, rather than medical, problem. Psychologists Alexander Kurz and Nicola Lautenschlager assert, "[F]rom the earliest of times dementia has been associated with reduced civic and legal competence on the one hand, but with entitlement to support and protection on the other."[2] While this may be the case, a public health perspective shapes current entitlements and supports for individuals with dementia diagnoses and their family and friend caregivers. A public health perspective on dementia, as embodied in the 2015 Organization for Economic Co-operation and Development (OECD) report *Addressing Dementia: The OECD Response* and the 2012 World Health Organization (WHO) and Alzheimer's Disease International report *Dementia: A Public Health Priority*, represents dementia as a global economic and social burden that, as a result of global population aging, can only be expected to get worse.[3] This is illustrated in the opening paragraph of the OECD report, which frames the OECD's position on dementia as a debilitating condition of dependency and disability, a global cost with a negative value equivalent to the positive value of a prosperous Western country:

> Dementia is a debilitating condition for which there is currently no cure. As the condition progresses, those affected can be left dependent on others for support in their daily lives. The human and financial costs of dementia are of a worrying magnitude. Globally, it is the second largest cause of disability among those over the age of 70, with an estimated 44 million people living with dementia worldwide. In terms of financial burden, the global cost of dementia is well over half a trillion US dollars each year—roughly equal to the GDP of Switzerland.[4]

The proposed solution to the social and economic consequences of the projected exponential increase in the prevalence of dementia consists of globally coordinated national dementia strategies. Eight countries currently have strategies for dementia in place: Australia (2005), Denmark

(2010), England (2009), France (2008), Norway (2011), Scotland (2010), United States (updated 2014), and Wales (2011).

Within Canada, the focus of this chapter, there is currently no national strategy for dementia and no consensus concerning effective treatment.[5] However, efforts are currently underway in support of the development of a national dementia strategy by the federal government in consultation with the provinces. Strategic policy documents addressing dementia have been released in Alberta (2002 and updated in 2015), British Columbia (2012), Manitoba (2001), Newfoundland and Labrador (2001), Ontario (1999), Quebec (2009), Saskatchewan (2004), and one was recently released in Nova Scotia (2015). Within these strategies, a person-centered approach to dementia care is promoted. Person-centered dementia care is an emerging paradigm widely understood as having great potential to improve the lives of individuals with dementia diagnoses by privileging personhood over the disease process.[6] The expressed aim of person-centered dementia care is to individualize treatment to meet the needs and preferences of the person living with dementia through the use of a biographical approach centered upon the person, rather than the disease. In his influential text *Dementia Reconsidered: The Person Comes First*, Tom Kitwood prioritizes the person via text, capitalizing each letter in the word "PERSON" and creating a visible distance between the "PERSON" and the all lower-case lettered word "dementia" using a dash, "PERSON-with-dementia."[7] A biographic approach uses the "life stories" of the person with dementia as a basis for care planning and as resources that can be used to encourage healthcare practitioners and residential care staff to perceive individuals living with dementia *as people*, with experiences, needs, and preferences—as a "self."[8] While person-centered dementia care is promising in its aims, it has been critiqued on the grounds that its underlying concept of personhood has yet to be fully clarified and empirically developed.[9]

Western research communities and news media share daily reminders of the rising global prevalence of Alzheimer's disease and related dementias, and the projected burden that care for older adults living with dementia places on everyone. For example, some projections suggest that as many as one in 85 people will have Alzheimer's by the year 2050.[10] On their website, "Dementia Numbers in Canada," the Alzheimer Society Canada states that "in 2011, 747,000 Canadians were living with Alzheimer's disease and other dementias—that's 14.9 per cent of Canadians 65 and older. By 2031, if nothing changes in Canada, this figure will increase to 1.4 million."[11] Typically, representations of dementia as a "global problem" are situated within a discourse of population aging, which depicts old age as a threat to national prosperity, and a danger to the health and well-being of older adults' families and communities. According to Ron Brookmeyer et al., "As a proportion, prevalence does not imply the risk or probability of a person becoming affected by the disease in question. Instead, prevalence portrays the potential burden—for care, services, and other things—that the disease places on the population."[12] As compelling as the projections are, they may reveal as much as, if not more, about contemporary social ideals and political objectives, which view dementia as a social "burden" that can be "overcome" largely through an increasing medicalization of eldercare driven by neoliberal market forces.[13]

Within current political and economic systems, modalities of care, including regimes of self-care, are marketed and purchased. For example, Andrew Lakoff advises that information regarding the increasing prevalence of psychiatric conditions should not be interpreted solely from the perspective of medical science.[14] For Lakoff, "What is being constituted through numbers [of those labeled with psychiatric conditions], in this case, is not a population of living beings with certain biological regularities, but rather a market of consumers characterized by purchasing trends."[15] While information on age- and disease-based projections plays a vital role in health and social services research and policy, it is important to bear in mind that such information is produced and circulated within Western sociopolitical and economic milieus that privilege a market mentality, and that sell this mentality through, among other things, the promotion of an eldercare system capable of supporting and even enhancing the health, well-being, and "quality of life" of individuals, while at the same time maximizing the efficiency of health and social systems, reducing labor costs, and increasing profit margins.[16]

There are many ways of knowing, talking about, and treating dementia. Although commonly thought of as a disease, and routinely confused with Alzheimer's disease, dementia is better understood as a collection of symptoms. This, when considered with the fact that there are at least 45, and some suggest 70, different manifestations or types of dementia, has led many professional educational advocacy groups such as Alzheimer's Disease International to define dementia as an umbrella term.[17] The lived experience of dementia has been compartmentalized and broken up into different stages, or levels, with capacity and competence being perceived as possibly impaired but still preserved in "early-stage" dementia, and less so in moderate or late-stage dementia (terms used to characterize the majority of older adults living with dementia in nursing homes). And yet this staged conceptualization of dementia is itself problematic and does not hold true for all types of dementia or even all individuals identified as living with any one type of dementia. Questions remain concerning the ambiguity and uncertainty with which dementia is diagnosed.

Local, national, and global dementia strategies advocate pre-screening for dementia, with the caveats that there is currently no known cure for dementia, and that a lack of capacity and effective coordination in dementia-specific research, policy, and practice can present barriers to effective care in response to early diagnosis.[18] The increasing emphasis in social and health policy on pre-screening for dementia and cognitive impairment in older adults provides the impression that the diagnosis of dementia and related cognitive impairment is easily done, despite the heterogeneity of dementia. David Le Couteur et al. are suspicious of what they refer to as the "political drive" to initiate pre-screening due to the lack of evidence to support good outcomes.[19] They caution that the expected benefits of a policy focus on dementia that emphasizes services and research, such as an ability to plan for the future and seek early treatment, typically in the form of pharmacological treatments, may not outweigh potential harms, including misdiagnosis/overdiagnosis. The result is a distorted understanding of the actual prevalence of dementia, and unnecessary interventions that may produce adverse side effects and outcomes, and lead to a diversion of resources and support from the people who need it most.[20]

Within Canada, there is increasing recognition of the problematic use of psychopharmaceuticals as "chemical restraints" in nursing home care, and particularly, of antipsychotic medications prescribed despite widespread awareness of "black box" warnings and research that displays evidence of poor outcomes and increased mortality.[21] A provincially commissioned report notes that over a two-month period, over 50 percent of nursing home residents in British Columbia were prescribed antipsychotic medications, many of which were atypical, or second-generation major tranquilizers and neuroleptics, which may not have received regulatory approval for use in older adults with dementia and which are described as more effective in treatment-resistant patients.[22] In 2005, Health Canada reported that when taken by people with dementia, the side effects of drugs such as Risperdal are fatal and include stroke, heart failure/irregular heartbeat, and pneumonia, all of which are conditions that are routinely attributed to an unfortunate consequence of aging for older adults, particularly those with chronic conditions that may or may not include dementia or other cognitive impairment.[23] Such drugs are routinely prescribed and administered without the full understanding and consent of residents and their families, and while such drugs may be perceived as acceptable for use in "extreme cases" in which a perceived "high level of care" is required, the reality is that the exception is becoming the rule. This practice known as "polypharmacy" involves the use of medications that are not clinically indicated, that are used inappropriately, that lead to adverse reactions, such as death; and that can produce the very symptoms that are used to justify the need for treatment.[24]

Within North American nursing home settings residents with dementia are often positioned in ways that can diminish their authority to refuse medication. This positioning occurs at the symbolic level, by way of infantilizing language that strips the person living with dementia of the insight to exercise control over their own care; as well as materially and physically, insofar as people living with dementia within nursing home settings also live within the present reality or constant threat of physical segregation within dementia care units. Even in the absence of segregated dementia care units, nursing homes are themselves segregated spaces (what Goffman refers to as "total institutions") that create physical and communicative barriers between the people who live there and those who live in the "outside world."[25] Considering the fact that up to 80 percent of people living in nursing homes in Canada are viewed as living with some form of dementia, the real and present danger of physical segregation could be interpreted as a mode of regulating and policing resistance to pharmacological treatment regimes within nursing home populations, greatly diminishing the autonomy of aging populations and contributing to the ultimate negation of their personhood.

In many cases, communication plays a fundamental role in the elimination of nursing home residents' capacity for personhood. Stripped of capacity and competence, the right to informed consent for residents with cognitive impairment is often revoked through a "de-authorization of personhood," or positioning of the individual outside of knowledge exchange and as an object of care. This rhetorical (and often quite literal) repositioning of nursing home residents is justified on the grounds of perceived or lived impairment. The term *perceived impairment* refers to processes of pathologization of residents' refusal or resistance to medication as a sign or symptom of cognitive or behavior disorder. *Lived impairment*, on the other hand, references a disjuncture in communication between the prescriber and resident, such that the resident is neither fully informed nor consulted regarding the treatment decision due to the expectation that the resident will make a nonautonomous or "an incompetently made choice."[26] In the first situation, a resident with cognitive impairment (dementia) is socially constructed as lacking the capacity to give voice to experience and speak out or against care. In situations of lived impairment, care is communicated in a way that fails to recognize and engage embodied difference from the perspective of the individual living with cognitive impairment. Perceived and lived impairment overlap. This overlapping, moreover, undergirds discourses of vulnerability that dominate current understandings of informed consent. Without dismissing the lived realities of cognitive decline, or the real and potential vulnerability of this population to exploitation and abuse, it is important to examine how assumptions about choice authorize the privilege and power of normative embodiment.

The remainder of this chapter further develops the meaning of capacity within the context of dementia care in nursing homes by way of an analysis of interviews with residents conducted as part of a Nova Scotia-based provincial research study (ca. 2011–2014) that assessed the impact of models of care on resident quality of life.

Deconstructing Domesticity in the Nursing Home Setting

Currently within Canada and across North America and much of the westernized world, "nursing homes," or long-term residential care facilities, provide the primary domicile for an increasing number of older adults with multiple and complex care needs that cannot be met at home or in other community-based settings, due to lack of adequate and accessible social, interpersonal, and individual supports and services. Older adults make up the majority of nursing home populations; however, young adults whose care needs cannot be met within home- and community-based settings may also be residents. According to a 2010 report by the Canadian Institute for Health Information (CIHI), three in five people aged 65 and older receiving publicly funded residential care had a diagnosis of Alzheimer's disease and/or other dementias, which as we have shown can often be a vague and capacious but ultimately powerful diagnoses.[27]

For this chapter, we have conducted a secondary data analysis of interviews from the *Care and Construction: Assessing Differences in Nursing Home Models of Care on Resident Quality of Life* project with the aim of examining the conceptualization of the person with dementia within current approaches to dementia care in the nursing home environment. A tension between situating dementia as an intersubjective relation, a significant connection experienced by and between people, and as the routinized task of documenting lived and felt experiences, often involving the creation of voluminous written documents—texts—animated the discussions researchers initiated with residents, their family members, and nursing home staff. The tension between dementia as relational and dementia as documentable, embodied, and experiential stemmed from contradictory assumptions about persons living with dementia that treated them as unique individuals with values, preferences, and life stories and as objects of care. The notion of the PERSON-with-dementia as *work*, as a site of effort and labor performed to fulfill a moral purpose, reconciled this tension. Residents "without" dementia described their co-residence with residents "with" dementia as work, both in the sense of "bed and body work" and "person work."[28] Where "person work" is intersubjective and prioritizes self-actualization through interrelationships, "bed and body work" describes a task-oriented form of medical custodial care that is informed by the intensification of labor and the assumption that dementia is a debilitating condition that cannot be cured and can only be expected to get worse. Residents shared accounts of the work involved in making others appear within public spaces in the everyday life of the nursing home. Imagining and articulating personhood within the context of dementia as performance made it possible for residents to imagine and articulate themselves as moral actors, and the nursing home as already and potentially more than a place of beds and bodies. But it did so by scripting the resident with dementia as a passive recipient of personhood.

Transcripts were critical in constructing the dementia patient. They, among other things, displayed residents' negotiations of the meaning and significance of the affective work involved in the routinized performance of domestic life within the nursing home. Some descriptions of work revealed a desire to bear witness to the precarity of life from an "insider's perspective" in ways that promoted the participation of the most marginalized members of nursing home communities. This was expressed by one nursing home resident study participant in terms that related the experience of co-residence to that of "family":

> Even though it's a small family now, it's a very close one and we do relate well in here. Sometimes you have to work at it because everybody has

> different levels of why they are here—I have to make the best of it, or I am just here sort of thing—and we had this in our own house. And if they don't feel well or they have something which is not going to get any better or it is going to get worse, you still have to be a bit upbeat with them, otherwise it, they can't change their own feelings about themselves or anything else and … some of them won't get any better, and they will get worse and of course you see them move to other floors and what not, and that's not something you see when you are outside.

Working at maintaining their "small family" is important to nursing home residents. So much so that they take great care to maintain comforting and supportive relationships with them, noting that they remain "upbeat," especially for those family members who "won't get any better," and "will get worse."

Data analysis informed by social philosophical understandings of personhood has revealed an interesting contradiction in how preference is understood within nursing home settings: residents cannot fully realize preferences because of feelings of responsibility/accountability to other residents similar to those described above, and in other accounts as well. One resident discusses playing cards even though it is not her preference, on the grounds that she "knows" that if she does not, it will likely negatively impact the quality of life of the other residents with whom she lives. The decision to play cards is framed as more than a question of "saving face" or "impression management."[29] It rather evidences resident awareness of the need to appear happy and to participate in group activities, considering the reality that within this setting people one once shared their life with are going to "other floors" and are not going to get any better. Within this setting, hierarchically divided by levels that materialize in the form of other floors, resident personhood is achieved through actions that recognize and reach out to other residents recognized as on their way up, or down, or out.

Within the interviews, residents identified doing things they did not want to do out of a sense of commitment to a shared community with other people that were not immediate friends or family. Responses revealed a sense of kinship tempered with a trace of remorse. They claimed to know that things were not going to get better, at least not in terms of normative understandings of "progress." The ways residents reconciled the factual reality of separation and decline displayed recognition of proximity to illness and death (if not in the immediacy of their own lives through their co-residence with other people who do or might or could soon have dementia). The residents' testimony raises the issue of how such a regulated space as the nursing home can be inhabited, and recognizing this opens radical possibilities for rethinking the kind of world in which nursing homes are not just possible, but ordinary.

And yet, the fullness of life does not appear through the negation of other residents. Rather, life is made significant through a reaching out to them. Kitwood describes this within the context of dementia care in terms of a "journeying out toward the other."[30] Co-residence comes to mean so much more than merely living with or living through or even living for another person. Co-residence becomes a question of living toward one another, a movement out of oneself toward becoming otherwise. This journey involves a process of self-recognition in which one becomes other, and also more than someone in need, to someone whose presence is needed. Recognizing oneself as needed does not negate the reality of one's own needs; if anything, it can make those needs more real, more visible, tangible, objective, and more intensely experienced. Journey as experience and analytic construct can reveal the interconnected nature of needs as lived and felt by people who share a common domicile. Interpreting nursing home residents' stories, gestures, and interactions as expressions of a desire to reach out and to recognize themselves as people who are not only in need but also people who are needed can offer a powerful counternarrative to the at times reductive understandings of successful living (i.e., appearing happy, healthy, and well) at the heart of neoliberal regimes of "positive aging." It can also create space to dwell with the social significance of the appearance of interpersonal anguish as a productive force within nursing home settings in need of further understanding, rather than a sign of an individual with a problem and in need of medication.

Interview transcripts provoke questions concerning the kin networks that both structure and enliven nursing home settings. As Donna Haraway reminds us, "there are all kinds of unconscious processes and solidarities at work that aren't about choice."[31] The residents that were interviewed described reaching out to other residents, their neighbors, and strangers, as a form of domestic duty and a routinized household activity that created a sense of community within an environment that had transience built into its design, an environment that anticipates regular arrivals and departures, much like a hotel.[32] The construction and concomitant treatment of the "resident in need"—of care, compassion, empathetic understanding, and most importantly, other residents—is used to create a sense of intimacy within the space of the nursing home. This also creates a sense that the nursing home is a home, or thinking with Gaston Bachelard, a sense that the nursing home is an object of human dignity and thus holds a legitimate presence in the "human" community. Even if it may not always, nor ever, be experienced as home by one and all, it is a space of creation, a product of socially oriented action, and a site and scene of homemaking.

Not surprisingly, there is a distinctly gendered dimension to homemaking in the nursing home setting. This form of care that reaches out toward the co-resident, the neighbor, the stranger, this transformative process that both extends and encloses, and that does so in response to perceptions of a shared precarity of being, feminizes and infantilizes the people who live in nursing homes. It recalls patriarchal assumptions about a hierarchical "natural order of things" that (de)legitimizes authority on the grounds of the demonstrable presence or absence of (white, bourgeois, masculinist) reason. Disability studies scholar, Robert McRuer remarks that "able-bodiedness … still largely masquerades as a nonidentity, as the natural order of things."[33] Displaying one's capacity, by acting and being "reasonable," involves recognizing that natural order and asserting one's place within it.

Nursing homes are situated within, and informed by, broader historical, social, economic, cultural, and political contexts. Life in nursing homes in Canada is shaped by neoliberal governmentalities that prize self-sufficiency and flexibility.[34] Under these conditions, appearing happy, healthy, and well and participating in household activities is one way that the capacity to reason is demonstrated, regardless of how one actually feels or whether one experiences the household as a home.[35] It operates on the basis of an internal contradiction. This form of care affirms the inevitability of arrivals and departures (entry and exit), simultaneously acknowledging and negating transience, making it a permanent feature of the environment. It does this through the construction of an "us/them dichotomy" within the home, a way of caring that acknowledges and reinforces a common sense that, as one interviewee shared, "some of them won't get any better, and they will get worse."[36] But what are the social and material conditions that organize perceptions of "some" residents as a "them" in need of the presence of residents who will journey out toward them, but who cannot change their life (and death) trajectories? Care that is oriented to the preservation of the personhood of lives lived beyond cure establishes a relation between neoliberal governmentalities and the natural order of things in which some of them (unlike us) are positioned as occasions to reaffirm the meaning and significance of co-residence through the performance of human dignity and with it a "community of order."[37] Interpretations of human dignity as a tool that can facilitate the achievement of personal and collective transformation, the individual constructed as beyond cure becomes what Giorgio Agamben refers to as "the figure of the scapegoat… in whom sacrificial innocence and guilt, sanctity and abjection, victim and executioner are unified for the sake of catharsis."[38] What is not entirely clear is who embodies this figure; is it the resident who displays capacity, the co-resident with dementia, the nursing home, or contemporary society? Boundaries become blurred in and around the nursing home.

The interviewee's assertion that the system of relations with other residents in the nursing home resembles a family ("it is like a small family now") can further enhance understanding of a blurring of boundaries between public and private domiciles within the nursing home setting. As one interviewee shared, being present and participating in household activities provides both direct assistance and emotional support to the other people who live in the nursing home. Yet she says nothing of how their presence aids and supports her personally. According to political philosopher Hannah Arendt, it is through labor that we are made human, that our lives are imbued with significance.[39] People who live in nursing home settings describe the relational work they perform to make the place more "homelike." Unspoken assumptions about dementia, made to appear in the form of an address to the absence of reason, organized how this work was done, and with whom. Even as tacit knowledge about dementia provokes a reaching out toward others and a transformation of self, it also carries the risk of rigidity. Knowledge of dementia does not only extend interpersonal relations, it also encloses them. The assertion that some people are not going to get better reflects the stereotypical assumption that people go to a nursing home to die. This is reinforced by the experiences of the people who live in nursing homes, but whose frame of reference is likely already informed by popular lay and medical understandings (and stereotypes) of the meaning and purpose of nursing homes.

In positing a population within the nursing home that realizes the manifest purpose of the nursing home, and in distancing herself from this group (expressed in the reference to "some of them"), the interviewee charts a new journey for herself and for the nursing home as a place where people can and do live, and where they may even get better. The anticipation of other residents "being moved" to other floors provides the impetus for her movement outwards, and her participation in the communal life of the nursing home. "Being moved," or placed, somewhere else is treated as fate (and a fact) for "some of them," but not those who retain the capacity to reason, as demonstrated through participating in household activities despite a lack of the desire to do so. In this way, the interviewee describing the pressures to play a game of cards also shows her bluff. Her words display consciousness of the nursing home as a divided space: a place of deterioration and death for some, but of life and growth for the rest who are in a position to recognize and respond to the significance of their positions within, and to the nature of the work that ought to be done. While this negotiation of life on the "inside" may prove life sustaining and even enhancing for the interviewee, it also comes at the cost of cementing an understanding of "some of them" living in the nursing home as statues subject to decay and ruin. "Some of them" (the residents) are reduced to objects that can either facilitate or get in the way of the work of making a home for the rest of us (the "people" living in nursing homes). Like furniture, they become fixtures in the environment that can be mitigated or capitalized on to make that environment more or less livable ("homelike"). Those on the inside have experiences that are distinct from the experiences that characterized their lives outside of the nursing home setting. As the interviewee says, "you see them move to other floors and what not, and that's not something you see when you are outside." At the same time, resident responses to questions about nursing home life (as well as current treatment regimes) could also be read as affirmations of the persistent force of the social conditions and cultural ideals that structure experience on the outside within nursing home settings.

What roles do images and ideas about dementia play in upholding and/or disrupting firmly entrenched assumptions about who lives in a nursing home and public understandings of the meaning and purpose of a nursing home? How is the "nursing home resident" made visible in public spaces, and how might such visibility shape what participation, and resistance, look like within nursing home settings? Articulations of experience on the "inside" serve as expressions of the public mind. As such, they communicate individuals' interpretations and negotiations of popular cultural imaginaries about what it is like to live in a nursing home.

Although the aforementioned interviewee's account makes it possible to imagine a meaningful life within the nursing home, the only perspective present is an ableist perspective. The imagined others that make life both meaningful and challenging (and perhaps even tedious in the sense of eliciting a sense of duty to participate in undesired activities) provide a means for the resident to experience herself as different from the "some" since she can make the choice to participate where they cannot, to move while they are moved, which provides a means to experience herself as reasonable and purposeful, as a person.[40] Reciprocity is limited to a question of how "they" do or do not make it possible to expand self-awareness. But who are "they?"

Thinking in terms of reasonableness and purposefulness, agency and volition exemplifies what McRuer, drawing from Adrienne Rich, describes as "compulsory able-bodiedness—the experience of the able-bodied need for an agreed-on common ground" in which everyone agrees that "able-bodied perspectives are preferable and what we all, collectively, are aiming for."[41] According to McRuer, "compulsory able-bodiedness functions by covering over, with the appearance of choice, a system in which there actually is no choice."[42] It becomes difficult and even dangerous to imagine value in disability perspectives. When disability experiences are present, they are typically framed and mediated by nondisabled cultural ideals of autonomy, and appear primarily in the form of a problem, usually in terms of dysfunction, deficiency, and disorder that must be eradicated or mitigated in some way.[43] Reading the interviews (grouped into cases that include residents, their families, and the staff who worked with them) together, the concept of autonomy commonly appears across all of the cases and could be interpreted as the glue that binds each case together as one coherent story. This is not surprising considering the research objectives that shaped the study design and the nature of the questions participants were asked.[44] However, it does have special relevance once we consider one of the dominant thematic tropes within discourses of dementia—the continuity of the self. And, some might say, what is a self but the story of a person?[45]

In the primary analysis of the interview transcripts, the original research team observed that autonomy appeared in the form of a question of the extent and quality of continued participation in activities, where activities included the activities of daily life related to primary health needs such as being in a position to self-administer medications, but also managing finances, and hobbies such as knitting. For the purposes of this chapter, we are most concerned with the team's finding that advocacy on behalf of oneself and/or others appeared as an activity that made autonomy visible in the lives of nursing home residents.

Cultural conceptions of autonomy privilege noncognitive impairment. Returning to Kitwood's conception of "PERSON-with-dementia," where the person is capitalized and abstracted from dementia, one can observe how the concept or construct "autonomy" foregrounds the person without dementia, with the effect of reinforcing taken for granted assumptions that whatever personhood means it involves being able to make decisions for self and on behalf, or in the best interests, of others.[46] Formal and informal knowledge of dementia that treats dementia as a "problem that can only be expected to get worse" constructs the "PERSON-with-dementia" as a site for the production of autonomy as a concrete thing that is separate from (and that can be separated from) lived experience. Lived experience becomes a property of the self (private). Autonomy becomes sayable as a measure of an individual's relation to, and control over, lived experience (private property). This way of thinking about autonomy is very much in line with cultural notions of the "rational subject," which have been strategically deployed throughout history to marginalize, exploit, and disenfranchise groups—women, people of color, and disabled persons.[47]

What are the practices that organize the appearance of dementia? The production of knowledge about people who live with dementia can be examined from the perspective of social relations to time as made to appear in histories of difference (marked by race, class, gender, and sex). Rather than simply another other, or additional exemplar of difference, dementia makes a distinct difference in terms of how lives and worlds are experienced and understood. The difference that dementia makes will now be discussed, in relation to paper and paperwork.

Dementia and the Evidence of Experience

An exclusive focus on personhood, at the expense of a more multidimensional understanding of the social, political, and economic changes that have occurred throughout history, and the power structures through which knowledge of dementia is established and institutionalized, shifts attention away from how dementia is what it is, and away from an examination of the methods through which people with dementia are produced and the role that texts play in what Clive Baldwin refers to as the narrative dispossession of people living with dementia.[48]

The discourse of experience communicates the hegemony of the visible. Joan Scott's critical interrogation of the "evidence of experience" can offer insights about the significance of social constructions of dementia in the reproduction of knowledge about what constitutes the validity of a distinctly human life. For Scott, "Experience is, in this approach, not the origin of our explanation, but that which we want to explain."[49] Scott contextualizes the evidence of experience within the history of difference. She states,

> When the evidence offered is the evidence of "experience," the claim for referentiality is further buttressed—what could be truer, after all, than a subject's own account of what he or she has lived through? It is precisely this appeal to experience as uncontestable evidence and as an originary point of explanation—that weakens the critical thrust of histories of difference.[50]

Drawing from a study which made use of Max van Manen's phenomenological method of researching lived experience and "understanding the 'particular' in light of the 'universal,'" Alison Phinney casts a critical gaze on studies that question the awareness of people with dementia over their own lives, and specifically, over symptoms.[51] In contrast to such studies, Phinney frames participants' expressions of forgetfulness, loss, fear, and confusion as demonstrations of an enhanced reflectiveness, a reflectiveness that resists being reduced to the product of lessons learned over time. This reflectiveness, an inability to take things for granted, is steeped in corporeality and displays the limits of minding and being minded. Since stepping out of the routine or the usual can produce symptoms that lead to frustration, participants are more attentive to their environments, acting in intensely strategic and self-aware ways.

Phinney notes that people with dementia operationalized loss in terms of challenges to being in the world in an unreflective way. She says, "Feeling lost was experienced by many as a sense of being in unfamiliar terrain, feeling that the world around them did not make any sense."[52] Rather than reduce the meaning of the experiences of people living with dementia to evidence or originary points of explanation, Phinney treats articulations of dementia-specific experiences as occasions to dwell with how people reconcile questions about what needs to be done when they find themselves in "unfamiliar terrain."[53] Phinney makes it possible to imagine that dementia is not merely written but is also a way of writing and of making a home, and negotiating one's way home.

Describing an interview with Jacques Derrida published under the title of "Le papier ou moi, vous savez… (nouvelles spéculations sur unluxe des pauvres)," Kevin McLaughlin considers what Derrida means by his reference to ours as "'an epoch in the history of technics and in the history of humanity' delimited by the 'hegemony' of paper."[54] McLaughlin assures his reader that he does not mean to mistake paper for a metaphor, and that in fact, paper appears as an unobserved subject rather than a sign of the time. For McLaughlin, paper comes to appear as something missed (whose recollection allows for the mourning of the subject). Like paper, dementia appears in the form as an unobserved subject in ways of talking and writing that treat dementia as a sign of the times (a "now" distinguished by an aging population), and as a symptom or metaphor of modernity (where modernity is understood as a break from tradition that can be accompanied by disorientation, nostalgia, and anomie). But, what kind of subject is dementia? In considering this, one could return to the material and symbolic significance of paperwork. Like the resident who plays cards even though she would prefer not to, people invest time and energies in paperwork because of the influence it is assumed to have over people's capacity to be recognized as belonging to the group of "those" who are flexible and can adapt to "unfamiliar terrains," "those" who are perceived as capable of reaching out toward the others with whom they live, and in so doing avoid or delay being "moved to other floors." Paper provides the material for an archive of experience, and as such, represents a condition of possibility for modern understandings of memory.

Paperwork is central to the social accomplishment of personhood in a nursing home setting. Policy documents and reports coordinate relations to dementia and those perceived to be it or have it, making it possible to recognize and respond "appropriately," often through the administration of psychotropic drugs, but also through "person-centered" approaches. Despite this, the social significance of paperwork within such settings is routinely reduced to a task that duplicates efforts and produces redundancies, and as a surplus of modern bureaucratic organization and practice.

Harrigan and Gillett assert that "[e]ach of us is constantly a being-in-the-process-of-becoming who has to adapt to the world in new ways; and one is not along in this task but is held in personhood by relationships which support us and enhance our abilities."[55] As McLaughlin notes, a simple question about paper turns Derrida to trace the specter of the subject of his life's works—of who he is and who he understands his self to be. Discourses of person-centered dementia care rarely occasion such a turning. Dementia tends, rather, to materialize as an apparition of the subject that both manifests as and gives rise to an uncanny sense of "ambiguous loss."[56] Who, or rather what this subject is, is the *PERSON-without-dementia*. Like paper, and dementia, PERSON is not a metaphor. It does not stand for a historical period, despite Western associations between the ascendency of the person, the self-actualized individual of fully realized potential, with moments in enlightened thinking, science, progress, colonialism, and global imperialism.[57]

Despite dominant institutional discourses on personhood in residential dementia care, families, residents, and staff seem to share the impression that being in places and situations that one does not want to be in can cause mental, emotional, and physical discomfort or distress. Yet those situations and those places can be bearable, as long as one is given the impression that despite one's "level of being there," one's personhood, is acknowledged. There is a will to recover and recapture the present that accompanies a longing for impression. This will to the present, to be present, is made legible in constructions of the present as a potential past or future. Like paper, personhood is operationalized in ways that represent it as the mind or subject. And like paper, it can be very difficult to question the actual meaning and significance of personhood because we become accustomed to thinking about personhood as a condition of human action, some "thing," and a tool that can be used to make visible the work that needs to be done.

CONCLUSIONS

In interviews with older adults living in a nursing home, dementia appeared in at least three ways: as a means of making sense of vulnerability, as a question of capacity and competence; as a mode of performing capacity and competence by participating in domestic activities; and as affirmation of presence and being with others. Assumptions about dementia shaped how residents understood what it means to be a person, why being a person is important (what being a person does), and what is at stake when personhood becomes questionable (e.g., the imposition of uninformed or unwanted interventions). Interestingly, interview participants' expressed relations to dementia paralleled the assumptions of global policy and institutional practice texts. In such texts, dementia is imagined as a global problem. Conceived as a global problem, dementia represents an occasion to reflect on national and international vulnerability, what domestic policy means within an increasingly globalized world (what effects it can have at home and abroad), and what is at stake for countries that do not possess the expert knowledge and wherewithal to adequately address a problem of such magnitude. Our parallel analysis of interview transcripts alongside texts such as the WHO and Alzheimer's Disease International's *Dementia:*

A Public Health Priority yields new insights regarding the multiple levels of assumptions that structure the meaning and experience of nursing home life.

Assumptions about choice, made present in research on medical interventions for people living with dementia in nursing home settings, the interviewed residents' expressed commitment to a notion of the person as "rational subject," and textual representations of dementia as a global problem, are organized by a discursive dichotomy. Dementia is perceived as either a threat to personhood and to being and feeling at home or an opportunity to reaffirm personhood and recreate home through responsible home making. Our analysis illustrates how the assumption that there is choice can affect the self-perceptions, everyday lives, and aspirations of residents. For example, for some residents it promoted activities oriented to reaching out to others, and working with others to make the space more homelike, despite differences in condition and changes in with whom and how that space is shared. Thinking with the textual organization and activation of the rational subject, through an examination of paperwork, may shift how personhood is recognized within the nursing home away from an imagined quality of life that can be preserved through the administration of psychotropic drugs, and even contribute to what van Manen refers to as a "broadened notion of rationality," which he understands as a faith in reciprocity and a shared life.[58]

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41. McRuer 2006, 8, 9.
42. Ibid., 8.
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44. The mixed-methods project examined to what extent and in what ways differences in the nursing home model of care impact resident quality of life. Research objectives focused on “quality of life” as variously experienced and described by residents, their families and nursing home staff across Nova Scotia. Twenty-two nursing homes participated as study sites, but all facilities in the province were invited to participate in a research ethics board approved survey. Interview questions elicited accounts of individuals’ perceptions and experiences of choice within the nursing home environment, and explored possible constraints and facilitators to the exercise of choice.
45. For a description of the importance of the stories of disabled people and their significant others to understanding the meaning of care within a Canadian context, see Anne Martin-Matthews and Janice Keefe’s “Work and Care of Elderly People: A Canadian Perspective,” In *Working Carers: International Perspectives on Working and Caring for Older People, edited by* Judith Phillips (Aldershot, UK, 1995).
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PART III

Family

CHAPTER 10

Contesting the Neoliberal Affects of Disabled Parenting: Toward a Relational Emergence of Disability

Kelly Fritsch

On a sunny afternoon in September 2012, I wrapped up my then six-week-old daughter in a sling, got onto my mobility scooter, and headed out to the local drugstore.[1] Just a few blocks from my apartment, an elderly woman stopped me on the street to admire the sleeping creature on my chest, exclaiming: "Look at you! It's so nice to see people like you being included!" In just the few short weeks after my daughter's birth, her comment—or something like it—had become a common refrain: of the many places I traveled while carrying my daughter on my lap, people nodded approvingly, remarked how great it was to see a visibly disabled person with a child, and more often than not, gestured toward just how far our society had come in including people historically discouraged or prevented from becoming parents. There I was, a rolling success story full of good feelings for all to witness.

The barriers I, like many disabled parents, face on a daily basis are numerous. Rather than my physical limitations characterizing my

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individual failure to be an adequate parent, my limitations are social and relational: they are failures of my communities, even my disability communities, to address a lack of access to sustainable forms of disabled parenting. Nonetheless, it can be difficult to specify how the physical limitations I face as a mother are not just mine. Part of the trickiness in marking these failures is a result of the ways in which normative notions of both mothering and disabled mothering circulate to figure individual mothers as the site to determine whether one is good or bad, rather than placing mothering as always embedded within broader social relations. Another impediment to marking the social barriers I experience as a mother is the way in which the inclusion of disability within neoliberal economies makes systemic barriers out to be individual problems that can be solved within neoliberal market logics. It is hard to develop a relational understanding of disabled mothering because of the ways in which disabled mothers are capacitated in neoliberal economies to become good mothers, and because of the ways in which the good and bad feelings that circulate around becoming or failing to become a good disabled mother individualize disability. Neoliberal logics are pervasive, contradictory, and insidious, capable of orienting even the most critical, radical, or social-justice-oriented communities toward celebrating the neoliberal capacitation of disabled parents.

This chapter addresses the ways in which dominant cultural discourses of disabled parenting, with a particular focus on disabled mothering, re-enforce disability as located in an individual body. I begin by mapping out the extensive social barriers faced by disabled parents. Then, in tracing out the narrative accounts of disabled mothers appearing in popular media, I show how neoliberal processes of capacitating disabled people as parents sustain and celebrate disability as an individual problem that can be overcome by an inclusive society. I show how disabled women are hailed to feel good about being capacitated into ideal normative mothers through neoliberal forms of care. The problem, then, is that disabled mothers, by coming to feel good about themselves, or in being hailed to feel good by others in order to feel like good mothers, re-inscribe normative forms of parenting that support neoliberal forms of care that capacitate some as the successful abled-disabled, while leaving others to wither. In contrast to these individualizing cultural discourses of mothering, in the last section of this chapter I take into account the capacitating and debilitating logic of neoliberalism to think through how disabled mothering emerges within and between bodies. In this relational model, disabled mothering marks the barriers some disabled parents face as not individual problems to be solved, but rather as social relations in which we are all implicated. Such an approach to disability, I argue, contests the affective neoliberal forms of good feelings that re-enforce individualizing understandings of disabled parenting.

Barriers to Disabled Parenting

Nearly 10 percent of American children have one or more disabled parent(s).[2] Despite their prevalence, disabled parents are often considered incompetent and put under increased scrutiny and surveillance. They face significant systemic barriers that often lead to social isolation. Not only do inaccessible playgrounds, parent-and-tot groups, and school buildings limit disabled parents, but disabled parents are also significantly constrained by poverty, and inadequate and inaccessible housing, transportation, and daycare.[3] Systemic ableism leads to disabled parents as a group having less access to educational and occupational opportunities and heightens the chances of living in poverty, which in turn contributes to increased social marginalization and vulnerability, further opening the disabled parent up to negative judgments about their capacities to parent. Disabled mothers in particular frequently face stigmatizing public perceptions that serve to challenge their capacity to mother adequately.[4] If, as Claudia Malacrida notes, the normative relationship between motherhood and femininity is a "tightrope upon which to balance dependency and nurturance," for disabled women, this "tightrope" can be "particularly difficult to negotiate" because disabled mothers are more often embedded in relations of material and social dependency.[5]

Malacrida's research on disabled mothering shows that disabled women "are more likely to experience dependency on institutional supports as a result of their unequal access to education, their difficulties in obtaining adequate employment and their higher likelihood of living in poverty."[6] If disabled mothers are employed, often the accessible transit service is "unreliable, inflexible, and unsuited" to the responsibilities of working mothers.[7] And while physical access may not typically be a barrier to disabled mothers with cognitive impairments, "these women are more likely than others to be lone parents, living with poverty and unemployment" and facing higher levels of stigmatization, social isolation, and charges of incompetency.[8] Disabled women are also at an increased risk of having a partner who is emotionally or physically abusive.[9] Of course, disabled parents have varied experiences depending on social factors such as marital and socioeconomic status, geographical location, race, ethnicity, age, gender, sexuality, and access to social, cultural, and symbolic capital. According to Malacrida's research, racial, economic, and sexual difference intensified the negative outcomes for disabled women. For while disabled women as a group are more likely to experience poverty, discrimination, and violence, "women who are poor, queer, living in rural isolation or members of racial and ethnic minority groups are likely to experience disability oppression that is complicated by their raced, classed, geographical, sexual and social locations."[10]

Regardless of social position, however, all disabled mothers (differentially) experience the cultural pressures that accompany the idealization of motherhood within a Western context as a gendered role of selfless devotion and natural seamless attention to the needs and desires of her child. Sara Ruddick argues that mothering involves protection, nurturance, and responding to the needs of children with care and respect, qualities that Malacrida notes are "stereotyped as core attributes of hegemonic femininity."[11] Women are expected to nurture their children "through active, involved and expert mothering," and are "ideally expected to be all things, at all times, to their dependent children."[12] Martha McMahon underscores the ways in which women are re-socialized in becoming mothers and transform into "loving, caring, responsible" parents.[13] Thus, motherhood can be understood as a learned set of behaviors that is continually reproduced through performing normative forms of mothering-femininity that imbues women with a sense of themselves as naturally devoted, attentive, and nurturing.[14]

Sharon Hays first coined the term "intensive mothering" to express how normative mothering is "*child-centered, expert-guided, emotionally absorbing, labor-intensive, and financially expensive*."[15] Women are "expected to create child-centered homes that shield children away from responsibility and hardship" and are tasked with being all things to their children whether it is being immediately available, a strong role model, endlessly nurturing, or completely child focused. Despite long-standing feminist critiques of naturalized gender roles, mothers in modern Western societies continue to be "idealized as 'natural' and limitless caregivers for their children."[16] Despite feminist attempts to challenge and denaturalize normative mothering and politicize intensive mothering discourses, failure to meet this normative standard of selflessness often results in "mother-blame" especially when the mother's behavior becomes a means of explaining the aberrant behavior in her children.[17]

While it is common for all parents to struggle with doubts about their parenting abilities and to live up to normative gender roles and expectations, for disabled mothers in particular "these doubts are repeatedly confirmed in the comments of strangers, health-care professionals, even family members."[18] Such doubts are reinforced through various levels of community and state surveillance, which often results in the removal of children from their care, or creates additional burdens through the fear and threat of possibly losing the right to care for one's child.[19] As Malacrida points out, "Because ideal mothering includes women's responsibility for the protection and care of their children—even against their husbands and partners—women who are vulnerable to abuse are likely to be blamed for failing to live up to cultural norms relating to ideal mothers as protectors and guardians against any and all harms that may befall their children."[20]

In 37 US states, disability, as an identity status, can in itself be the legal grounding to terminate parental rights.[21] As Angela Frederick's research shows, "Many mothers with disabilities report living with a sense of fear that they will be scrutinized by medical authorities. At times, when members of the public see a disabled woman out with her children and become concerned, they report the family to child protective services."[22] Too frequently "safety" is a guise used to question the abilities of disabled parents and disability status ends up being used as a proxy for real evidence that the parent cannot adequately care for their children.[23] Of her experience as a disabled parent, Deborah Kent comments: "The exhaustion and isolation I felt are common to many, if not most, new mothers in middle-class America. Yet I had one added burden sighted mothers did not share. I knew that wherever I went people were observing me, wondering about me, at times doubting my abilities. All too many people, both strangers and acquaintances, questioned my capacity to care for my daughter and to keep her safe."[24]

Surveillance and questioning of capacity play a role in how disabled parents present and monitor themselves and their children. Carol Thomas' 1997 study marks the ways in which disabled mothers feel pressure to demonstrate that they are "good enough mothers," above and beyond the normative pressures placed on nondisabled mothers.[25] Thomas also found that disabled mothers desired to present themselves as managing normally in order to avoid attention or judgment. Lars Grue and Kristin Laerum affirm this finding, noting that several of the disabled mothers in their study found it important to "work hard in order to convince other people that they were competent mothers."[26] One participant in their study, Lise, stated: “There are very few children who are as nicely dressed and well-kept as my children. I was the first parent to put nametags in my children’s clothes when they started at the nursery. Nobody should have a reason to criticise me.”[27] Kent comments on her own experiences of being a “blind mother” in a similar way:

> Many a new mother lives with “performance pressure.” When the baby won’t stop crying, she notes her mother-in-law’s disapproving frown or her husband’s sigh of exasperation. But I feel that in my case such anxiety was heightened. In public places I could seldom forget that the critical eyes of the world were upon me. If my daughter fussed, if she had a spot on her dress, or if any minor accident befell her, I knew it would be attributed not to the ordinary ups and downs of babyhood, but to the fact that I, her mother, couldn’t see. I tried to keep Janna immaculate, cheerful, and of course safe from all the perils of childhood—not only for her sake, but in order to fend off the naysayers, to prove myself worthy for the parental role.[28]

Grue and Laerum note that disabled mothers often feel that they need to “demonstrate a better than ideal performance of motherhood in order to pass as socially acceptable” and often monitor their gender performance in order to appear “as a mother in a way that makes them equal to other mothers.”[29] Crucially, however, they point out that such attempts at “passing” were more difficult for disabled mothers who have speech impairments or difficulty maintaining their balance while walking, as these types of disabilities can appear as intellectual disabilities or as related to alcohol or drug consumption.[30] Grue and Laerum additionally found that “mothers who had asked for practical help found that this was sometimes used as proof that they were inadequate mothers, and any difficulties that their children had at school or kindergarten had been interpreted in the same way.”[31] As Frederick concludes: “Disabled mothers are more likely to experience unwarranted investigations from social service agencies. They are more likely to have their parental rights terminated, and when children are removed these families receive fewer supports for reunification.”[32]

That is, often when children are removed, “agencies offer disabled parents few supports to ease the effects of structural barriers such as lack of access to transportation and quality housing, and they rarely offer parents the opportunity to acquire adaptive training and equipment that might help them care for their children.”[33] Frederick describes the 2010 experience of Mikaela Sinnett of Independence, Missouri, who was taken into the American foster care system at just two days old. A nurse reported

Mikaela's blind parents to a social worker after Mikaela's mother experienced difficulty breastfeeding. Frederick writes: "Mikaela's parents cooperated with the social worker, answering questions about the care they would provide for their newborn. They could take their daughter's temperature with a talking thermometer; they had access to transportation; and they could take Mikaela to the hospital if she needed immediate medical attention. The one response the social worker wanted, which the parents could not provide, was that someone with sight would be with the child at all times."[34] Mikaela's parents spent two months entangled in legal proceedings and court hearings during which time they were only able to see Mikaela during supervised visits for up to a maximum of three hours each week. After 57 days of fighting, the state finally dropped the case. Mikaela's story underscores the way in which disability and incompetency are so culturally entrenched.

Because disability is so often associated with incompetency and lack, and because disabled mothers often require assistive devices or assistance to aid in their parenting, "the combination of cultural ideals of mothering as selfless devotion with visible indicators of attending to one's own needs and relying on institutional support increases the vulnerability of mothers with disabilities to the charge of bad parenting."[35] As such, disabled mothers "pose a threat to the intensive mothering ethos as they can make visible the realities of imperfection, risk, and even pain and suffering—the very hardships from which mothers are now expected to shield their children."[36] This threat is more or less neutralized by representing the relationship disabled parents form with their children as unhealthy for the child. Indeed, disabled parents, and mothers in particular, are often depicted as having an "upside-down" relationship with their child, as it is assumed that the child is "burdened" with the responsibility of caring for the parent.[37] The notion of an "upside-down family" presumes that "disabled mothers not only fall short of ideal mothering, but that they depend on their children for care and services, exploiting these 'young carers' and robbing them of their childhood."[38]

In Grue and Laerum's study, they found that the majority of disabled mothers were very conscious of the role of their children as helpers. Even if able-bodied people expressed "how important it is for children to have certain obligations," these same people often saw a child helping a disabled mother as a different matter than when a child helped a nondisabled mother. That is, a child helping a disabled mother "was seen within a discourse of disability and not within a discourse of socialisation."[39] It was questionable to these observers whether the child helping a disabled mother was indeed good for the child's development.

Whether healthy for the child or not, such help is often necessary in an ableist world. McKeever et al. found that it was often "the unsuitability of the home and community care services," rather than the individual disability of the disabled parent which instigated the need for the child to help or care for the parent. Additionally, women without spousal support and those who relied on rental housing that could not be easily modified "appeared to be at the highest risk of requiring problematic levels of assistance from their children."[40] For many of these parents, assistance from their children was "the regretted detour" by which they were able to overcome limitations to full parenting. There is agreement across the research on disabled parenting on the need for nurturing assistance and increased personal and homemaking services for disabled parents. In a US national survey of 1200 disabled parents, 79 percent of respondents reported a need for daily personal assistance and 57 percent reported needing help with parenting tasks. Additionally, 60 percent of parents with psychiatric and/or physical disabilities reported that they would benefit from assistance with parenting activities, and 50 percent of parents with sensory or developmental disabilities said they would benefit.[41] According to the survey, 43 percent of respondents reported needing the most help to enjoy recreational activities with their children, 40 percent reported needing help with "chasing and retrieving their children," and an additional 40 percent reported needing assistance with traveling outside their home. Other significant areas of assistance included lifting/carrying children, organizing supplies/clothing, disciplining children, playing with children, bathing children, childproofing the home, and advocating for children.[42] And yet, while many disabled parents tout hiring an attendant as the best solution to the barriers they face, when disabled parents do hire someone to help care for their child, the disabled parent's ability to be a parent is questioned. Christina Minaki, a disabled woman reflecting on her intention to hire a nanny to care for a child she wishes to adopt writes: "if it is acceptable for an able-bodied mother to hire a nanny, to make juggling parenting, career and domestic responsibilities possible, why is this course of action assumed taboo for me?"[43]

In addition to being judged, getting help from nonfamily members is increasingly a problem of funding. As neoliberal changes to policy continue to download costs of caring for dependents onto the nonprofit and voluntary sector, families and individuals, funding and other supports for disabled parents are often hard to secure, underresourced, or nonexistent. For many disabled mothers, publicly funded assistance is not available and their families are forced either privately to pay for help or not to receive any services at all. In many cases where disabled parents were receiving funding for attendant care, the terms of their funding did not allow them to use their assistants to aid with the care of their children. For example, “a mother with a full-time caregiver might reasonably expect her worker to feed and clothe her but she could not ask that caregiver to put a bowl of cereal on the table for her child or to help that child button his shirt.”[44] McKeever et al. further found:

> Agencies that provided personal and homemaking services clearly viewed women as clients in need of individual assistance and often overlooked or refused to support their mothering roles. After repeated requests, only one of two mothers with very young children was provided with temporary outing assistance and then for only 4 hours per week. Several mothers were unable to receive adequate assistance with those housekeeping activities typically associated with mothering such as the cleaning of children’s rooms, grocery shopping and laundry.[45]

As the US National Council on Disability (NCD) notes, personal care workers, who have been found to be a cost-effective solution to the needs of many disabled parents, would greatly enhance the ability of disabled parents to parent, improving the quality of life for these families. In the USA, some states that have offered support to keep the children of disabled parents out of the foster care system have saved almost two dollars spent on institutional care for every dollar spent on the program.[46] The NCD also found that funding adaptive equipment and simple home modifications can also “prove cost-effective.”[47]

While the sum of all these findings about disabled parenting and the challenges disabled mothers in particular face is largely to draw attention to and chart out the precise barriers faced by disabled parents, what is missing from these studies is mapping out the ways in which disabled parents are welcomed and included as parents, and secondly, how these forms of inclusion and many of the “solutions” purported to aid disabled parents actually serve to reinforce neoliberal logics that individualize disability and care, capacitating some as the successful abled-disabled, while leaving others to wither.

WHAT KIND OF MOTHER? CHARTING THE NEOLIBERAL AFFECTS OF DISABLED PARENTING

Sarah Erdreich, in her 2015 *Slate* magazine article asks: “What kind of mother refuses to pick up her child?” At once both appealing to and resisting normative Western maternal standards, she answers her own question bluntly: “A mother with chronic pain.”[48]

Born with damaged nerves that have led to a lifetime of muscle spasms, scar tissue, atrophied muscles, and days where “even blinking hurts,” Erdreich notes the ways in which following the birth of her daughter, her health further deteriorated. She writes: “The early months of changing diapers and clothes, nursing, and lifting her in and out of her crib caused irreparable damage to my wrist and shoulders.”[49] As a result of the intense physical labor of taking care of a baby, Erdreich describes the ways in which she was left unable to push her daughter’s stroller “much farther than the three blocks between home and day care” and how she is unable to dress her daughter, tie her shoes, brush her hair, help her daughter write out the alphabet, or make the hand motions that accompany the children’s song “Itsy Bitsy Spider.”[50] With this laundry list of limitations, she marks herself off as a failed mother when she admits that because she cannot do these things she does not feel that she is capable of properly caring for her daughter by herself for more than an hour. And because “raising another child would take a much greater toll on my health than I am willing to accept,” Erdreich feels that she is further failing her daughter because she is unwilling to provide her with a sibling and, thus, preventing her daughter from having the experience Erdreich and her husband enjoyed of growing up in a larger family.[51]

Erdreich goes back and forth describing her disability in relational and individualistic terms. On the one hand, Erdreich notes that by the time her daughter was two she had taught her “how to scoot down stairs, climb onto the couch, and get into her stroller.”[52] In this telling, Erdreich’s relationship with her daughter was developed through her disability and her disability re-experienced through these lessons. On the other hand, Erdreich continues to fall back into individualistic and blaming accounts of how her chronic pain stops her from being the ideal parent she desires to be. She comments that she knows her daughter will soon be more independent and that it will become easier to take her to the “the playground or library or a restaurant without needing another adult present.”[53] But Erdreich feels so strongly that her condition makes her a failed parent that she has a hard time believing that the future might be easier. Ultimately, as opposed to taking a relational approach that emphasizes how disability is produced between her and her daughter—let alone within the wider sociopolitical context and environment—Erdreich instead stresses her own failure as a mother. And for Erdreich, failure at being a good mother stems from her individualized disabled body.

In another account of disabled mothering published in *The Atlantic*, Rachel Rabkin Peachman writes of feeling like "her back would break" if she cradled her sick daughter's "squirming 25-pound body any longer."[54] Leaving her toddler crying in her crib, Peachman notes that she was causing her daughter "additional suffering" as a result of her individual back pain, commenting that "[b]efore having children, I didn't consider how my pain might affect my parenting."[55] But as she goes on to describe, "Within two years of hoisting my precious cargo into her stroller and high chair, and yes, standing and rocking her to sleep—my body buckled under the strain. Back spasms made it impossible for me to stand or walk for long stretches and sometimes put me out of commission all together."[56] Despite Peachman's increasing pain and debilitation, she states: "[W]henever my daughter reached for me, I was there with open arms" because "How does a mother suppress her instinct to hold her child when those little arms reach out?"[57] Of course, by severely limiting when she can act on this maternal instinct, Peachman sees her disability as an individual condition that prevents her from being a good mother.

Interestingly, both Peachman and Erdreich express how their disabilities have negatively affected their family life on the whole. Referring to studies on the adverse effects on a child's emotional and behavioral development, Peachman states that when a parent has chronic pain, the "whole family suffers."[58] Erdreich comments that her condition affects her husband "in profound ways" as his life has become completely inflexible after the birth of their daughter, noting that "he is the only reliable and consistent parent our daughter has," leading her to describe her marriage as frustrating and unbalanced.[59] Erdreich comments: "If I had known how tough this would be before getting pregnant, would I have made the same choice? I want to say yes without hesitation or qualification, but that's not the honest answer. The honest answer is, I don't know. I love my daughter. That has never been in doubt. But I hate what a toxic combination motherhood and chronic pain are for me."[60]

Erdreich's and Peachman's sense of failure is consistent with the literature on parenting with chronic pain on the whole. A number of studies note the ways in which parents express a sense of missing out on social events and leisure time with their children as a result of their chronic pain, often labeling themselves as "burdens."[61] Evans and de Souza found that "[m]ost mothers felt that dealing with pain and bringing up children was difficult. Either children suffered and had to brave their mother's unavailability and distress, or mothers taxed themselves by performing parenting duties even when their pain made functioning difficult."[62]

While I do not experience chronic pain, I, like many disabled parents, can identify with the frustration and pain both Peachman and Erdreich express in caring for their children. I also appreciate how both Peachman's and Erdreich's accounts of being disabled parents with chronic pain are important for disability studies because of the way in which chronic pain is often a kind of disability that many do not take seriously, or consider to be "real."[63] It is often an impairment that people need to prove over and over again because those with chronic pain do not always "look disabled." As Maeve O'Donovan comments, when disabilities are not visible, or not always visible, disabled parents "may find themselves excluded from the community and support provided to those with [visible] physical disabilities."[64] Disabled parenting is governed by a normative understanding of disability that is dominated by visible forms of impairment and adaptive devices like that of the wheelchair.[65] In this way, both Peachman and Erdreich provide a compelling account of some of the barriers to mothering when one does not "look disabled" and as such, are expected to be fulfilling their normative roles of intensive mothering.

However, while their narratives begin to contest normative notions of disability, both narratives deeply entrench disability as an individual experience, with the authors blaming only themselves for not living up to ideal mothering norms. Failing to examine the barriers they face as social barriers, the individualizing narrative also reiterates a neoliberal logic that "individuals are primarily responsible for their own fates" and that "families and voluntary agencies, rather than local states, should bear the onus of responsibility for assisting persons in need."[66] Having privatized formerly public services and resources, the primary role of the neoliberal state is to discipline those who fail to maintain economic independence and to reinforce divides between those who are deserving of social welfare programs and benefits and those who are not. Increasingly informing common sense understandings of disability as an individual condition or form of impairment while also underwriting policies and practices concerned with disabled people and modes of access, disabled persons are hailed to become independent entrepreneurs who manage their own needs.

Michelle Murphy's work on the economization of life argues that as neoliberalism developed throughout the mid-to-late twentieth century, it became increasingly common to render and govern lives in purely economic terms (e.g., as more or less valuable) rather than through biological terms.[67] As disabled life has become economized, the biological difference of impairment has come to matter less in some cases than the potential of making disabled bodies productive through therapies, drug regimes, and assistive devices and, thus, profitable for private companies developing drugs and producing body-modifying equipment. As opposed to seeing disability exclusively as the basis for exclusion and disabled bodies as objects to be normalized, Jasbir Puar has come to question how economies of disability that capacitate some disabled bodies while leaving other unproductive disabled lives to wither produce differential forms of disability in neoliberal economies.[68]

While the objective of capacitation is not necessarily to transform disabled bodies in the image of able bodies but, instead, to create newly enhanced and productive bodies that often have the potential to exceed the capacities of able bodies, ableism has not, of course, disappeared. That some disabled bodies are capacitated and included in their difference does not mean that ableist norms no longer define disabled people as lacking. Instead, within neoliberal economies disability emerges in the ambivalent position between being capacitated or left to wither and normalizing standards. With particular forms of disabled lives capacitated and marked as worthy for valorization, while other disabled lives are denigrated and left to wither, disability as difference works alongside ableist norms.

In the mothering literature, this ambivalence between being capacitated or left to wither and normalizing standards is best expressed in the tension between the logic of intensive mothering in which being a mother is its own reward and the neoliberal logic that requires parents to take on the full cost of parenting. For disabled parents, more often than not, this effectively results in the neoliberal state disciplining those who are unable to afford this task through measures such as removing children from their care.

The ambivalent economies in which disability is both valued and capacitated, and policed and debilitated, inform nondisabled persons' understanding of disability and feelings toward disabled people as well as disabled persons' desires. For example, the woman who took such pleasure in me being both disabled and being a mother as I carried my infant daughter on my scooter expressed this ambivalence as she both celebrated my capacitation as mother—my scooter, my ergonomic sling—and the image of being a competent, independent mother like other mothers this form of capacitation produces. I can only wonder what she would have said if my daughter were fussing or appeared to be in danger of falling off my lap? I can only imagine what type of mother I would have been if my child were older and struggling with the bags of groceries I could not carry myself, or if I, or my child, did not appear white?

Erdreich and Peachman desire to be good mothers by both overcoming their disabilities that prevent them from always being good mothers and embracing the moments in which they can be good disabled mothers through participating in affective neoliberal economies.

As their individualized disabilities continue to sit more or less nicely within affective neoliberal economies of disability, it is perhaps no surprise that the pain and joy Erdreich and Peachman feel in being mothers continues to circulate within neoliberal relations. Presumably not wanting to end on a sour note or to be a killjoy, but instead to leave their readers hopeful, both Erdreich and Peachman end their articles by expressing their determination to be good mothers despite their individual challenges. For Peachman, this is expressed in two key statements. In the first, she states: "I'm still the one my girls reach for—and I refuse to let the pain take that away from me. Motherhood may have weakened by body but my love for my daughters has strengthened my spirit."[69] And in the second, she notes: "I know there are days when I'm sidelined and short-tempered. But I'm determined to raise children who feel supported, secure, and loved. I don't know what my future holds—surgery, therapies, or a lifetime of pain. But I have to believe that despite a deteriorating body, it's possible to be a successful mother."[70] For her part, Erdreich makes the best of her limited situation by commenting:

> And even though there is so much that I can't do with my daughter, and more that I might not ever be able to do, there is still this: She can sit on my lap and listen to me read *Harold and the Purple Crayon* and *Hop on Pop* over and over. I can lie on the floor of her room and make her giggle just by letting her cover me with stuffed animals and toy ducks. And when we get home from day care and stand at the bottom of the porch steps and she lifts her arms to be carried, I can sit down on the lowest step and put my arm around her as she leans against me, and we can watch the evening settle around us until we're both ready to walk into our house.[71]

Pervasive cultural discourses such as those expressed by Peachman and Erdreich re-inscribe the good feelings of disability as an individual who will persevere and overcome their challenges. In doing so, the grounds upon which the individual grins and bears their situation are not contested but rather re-enforced. Similarly, Erdreich and Peachman both place hope for a better future in what they can do as individual mothers. That is, for Erdreich and Peachman, hope is found in their individual capacities to still provide the selfless care—although somewhat adapted to suit their disabled bodies—that good, able-bodied mothers provide.

While normative and ideal motherhood is "both unachievable and blaming for all women," it also creates additional barriers for nonnormative family formations, including, but not limited to, families with one or more disabled parent.[72] In contrast to Erdreich and Peachman's individualizing narratives that isolate them as lone outcasts, their experiences as disabled parents are not unique. And yet, their accounts are compelling precisely because of the ways in which they participate in ambivalent neoliberal relations.

In Hilde Zitzelsberger's 2005 study of how 14 disabled women accounted for their embodiment, one participant who was visibly disabled when using her mobility scooter commented:

> When people see me or even get to know me and they know that I'm married and have a family… they're really surprised and they'll say… "*That's great.*" Well, you wouldn't go up to somebody and say, "*That's great, you have children.*"[73]

Many contemporary accounts of disabled parenting describe similar encounters as the one I described at the beginning of this chapter in which nondisabled persons tell disabled people how great it is that they have kids. In the disabled parenting literature, this celebration of disabled mothers gets expressed in comments like: "[D]isabled women choosing to have children are resisting preconceptions of what social roles they may fulfill,"[74] or "To imagine one's self as a mother, making the decision to become a mother, and acting on this choice is an act of bravery for disabled women."[75] Even as these positive remarks stand in stark contrast to past eugenic-like projects of sterilizing disabled people, these good feelings and celebratory remarks are nonetheless problematic because they tend to make the inclusion of disabled women as mothers the desired end of having kids. As a result, becoming a good disabled mother does not necessarily challenge the normative production of ideal intensive mothering, or the way in which some disabled people are capacitated within neoliberal economies at the expense of others who are left to "slow death."[76] In short, extoling the virtues of disabled parents does not necessarily challenge or change the inequitable neoliberal social relations in which intensive mothering is normalized and in which disabled parents parent.

Disability studies scholars O'Toole and Doe, disabled parents who adopted disabled children, confirm these neoliberal discourses. They note that they did not receive any kind of state support to enable them to parent but rather created mutual support themselves, remarking: "We are, surprisingly, everywhere. Though not exceptionally visible, we are very good at mutual support."[77] Such mutual support is evident in Kent's account of being a blind mother. She searched out and met other blind mothers, who shared adaptive tips with her such as using a baby carrier so that her hands would be free for a cane or a guide-dog harness, and attaching bells to the clothes of crawling infants or walking toddlers so as to be able to keep track of their whereabouts.[78] Of this experience, she comments: "For the first time in my life I was hearing a new and welcome message… I would need to be well-organized, to plan carefully, and to build a strong support network. But… blindness was not an obstacle to motherhood."[79] Further as one participant wryly comments in Ora Prilleltensky's 2003 study on becoming a parent: "If I can't go in the front door I go in the side door. Or the back door. Or I create a door."[80]

Stories of mutual support, resistance to ableism, and finding solutions to create "ramps to mothering" are important, marking the creative means disabled people utilize in order to live their lives.[81] However, these stories do not fall outside of neoliberal logics and we must continue to attend to the ways by which disabled people are included/excluded within such troubling logics. In contrast to these discourses, in the next section I show how disability emerges within and between bodies so as to mark the barriers some disabled parents face as not individual problems to be solved, but rather as social relations in which we are all implicated.

TOWARD A RELATIONAL EMERGENCE OF DISABLED PARENTING

Heather Kuttai, in *Maternity Rolls: Pregnancy, Childbirth and Disability*, recounts a story of going swimming with her two-year-old daughter, who asks to be taken down the waterslide at the pool. Kuttai, a paraplegic, tells her daughter that she is unable to take her up the stairs, to which her daughter says, "I need a walking person."[82] In this moment, Kuttai feels like she is letting her daughter down. She comments: "I feel compelled to say, 'I'm sorry' a lot—to my husband, for costing us more money, to my children, when I cannot go to the places other moms go, to the earth, for making more pollution."[83] Kuttai not only intensely feels the ways in which her limitations affect her family, but also is aware of the impact her mobility and adaptive equipment have on the environment. And yet, these feelings and expressions of sorrow, which are familiar to so many disabled people, are very much wrapped up within an individualistic logic of disability that is continually reaffirmed and reproduced within neoliberal relations. Later in the text, Kuttai notes the sociality of her disability, stating: "I need a park in our neighbourhood without gravel or sand so I can push Chelsea on the swings and catch her when she comes down the slide. I need curb cuts."[84] And yet, Kuttai's needs remain couched in an individual accounting: "*I* need…"

Such individualistic accountings of disability lead disabled parents to feel out of place in an ableist society. McKeever et al. note: "The experiences that mothers reported were fundamentally embodied. As women moved through physical and social spaces primarily designed for adults who can walk, they were often made to feel 'out-of-place' as mothers."[85] Indeed, McKeever et al. further found:

> One mother commented that while parenting is an equally difficult task for all, parenting from a mobility device is "more of a production", given the significant complexity of co-ordination required to maneuver the bodies of herself and her child, a wheelchair, and a stroller during the conduct of mothering and homemaking activities. This production of motherhood is embedded within the demands and structures of a socio-spatial context of social exclusion and discrimination, inadequate home care services and awkward or inaccessible built environments. Hence, recognition and amelioration of the challenges to successful mothering with a disability requires an understanding of its embodied and emplaced nature, and the recursive relations of people and places.[86]

The embodied and emplaced nature of disability is not simply to invoke the social model by which external barriers disable an individually impaired body. Rather, taking disability as a relational emergence contests the affective neoliberal forms of good feelings that re-enforce individualizing understandings of disabled parenting.[87] To further elaborate on this point, I briefly turn to the oft-cited solution of nurturing assistance, or having direct funding for attendant care apply to disabled parenting so as to overcome its structural barriers.

Elsewhere, I (and others) have marked the ways in which attendant care provides an opening to consider the problematic foundation of independent living models that assert a normative encounter between autonomous and sovereign selves.[88] In complicating the usual ways in which the attendant is considered an employee and as such is expected to be a "detached tool," performing a series of mechanical tasks in facilitating the needs and desires of the disabled person, I argued for the importance of approaching the interaction between a disabled person and an attendant as a relation that extends both bodies into one another, displacing the limits of their assumedly contained individual selves.[89] In relation, both the disabled person and the attendant experience a leaking of their identities, a mingling of their sexualities, and multiple intimate slippages of their bodies as the attendant participates in the daily work of feeding, bathing, shopping, facilitating sex, and numerous other activities.

It is important to take a relational approach when considering attendant care because of the way in which the independent living model of direct funding figures disabled employers and personal attendants within neoliberal agendas that commodify care.[90] It is of no coincidence that the disability movement's stress on independent living has emerged alongside the neoliberal privatization of many health services, for "neoliberalism does not only 'happen to' social movements in a top-down fashion, but also in and through their actions."[91] While independent living programs may provide many advantages for disabled people, they must be contextualized as part of a larger trend to privatize social services and download responsibilities onto individuals. Hughes et al. argue that the disability rights movement has placed too much emphasis on gaining equal access to the marketplace and on fighting for the right to be "wage slaves."[92] Being employed and a productive member of society is seen as a form of empowerment, capacitating the disabled as the abled-disabled, rather than fighting to dismantle the oppressive system of capital all together, which systematically produces disability and abandons some disabled bodies to wither. In calling into question the modes by which disabled people seek better lives, we discover that the struggle of disabled people is also the struggle of those people who have been racialized or gendered, those who are queer, those who have tenuous immigration status, and so on, as they also experience disproportionate assault by the state and capitalism. All too often the struggles of disabled people are individualized and seen as a problem to be solved within the realm of social services, or understood as a medical problem that resides outside of the collective social body.

What I wish to add to these previous conclusions, in the context of barriers to parenting, is to mark nurturing assistance as a site of the relational emergence of disability that can contest the neoliberal individualizing of disability. This is to say that a relational approach to disability highlights the ways in which disability does not reside in an individual body that requires help to parent, but rather marks the ways in which disability is always within our social relations. Thus, to return to Minaki (2014), who is critical of the taboo of hiring a nanny to help care for a child she wishes to adopt: what should be taboo is not the desire for a nanny, but rather acquiring a nanny in order to achieve intensive mothering, or as a way to overcome her individual problem. Displacing disability away from the individual body of the failed mother and emphasizing instead the macro and micro ways in which disability emerges within relations that have social, political, economic, and cultural consequences opens up room for reflection and concerted political action.

I do not want to be a good disabled mother if it means re-inscribing the ableism of intensive mothering and supporting the neoliberal economies of capacitation that promise to enhance my individual difference so as to be a good mother without being the same as able-bodied mothers. I want to be able to take advantage of assistance and attendant care but I do not want to participate in neoliberal economies of providing care. The point is not to ignore inequitable social relations but to highlight how we are always already producing disability and how we can hold the state, our communities, and each other accountable for the kinds of production that rest on and reproduce inequitable social relations. This is to place the emphasis, then, not on what an employee can do for me as a disabled parent but rather what we can create together that does not re-inscribe individual accounts of overcoming disability, nor simply evoke creative individual solutions in the face of austerity. The goal is not for the re-emergence of the welfare state, but rather to mark and mobilize the relational emergences of disability as a way to hold ourselves accountable and work collectively to overcome the ways by which neoliberalism individualizes disability and leaves parents to rely on market-based solutions to achieve and celebrate intensive mothering.

NOTES

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11. Sara Ruddick. *Maternal Thinking*. (Boston: 1989); Malacrida, "Negotiating," 471.
12. Malacrida, "Performing," 99.
13. Martha McMahon. *Engendering Motherhood: Identity and Self-transformation in Women's Lives*. (New York: 1995), 130.
14. Malacrida, "Performing."
15. Sharon Hays. *The Cultural Contradictions of Motherhood*. (New Haven: 1996), 8. Italics original.
16. Frederick, "Mothering," 33; Malacrida, "Performing," 101.
17. Malacrida, "Performing," 99; Maeve O'Donovan, "The Practical and Theoretical Challenges of Mothering with Disabilities: A Feminist Standpoint Analysis." In *Philosophical Inquiries into Pregnancy, Childbirth, and Mother: Maternal Subjects*. Edited by Sheila Lintott and Maureen Sander-Staudt, 93–106 (New York: 2012).
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19. Malacrida, "Negotiating."; Track 2014; Frederick "Mothering"; O'Donovan "The Practical,"; Ora Prilleltensky, "A Ramp to Motherhood: the Experiences of Mothers with Physical Disabilities." *Sexuality and Disability* 21, 1 (2003): 21–47. doi:10.1023/A:1023558808891; Grue and Laerum "Doing Motherhood"; Deborah Kent, "Beyond Expectations: Being Blind and Becoming a Mother." *Sexuality and Disability* 20, 1 (2002): 81–88. doi:10.1023/A:1015238505439
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26. Grue and Laerum, “Doing Motherhood,” 677.
27. Ibid.
28. Kent, “Beyond,” 85.
29. Grue and Laerum, “Doing Motherhood,” 678.
30. Ibid.
31. Ibid.
32. Frederick, “Mothering,” 35.
33. Ibid., 34.
34. Ibid., 31.
35. O’Donovan, “The Practical,” 94.
36. Frederick, “Mothering,” 33.
37. Malacrida, “Negotiating,” 472; Ora Prilleltensky, “My Child Is Not My Carer: Mothers with Physical Disabilities and the Well-Being of Children.” *Disability & Society* 19, 3 (2004): 209–223. doi:10.1080/0968759042000204185
38. Malacrida, “Negotiating,” 472.
39. Grue and Laerum, “Doing Motherhood,” 679.
40. Mckeever et al., “It’s More,” 193.
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43. Christina Minaki, “Scrutinizing and Resisting Oppressive Assumptions about Disabled Parents.” In *Disabled Mothers: Stories and Scholarship by and About Mothers with Disabilities*. Edited by Gloria Filax and Dena Taylor, 31–48 (Bradford: 2014), 32; Through a disability justice framework, it is possible to recognize that neoliberalism is a system in which both a nanny and a disabled mother are separated from their children.
44. Malacrida, “Negotiating,” 484; Interestingly, home care policy in Ontario, Canada, allows for care for a disabled mother’s children, but not for any others in the household.
45. Mckeever et al., “It’s More,” 183.
46. NCD, “Rocking,” 242–243.
47. Ibid., 243.
48. Sarah Erdreich. “Parenting with Chronic Pain.” *Slate,* January 2, 2015. http://www.slate.com/articles/life/family/2015/01/parenting_with_chronic_pain.single.html

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59. Ibid.
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62. Ibid., 497.
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72. Malacrida, "Performing," 100.
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80. Prilleltensky, "A Ramp," 45.
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82. Heather Kuttai, *Maternity Rolls: Pregnancy, Childbirth and Disability* (Halifax: 2010), 99.
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CHAPTER 11

The Mad Woman in the Garden: Decolonizing Domesticity in Shani Mootoo's *Cereus Blooms at Night*

Jeffry J. Iovannone

In her 1996 novel *Cereus Blooms at Night*, Indo-Caribbean-Canadian writer Shani Mootoo examines the interconnected nature of colonial violence, queer expressions of gender and sexuality, and disability in the form of madness and trauma. Set on the fictional Caribbean island of Lantanacamara (a thinly veiled version of Trinidad), the novel relays the story of Mala Ramchandin, a sexually traumatized and "insane" woman, through the perspective of her caregiver, Tyler, a queer (in terms of both gender and sexual identity) nurse. Through Mala's story, Mootoo illustrates how the trauma of colonialism, in the context of South Asian migration and immigrant labor in the Caribbean, both effaces and disables queer subjects, for as she observes, such persons "either end up running away from everything [they] know and love, or staying and simply going mad."[1] In this context, the term "queer" can be applied to characters who defy not only normative boundaries of gender and sexuality, but any

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social conventions established through colonial violence and domination, including physical and or/mental “otherness.”

Colonialism within the novel produces a set of normative social conventions whereby queer subjects are expelled from the social order or are rendered “mad” as a method of coping with an environment hostile to their very existence. In particular, Mootoo suggests that this “othering” of queer subjects occurs through the maintenance of hetero-patriarchal domestic spaces inhospitable to those considered sexually and/or mentally inferior. The novel demonstrates that queerness (madness, gender nonconformity, sexual stigma, ethno-racial “otherness”) is not the result of individual or familial pathology, but is produced by the oppressive discourses that form practices of colonialism in both national and domestic spaces. The domestic, then, represents a space where multiple vectors of oppression coalesce. In response to these oppressions, the novel reimagines domestic reality so as to reimagine the lives of marginalized subjects in both private and public. To this end, I argue that the novel illustrates a critical link between the violence of colonialism as enacted upon familial and domestic spaces and both the production and erasure of queer and disabled mind/bodies. Mootoo’s reconfiguration of these domestic spaces through the creation of alternate, non-hetero-patriarchal kinship structures therefore functions as a practice of resistance against colonial violence engaged in by the novel’s racialized, queer, and/or disabled characters. Queerness essentially “saves” the novel’s nonnormative and traumatized characters from what would otherwise be unspeakable pain borne through colonialism. Through establishing new ways to understand colonial trauma’s impact on queer and disabled mind/bodies, the novel provides a space through which alternative visions of identity, family, and community can emerge.

While several scholars have specifically explored the interconnections of colonial violence and queerness in *Cereus*, representations of disability within the novel have remained largely unacknowledged. Furthermore, while the topic of trauma has been a central focus of this criticism, these discussions have not been placed in conversation with the field of disability studies. If one of the central projects of disability studies is to examine disability as not merely a biomedical identity, but also a sociocultural one, then such a framework offers important insights for a text that, as I argue, represents queerness and disability as both produced and erased by colonial ideology and practice. In other words, Mootoo represents physical, mental, and sexual deviance not as the product of individual pathology, but as constructed within specific historical and cultural contexts—in this case, colonialism in Trinidad from approximately the mid-nineteenth to the early twentieth century. Mootoo's examination of disability in the context of colonialism echoes disability scholar Rosemarie Garland-Thomson's assertion that disability is not a biologically evident category, but an identity that is produced as the result of social norms that rank bodies on the basis of ability (among other attributes). In her landmark work of disability criticism, *Extraordinary Bodies*, she argues, "disability is a reading of bodily particularities in the context of social power relations… Disability, then, is the attribution of corporeal deviance—not so much a property of bodies as a product of cultural rules about what bodies should be or do."[2] As *Cereus* further illustrates, colonial ideology—including normative ideas about gender, sexuality, and ability—is often disseminated and produced within domestic and familial spaces that function as microcosms of larger colonial societies. Colonial norms function to engender trauma not only within the nation as a whole, but also within the space of the home.

Trauma has long been a concern of literary theorists, as well as medical professionals. The notion of trauma itself has genealogy, a history, especially in modern westernized and global North contexts. Literary theorist Cathy Caruth defines trauma as "the response to an unexpected or overwhelming violent event or events that are not fully grasped as they occur, but return later in repeated flashbacks, nightmares, and other repetitive phenomena."[3] For Caruth, trauma is the narrative of a belated experience that we become aware of, or whose presence is made known through an act of repetition. Trauma scholars Shoshana Felman and Dori Laub further suggest that in some parts of the world and in some cultures, traumatic experience is defined by a profound need to give testimony, to construct a narrative of a traumatic event. Like Caruth, Felman and Laub emphasize the fact that a traumatic experience is one that is not fully grasped in the moment, but that often acquires significance through the belated creation of a testimonial narrative. In other words, a testimony does not represent the truth of a traumatic experience, but rather a means of accessing that is revealed through the narrative structure of the testimony itself.[4]

From her introduction in the novel, Mala is represented as a victim of colonial and sexual trauma, which has resulted in her alleged insanity and positioned her as queer within Lantanacamaran society. When she arrives at the Paradise Alms House into nurse Tyler's care she is weak, emaciated, unresponsive to human contact, and unable to speak. Due to his training as a nurse in the Shivering Northern Wetlands (a fictionalized version of the United Kingdom), Tyler is quick to construct Mala as a trauma survivor, telling his superior: "I was in Miss Ramchandin's room, Sister. She woke up and I detected what I think are symptoms of trauma so I did not want to leave her alone."[5] Mala's inability to speak through the use of conventional language due to the trauma she has experienced results in Tyler relaying Mala's story through both his expertise in trauma and their shared queer identity. Whereas Tyler is positioned as queer within Lantanacamaran society due to his expressions of gender and sexuality, Mala is regarded as queer due to the stigma of incest, the sexual abuse inflicted upon her by her father, Chandin, and her "madness" that is the result of these traumatizing experiences.

Experienced relationally, often through the body/mind, ideas about madness change over time and from one location to another. Sociologist Andrew Scull offers one way of thinking about madness. He characterizes it as "massive and lasting disturbances of behavior, emotion, and intellect."[6] These disturbances affect not only individuals labeled as "mad," but madness as a state of being also "threatens the social order, both symbolically and practically; creates almost unbearable disruptions in the texture of everyday living; and turns our experience and our expectations upside down."[7] This definition of madness has significant implications for thinking through the ways in which disability is produced and defined by domestic spaces, as well as the extent to which domestic spaces can function as sites of disability resistance (and sites of resistance against related systems of domination as well). In this way of understanding, madness represents not necessarily a medical category or diagnosis, but a social designation used to identify persons who are mentally "other." This assignation of mental "otherness" then allows for the potential restoration of the social order disrupted by the mad person or persons through actions such as medical treatment or institutionalization, as in the case of Mala Ramchandin. Significantly, it is when her existence in the Ramchandin family home becomes overly disruptive to the fabric of everyday life in Paradise that a judge confines Mala to the Alms House. We learn that Mala's incarceration followed the discovery of her father Chandin's dead body in the basement of the family home by Otoh—a gender-variant man who is the son of Mala's former love Ambrose. Upon discovering the body, Otoh burns the house to the ground to destroy this "evidence" and protect Mala, which in turn results in her being sent to Alms House.

While Mootoo does not use specific dates within the novel, one can infer from the colonial history she fictionalizes that the narrative takes place roughly between the mid-nineteenth and early twentieth centuries. The Paradise Alms House, a home for the island's elderly or insane residents, is concurrent with other historical institutions during this timeframe that sought to manage and disappear not only the mad person, but the social disruptions caused by madness as well. In nineteenth-century Western societies (here we can assume that Paradise, as a colony of the Shivering Northern Wetlands, a fictionalized Britain, has been influenced by Western medical ideologies) regarded madness as a medical condition rooted primarily in the body.[8] In other words, madness resulted from deviance or disease located within the body of an individual and therefore could be heritable. As such, medical professionals sought in part to expand institutional infrastructures, such as state-run asylums, for the management of madness.

Late-nineteenth-century medical professionals (as well as others) also sought to establish a link between madness as biological pathology and multiple types of degenerate and immoral behavior, such as alcoholism, criminality, and sexual impropriety.[9] The notion of moral failings as both cause and symptom or indicator of madness drew important connections between madness, mental disability, and queer expressions of gender and sexuality—often regarded as both a moral failing and a mental "illness" itself. Mootoo, however, dismisses notions of madness as the product of heredity and embodied deviance, though she gestures toward them by critiquing the common belief that Mala's "deviance" is a direct extension of her parents, Chandin and Sarah. This popular (mis)conception is evidenced by the opinion that Mala is "a woman whose father had obviously mistaken her for his wife, and whose mother had obviously mistaken another woman for her husband."[10] The residents of Paradise are aware of Chandin's sexual abuse and incestuous behavior, though as opposed to regarding Mala as a victim, they instead transfer her father's deviant behavior onto her via the interconnected stigmas of incest, sexual abuse, and the trauma and mental disability they produce. Likewise, Sarah's queerness, represented by her romantic and sexual relationship with a woman, causes Mala to be regarded as queer as well. As opposed to these dominant narratives of "otherness," Mootoo allows for an understanding of madness as having both social and embodied dimensions. Through Tyler's astute ability to discern Mala as a person who has been multiply traumatized, madness is presented as a state of being that is embodied, but intimately connected to a larger social and cultural context of colonialism that polices the boundaries of gender, sexual, mental, and ethno-racial normativity.

While Mala is unable directly to narrate the story of her trauma, it is nonetheless exposed through her bodily performances, echoing Caruth's notion that traumatic experience can never be fully grasped in the moment, but can be deciphered and understood through the repetitive behaviors that trauma incites. Mala is, in part, positioned as a victim of trauma through her repetitive behaviors of building furniture walls to isolate herself from experiences she perceives as threatening, her ingestion of hot peppers to deaden her senses, her retreat into the wildness of her garden, her collecting of snail shells as symbols of protection, her mimicry of insect and bird languages, and her imagining of her childhood self, Pohpoh, as a separate person for whom she must care and whom she protect. Perhaps most significantly, Mala keeps her father's body chained to a bed in the basement of the Ramchandin house long after his physical death. Due to his medical training, his close physical contact with Mala's body, and the information told to him by Otoh, Tyler is able to construct and narrate Mala's past by reading her bodily performances, which continue to reenact the traumatic history not only of Mala Ramchandin, but also of colonial Lantanacamara as a whole. Mala thus functions within the novel as the vehicle through which a cultural history of trauma is carried, transmitted, and understood.

Tyler is also able to read Mala's traumatic history because of the pair's shared queer and outsider status within Lantanacamaran society. As cultural scholar Gayatri Gopinath, whose work examines the intersection of queer sexualities and South Asian diasporas, argues, "Queerness in *Cereus* … extends to all those bodies disavowed by colonial and national constructions of home: bodies marked by rape and incest; biologically male bodies that are improperly feminine … and biologically 'female' bodies that are improperly masculine."[11] Though Gopinath does not explicitly mention disability in her definition of queerness, it can be argued that characters positioned as mad, mentally ill, or traumatized fall within the types of queerness explored within the novel. Likewise, bodies whose expressions of gender defy social norms in that they are improperly masculine or feminine, or who move away from the gender identities they were assigned at birth, can also be read as disabled to the extent that they are pathologized for their defiance of gendered cultural expectations.

Mala and Tyler's shared queerness is emphasized during a scene in which Tyler performs for Mala dressed in a female nurse's uniform that she has stolen expressly for him. Tyler describes this experience as follows: "I stared speechlessly at the calf-length dress and the stockings… I felt she had been watching me and seeing the same things everyone else saw. But she had stolen a dress for me. No one had ever done anything like that before. She knows what I am, was all I could think. She knows my nature."[12] During Tyler's performance of femininity, Mala reacts indifferently, exhibiting neither joy nor displeasure. Tyler reads Mala's unusual response in the following manner: "The reason Miss Ramchandin paid me no attention was that, to her mind, the outfit was not something either to congratulate or scorn—it simply was. She was not one to manacle nature, and I sensed that she was permitting mine its freedom."[13] Mala's understated response can be read as recognition of a commonality, a shared identity, between herself and Tyler as queer survivors of trauma. It is also during this scene in which Mala first builds one of her furniture walls at the Paradise Alms House. Just as Tyler has exposed his queerness through performing femininity, Mala similarly exposes herself through her own performance of building the wall, a clue that will give Tyler a point of access into the narrative of her traumatic history and Mala's resulting disabilities. Tyler thus becomes established as a capable witness for Mala's traumatic testimony and disabled subjectivity.

Tyler and Mala's shared status is also made apparent in Tyler's direct discussion of the difficulties involved in witnessing or relaying her testimony. Although Tyler notes that his intentions are to tell Mala's story as accurately as possible without overtly including his own traumatic history, he also notes that to do so is impossible, as his experience is intricately bound not only to Mala's, but to the larger history of Lantanacamara itself, an association which echoes cultural scholar and affect theorist Ann Cvetkovich's notion of a "culture of trauma" as opposed to an experience of trauma isolated to the lives of particular individuals.[14] Such an understanding of a larger history of colonial trauma that impacts Lantanacamaran society as a whole allows for a reading of Mala, in particular, not as pathological or mentally ill, but as a subject enmeshed within a collective narrative of trauma that both produces and negates queer and disabled subjects. Tyler opens the novel by stating: "Might I add that my own intention, as the relater of this story, is not to bring notice to myself or my own plight. However, I cannot escape myself, and being a narrator who also existed on the periphery of the events, I am bound to be present. I have my own laments and much to tell about myself."[15] While Tyler is writing to a general audience, more specifically, his narrative seeks to address Mala's lost sister Asha, who fled from Lantanacamara many years ago: "It is my ardent hope that Asha Ramchandin, at one time a resident in the town of

Paradise, Lantanacamara, will chance upon this book, wherever she may be today, and recognize herself and her family."[16]

In creating a textual account of Mala's trauma, Tyler draws attention to how the performance of reading and interpreting a text continues the transmission of traumatic memory. While Tyler functions as a witness to Mala's testimony, his specific address to Asha exposes his desire for her to function as a witness not only to Mala, but to his own testimony of trauma as well. The recirculation of a trauma is not restricted to a singular performance of a testimony, but rather, traumatic knowledge is transmitted through multiple interconnected acts of testifying and witnessing. That Tyler's address is both general and specific also seeks to implicate not just Asha, but every potential reader within the traumatic history represented by his written account. Here, Mootoo posits that writing, or the creation of narrative, functions as a means of understanding trauma, allowing subjects to reflect and remember so that they can eventually move on. Despite Tyler's attempts to downplay the trauma he has experienced due to his gender and sexuality, he ultimately realizes that his own trauma is merely an extension of Mala's, of Lantanacamara's, and of a greater colonial history.

Like Tyler, the character Otoh Mohanty is also positioned within the novel as a sensitive and insightful reader of Mala due to a shared queer status and history of traumatic experience. Otoh's initial interest in Mala's story stems from an earlier site of trauma between his father Ambrose, Mala's former love, and Mala. When Chandin discovers the relationship between Ambrose and his daughter, he flies into a rage, brutally raping Mala while Ambrose helplessly looks on, unable to intervene. Although Ambrose later goes on to marry Elsie and father Otoh, he too, is scarred by his witnessing of this traumatic experience as his past ties with Mala haunt him, remaining ever-present. Like Mala, Ambrose's experience is also marked by a series of repetitive behaviors that label him a trauma survivor. Most obviously, he spends much of his life asleep, awakening only long enough to replenish Mala's house with supplies. Sleep, for Ambrose, acts in ways similar to Mala's ingestion of hot peppers, which she uses to block the pain of the past. Although Otoh is initially unaware of his father's history with Mala, he is indirectly affected by the lingering effects of their collective traumatic history. Otoh, who is assigned a female identity at birth but later identifies as masculine, can be read as assuming this role within the Mohanty familial structure, in part, as a means of taking the place of an absent father who is perpetually asleep.

As with Tyler, Mootoo again positions gender creativity and sexual diversity not wholly as sites of liberation from the confines of gender binaries, but as identities that profoundly intersect with histories of violence and trauma. Cvetkovich notes that "Mootoo constructs Lantanacamara … as a scene of both traumatized and queer sexualities … she refuses to present a simple picture of homosexuality, [transgender] identity, or other queer sexualities, which are also neither romanticized nor pathologized."[17] Otoh's desire to gain access to Mala's story is also a desire to understand the traumatic events and secrets that mark his own family history, and he soon establishes a tenuous trust with Mala, who mistakes him for Ambrose, returned from his self-imposed isolation. Of his strong compulsion to learn more about Mala, Otoh tells Tyler:

> I felt as though she and I had things in common. She had secrets and I had secrets. Somehow I wanted to go there and take all my clothes off and say, "Look! See? See all this? *I am different!* You can trust me, and I am showing you that you are the one person I will trust. And I am one person, for sure, for sure, that you can trust. I will be your friend."[18]

Otoh feels that Mala is the one person whom he can trust with his own secret, his own traumatic history, because he knows she is similarly marked. In removing his clothing, he desires to illustrate for Mala their shared queerness, made apparent through the physical text of Otoh's body (what in Lantanacamara would be regarded as "female" anatomy) that is incongruous with his masculine gender expression.

Together, the pair reenacts the unfinished scene of trauma between Mala and Ambrose, as Mala reveals to Otoh-Ambrose the secret contained in the basement of the Ramchandin house: Chandin's dead body, tied to a bed and covered in moths. Chandin's restrained body exposes the fact that, for Mala, the trauma of her father's sexual abuse is not over, or past, but remains continually present and threatening. When Otoh runs in fear from the sight of Chandin's body, fainting in the middle of the road and drawing the attention of the citizens of Paradise, Mala's secrets become exposed to the town and the narrative of the novel comes full circle, as Mala is subsequently sent to the Paradise Alms House and into Tyler's care. The structure of the novel mirrors the structure of a traumatic testimony itself, as it evolves circularly and draws attention to the fallible nature of memory and witnessing. As Tyler observes: "Forgive the lapses, for there are some, and read them with the understanding that to have erased them would have been to do the same to myself."[19] At a different point, Tyler also notes that the telling of Mala's story is an attempt at "fashioning a single garment out of myriad parts."[20]

Through an exploration of a collective, as opposed to an individual, history of trauma, Mootoo avoids placing blame for Mala's abuse on characters such as Chandin, Sarah, and Lavinia, instead positioning their actions within a larger framework that seeks to understand their motivations through a shared history of traumatic experience. Whereas it would be easy to read Mala's trauma solely within a narrative of sexual abuse, her connection to Chandin's traumatic history places both characters firmly within a larger narrative of colonial violence and exploitation that has been enacted on the lives of South Asian immigrants to the Caribbean and their descendants.[21]

Chandin left his village of birth to live as an indentured field laborer in Lantanacamara and receive a Christian education from Reverend Thoroughly and his family. Chandin is barred from marrying the Thoroughlys' daughter, Lavinia, due to his inferior ethno-racial status. He instead marries Lavinia's closest friend, Sarah, a fellow Indian immigrant. Chandin is later enraged to learn that Lavinia is slated to marry a man who is her cousin, and questions why this "unusual" union is to be permitted while the possibility of his own marriage to Lavinia has been foreclosed. When Chandin learns of the relationship between Lavinia and his wife, he is again enraged by the impossibility of a relationship with her. When both women flee the island, Chandin's rage is redirected at his daughters, who become the focus of his anger at a system of colonialism that has erased not only his desire, but the whole of his identity.

Chandin's hatred of colonial authority is also represented by the image of the gramophone that Ambrose brings from the Shivering Northern Wetlands as a present for Mala. When Chandin unexpectedly returns home from work, catching Mala and Ambrose dancing in the kitchen to the gramophone's music, he flies into his last abusive rage, a rage that motivates Mala to fatally injure her father, chain him to the bed in the basement, and build a wall of furniture to isolate her from the basement door. While on the surface, Chandin's anger appears to be directed at the relationship between Mala and Ambrose, it is also at the larger implications of what such a relationship represents. For Chandin, Ambrose and his gramophone represent a system of colonial power and authority that he cannot control or master:

> Chandin grabbed the edges of her [Mala's] bed and flipped it over. He saw the new box. Opening it and seeing the gramophone, he put his face in both

> hands and cried. For several minutes he contemplated the gramophone and what it seemed to signify. He lifted the needle arm and pulled it backwards. It snapped as easily as a crab's leg.[22]

Chandin's abuse of Mala is not a redirected sexual desire because of the loss of his wife and the object of his affection (Lavinia), but an attempt to gain agency through the possession and control of his daughter. Chandin cannot exert power over the discourses of colonialism that have dispossessed him, but he can exert power over Mala, just as he can seemingly overpower the gramophone and all it represents through the snapping of its arm. In creating such a narrative of (fictional) Trinidad's colonial history, Mootoo resists representing Chandin as the sole cause of Mala's disabilities, instead seeking to understand and reveal the motivations behind his actions through positioning him, as well as the novel's other characters, within a larger framework of colonial disempowerment. Cvetkovich observes that Mootoo "embeds sexual violence squarely within the context of migration, depicting South Asian diaspora as a crucial background for Chandin's history with Mala, and Sarah and Lavinia's flight from Lantanacamara central to the Ramchandin family trauma."[23] The erasure of Chandin's desire and the devastating effects of colonial power on the Ramchandin family are also linked to Mala's disabled/queer status and the near impossibility of the inclusion of Tyler and Otoh's identities within Lantanacamaran culture. Just as colonial violence has essentially queered the Ramchandins through a breakdown of the traditional hetero-patriarchal family, Mala, Tyler, and Otoh have similarly been positioned as queer through the public disavowal of their identities.

When Mala, Tyler, Otoh, and Ambrose unite at the Paradise Alms House, they construct a productive, affirming, and queer-disabled site of kinship in a location that is ironically a "home" designed for society's least valued members (the elderly and insane). Together, the group forms a new familial structure based not on biological ties, but on the shared experiences of trauma and queerness disability. As Gopinath observes, "The novel suggests that queer bodies and queer desires become the means by which to escape the totalizing logic of the colonial order."[24] This new structure forms just as the cereus flower, transplanted from Mala's garden to the Paradise Alms House, is preparing to blossom. The presence of the cereus draws an important connection between the newly created family and Mala's own resistance to colonial and patriarchal authority as represented by her unusual "care" of the Ramchandin family home, or what Gopinath terms as her alternative practices of "housework."[25]

Mala's intentional "neglect" of the house and the garden is not a product of mental instability, but rather, her wild cultivating of native Lantanacamaran plants and insects are acts of resistance not only against the abuses of her father, but against the destructive history of colonial domination. In allowing her father's dead body be taken over by the natural forces of the island, a similar act of resistance is achieved, implicating not only Chandin in the novel's representations of sexual abuse, but positioning him within a larger history of colonial exploitation.

Together, Mala and Ambrose resist colonialism through their shared interest in native species of insects. Whereas Ambrose trains to become an entomologist in the Shivering Northern Wetlands, returning to Lantanacamara with his newly gained knowledge in hopes of helping his people to repair the devastating effects of colonialism, Mala's use of insect and bird languages accomplishes a similar defiance of patriarchal colonial authority: "[Her] companions were the garden's birds, insects, snails and reptiles. She and they and the abundant foliage gossiped among themselves. She listened intently… Flora and fauna left her to her own devices and in return she left them to theirs."[26] Here, Mala attempts to understand and live with difference as opposed to eradicating it, a stance that positions her in profound contrast to colonial discourse.

The cultivation of plants and insects as a response to colonialism is made explicit during a scene in which a young Mala and Ambrose watch a group of boys torture and burn a praying mantis in the schoolyard. Ambrose realizes the boys are experimenting based on a lesson their teacher has taught them. He tells Mala, "You see, the other day we learned about the reflexes of plants. Teacher said plants respond to gentleness. He told us too that plants could show signs of trauma. Watch this. I bet they're going to experiment based on that idea."[27] Just as the characters within the novel exhibit signs of trauma, the physical landscape they inhabit does as well. After witnessing the torture of the praying mantis, Mala and Ambrose decide to rescue a family of periwinkle snails from the boys' violence by transporting them to safety. In allowing the snails to flourish, Mala and Ambrose directly resist a patriarchal colonial authority that seeks to control and tame both the physical and the psychic landscapes of Lantanacamara.

Mootoo's descriptions of the Ramchandin home and the landscape of Lantanacamara draw upon and revise tropes from nineteenth-century Gothic fiction, namely that of the atmospheric Gothic mansion, to further explore the impact of colonialism upon queer and disabled subjects. *Cereus* can be read, in part, as a Caribbean revision of a nineteenth-century

Gothic novel, namely, Charlotte Brontë's *Jane Eyre*. As literary critic Lizabeth Paravisini-Gebert notes, the Gothic was "from its earliest history in England and Europe, fundamentally linked to colonial settings, characters, and realities as frequent embodiments of the forbidding and the frightening," where the circulation of the Gothic form to the Caribbean can be read as a function of colonialism itself.[28] *Jane Eyre* was also one of the first novels to utilize representations of madness or mental disability as a central driving force of the narrative.[29] Therefore, it is not difficult to see why Mootoo appropriates the Gothic as a particularly effective form through which to examine and critique the intersections of colonialism and madness. Paravisini-Gebert further argues that "the Gothic, especially in the Caribbean, has become a part of the language of the colonized" themselves.[30] As Trinidad was a former British colony, it is plausible that Mootoo encountered *Jane Eyre* as part of her education, and utilized this text as a model for her own explorations of gender and madness, transposed to a colonial context.

Mootoo's use of a Caribbean landscape, in which the native plants and insects literally take on a life of their own and overrun the Ramchandin home, functions within the novel to evoke the terror of colonialism and gendered violence. The Ramchandin house can literally be read as the transposition of a Gothic mansion, such as Rochester's Thornfield Hall, into a distinctly Caribbean setting. As Cvetkovich observes, the Ramchandin house becomes "a Gothic house run wild with the tropical growth of a colonized island."[31]

In their landmark work of feminist literary criticism, *The Madwoman in the Attic*, Sandra M. Gilbert and Susan Gubar argue that Thornfield Hall "is more metaphorically radiant than most Gothic mansions: it is the house of Jane's life, its floors and walls the architecture of her experience."[32] Following this reading of Thornfield as not merely an atmospheric Gothic trapping that ornaments Brontë's novel, but as laden with metaphorical significance, the Gothic house in *Jane Eyre* can be read as a mirror representation of the human body in which the attic, where the "mad" Bertha Mason is confined, represents the masculine and patriarchal space of the rational mind or intellect. Bertha's confinement thus symbolically represents both the patriarchal forces that caused her madness and her continued imprisonment by male-dominated English society. Brontë's use of the Gothic-house-as-body illustrates the extent to which normative expectations of race, gender, sexuality, and ability are conveyed through both the physical and ideological structure of domestic spaces.

Through her alleged insanity and irrationality, Mala draws obvious comparison to Bertha Mason, Rochester's first wife. While Bertha is imprisoned by Rochester in the attic of Thornfield Hall, Mootoo enacts a reversal of Brontë's plot in which the so-called mad woman is left to her own devices within the space of the Gothic home, and the patriarch is imprisoned not in the lofty space of the attic, but in the dark, moist, feminine depths of the basement. As opposed to confining the madwoman and thus representing her mental differences as other, Mootoo instead condemns the sexual violence that often results in madness and trauma by confining the abusive patriarch in a feminized and anti-patriarchal domestic space. In Mootoo's revision of Brontë, the mad woman, as opposed to being imprisoned, is able to exact her revenge upon the abusive patriarch to the extent that her madness results not in her demise, but functions as a condition that allows her to cope with her experiences of trauma and thus ensures her survival. Following Chandin's confinement in the basement, Mala no longer enters the family house and instead seeks refuge in the freedom of her garden. Whereas the domestic space of the house represents the convergence of colonial and patriarchal oppression, Mala's reconfiguration of the garden-as-home positions counter-domestic spaces as important sites of resistance for colonized queer and disabled subjects.

Mala's use of the garden as a site of resistance echoes Mootoo's own experiences of sexual abuse during her childhood in Trinidad. Responding to the garden themes that appear frequently in both her literary and visual work, she states:

> I lost myself in the garden. The garden was the safest place, the best place for me. So, you will see a lot of garden stuff in my pictures and so on. It was much safer than inside the house, because there were repercussions from me being abused in the house, but my parents did not know that that's what it was. I don't know if they knew or not, but that's what part of the problem was. Anyway, my escape was the garden.[33]

Like Mala, because Mootoo's childhood home was not a space of safety, but rather one of abuse, her family's garden became, for her, a counter-domestic site of resistance, both physically and also ideologically through the use of botanical themes and metaphors in her work. In positioning the garden as home, Mootoo effectively queers/disables the notion of domestic spaces as representative of safety and refuge and nondomestic spaces as representative of risk, harm, and disorder.

Just as Mala queers/disables the Ramchandin house, Tyler and Otoh also create alternate forms of kinship throughout the novel. Otoh creates an alternate version of the home by assuming a masculine role while Ambrose is perpetually asleep and absent. Because Otoh was identified as female at birth, his assuming of a masculine posture challenges patriarchal masculinity, and by extension, the structures of kinship associated with it. While Otoh reimagines the masculine role of the father, Tyler reimagines the role of the mother through his assuming a feminine gender expression and the position of caregiver and nurse to Mala. Tyler effectively becomes Mala's mother, replacing Sarah, the mother who fled. Due to Tyler's care, Mala no longer has to live as a split self, being both the child Pohpoh and the adult Mala who must care for and mother her. Just as Mala takes pleasure in her queering of the Ramchandin home, she takes similar pleasure in Tyler's queer expressions of gender, again positioning queerness, multiply defined, as a strategy for resisting and reimagining colonial trauma.

In creating an understanding of colonial violence, madness, queer expressions of gender and sexuality, and the domestic as interconnected, *Cereus Blooms at Night* provides new understandings of the impact of traumatic experience on colonized subjects. Mootoo seeks to de-pathologize queer and disabled subjects by locating trauma not within the individual, but within a collective history of colonialism that impacts both nation and home. The novel further illustrates how trauma can function as a point of departure from which to construct alternate visions of community and identity, as the traumas of the past need not repeat themselves unaltered, but can be positively shaped toward the goals of empathy and healing. Such an understanding of trauma is productive, not destructive, transformative, not debilitating. Through claiming "otherness" in the forms of queerness and disability, Mootoo's traumatized characters gain access to a language that critiques, concurrently, violence within the nation and violence within the home.

The novel's queer, disabled, and traumatized characters transform domestic spaces, namely, the Ramchandin family home and the Paradise Alms House, which traditionally function as sites for the management and containment of difference, into spaces where difference is valued and can thus flower and grow. Within these counter-domestic spaces, "otherness" is embraced as a positive and socially transformative attribute out of a desire to create nurturing and supportive kinship structures otherwise denied due to the violence of colonialism in the Caribbean and its impact upon South Asian immigrant families and their descendants. Like the mysterious and short-lived night-blooming cereus itself, whose strange beauty and intoxicating scent mitigates the trauma represented within the novel, Mootoo's characters, through the revaluation of traditionally oppressive domestic spaces, construct pockets of resistance where "otherness" can, if only for a limited amount of time, bloom.

NOTES

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3. Cathy Caruth, *Unclaimed Experience: Trauma, Narrative, and History* (Baltimore: Johns Hopkins UP, 1996), 91.
4. Shoshanna Felman and Dori Laub, M.D., *Testimony: Crises of Witnessing in Literature, Psychoanalysis, and History* (New York: Routledge, 1992), 15.
5. Mootoo, *Cereus*, 14.
6. Andrew Scull, *Madness* (New York: Oxford UP, 2011), 3.
7. Scull, *Madness*, 2.
8. Ibid., 48.
9. Ibid., 59.
10. Mootoo, *Cereus*, 109.
11. Gayatri Gopinath, *Impossible Desires: Queer Diasporas and South Asian Public Cultures* (Durham: Duke UP, 2005), 184.
12. Mootoo, *Cereus*, 82.
13. Ibid., 83.
14. Ann Cvetkovich, *An Archive of Feelings: Trauma, Sexuality, and Lesbian Public Cultures* (Durham: Duke UP, 2003), 3–4.
15. Mootoo, *Cereus*, 3.
16. Ibid., 3.
17. Cvetkovich, *An Archive of Feelings*, 152.
18. Mootoo, *Cereus*, 133.
19. Ibid., 3.
20. Ibid., 113.
21. Gopinath, *Impossible Desires*, 179–181.
22. Mootoo, *Cereus*, 241.
23. Cvetkovich, *An Archive of Feelings*, 147.

24. Gopinath, *Impossible Desires*, 185.
25. Ibid., 185.
26. Mootoo, *Cereus*, 137.
27. Ibid., 97.
28. Lizabeth Paravisini-Gebert, "Colonial and Postcolonial Gothic: the Caribbean," in *The Cambridge Companion to Gothic Fiction*, ed. Jerrold E. Hogle (New York: Cambridge UP, 2002), 229.
29. Scull, *Madness*, 53.
30. Paravisini-Gebert, "Colonial and Postcolonial Gothic," 254–255.
31. Cvetkovich, *An Archive of Feelings*, 141.
32. Sandra M. Gilbert and Susan Gubar, *The Madwoman in the Attic: The Woman Writer and the Nineteenth-Century Literary Imagination* (New Haven and London: Yale UP, 1979), 347.
33. "Interview with Shani Mootoo," The British Columbia Institute Against Family Violence, fall 1993, http://www.bcifv.org/backiss/nf_shani.html/

CHAPTER 12

Gatekeepers of Normalcy: The Disablement of Families in the Master Narratives of Psychology

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The relationship between disability studies and psychology is problematic at best. Mainstream psychology, with its dichotomous formulations of normal and abnormal behavior, conceptualizes disability as pathology and locates it within individual minds or bodies; "problems" for people with disabilities are understood as originating solely from their impairments, rather than from sociopolitical environments in which they are often denied access or devalued.[1] Indeed, the central tenets of mainstream psychology, including its emphasis on empiricism and rejection of positionality, may be at odds with the constructivist perspectives in disability studies which, rather than focusing on individuals' impairments, call attention to the oppression and discrimination experienced by disabled people.[2] At its core, psychology is conceptually concerned with an understanding of the *individual*, and as Dan Goodley points out, perhaps it is this fundamental focus on individualization that lends sanction to disablement; in training its practitioners to intervene at the individual level,

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mainstream psychology leaves societal practices largely unchallenged and, consequently, the environment largely unchanged.[3]

In this essay, I unpack master narratives on families of children with disabilities and trace them to the theoretical frameworks in which they are based. To make my arguments, I use examples from research literature as well as preservice literature aimed at preparing mental health, social work, counseling, or rehabilitation professionals to work with this group of families. I discuss two categories of narrative themes with regard to these families which are pervasively present in this body of literature: (1) those which cast children with disabilities as representing burden, "tragedy," and profound loss for families and (2) those which position parents as pathological, dysfunctional, irrational, or in "denial." In the following sections, I problematize these institutionalized narratives, rooted in ableist ideologies, which lend support to perceived notions of the otherness of some families.

The Pathologizing of Families in Early Psychoanalytic Theories

The casting of parents of children with disabilities as part of the "problem" (of disability) is situated in a long history of ascribing blame to this group of parents, dating back to early Western civilizations, when the birth of children with visible malformations or disabilities was understood as indication that their parents had offended the gods.[4] Much later, the practice of institutionalizing children with disabilities was, at least in part, driven by beliefs about the inability of some people to be effective parents. Although the theme of "parent as problem" is a historically recurrent one, perhaps nowhere do we find it more emphatically pronounced than in early psychoanalytical theories. Freud explicitly located the blame for children's problems in parents; his original views were that neurosis in children was caused by actual sexual abuse in childhood, and it was only after these theories became rejected that his theories evolved to focus on children's fantasies of seduction.[5]

In the mid-twentieth century, troubling behavior among children was explained as being caused by "psychogenic mothers" whose personality, sexuality, or emotionality made for dysfunctional parenting.[6] Rooted in Freudian theories which held parents responsible for children's conditions, psychoanalysis cautioned against engaging with parents of troubled children in any way; according to Freud, any attempts to educate parents about their children's condition would make them interfere in their treatment, and similarly Anna Freud posited that parents' excessive demands caused children to retreat and become neurotic.[7] In psychoanalytic discourses, the notion of the "schizophrenogenic mother" took hold, supporting the idea that professionals were the experts on the care of children with disabilities—thus implicitly and explicitly sanctioning the institutionalization of disabled children and contributing to the disempowerment of families.[8]

During the mid-twentieth century, Kanner theorized about a connection between autism and a lack of maternal warmth. Theoretically based in a post-Freudian psychoanalytic framework, and championed by psychoanalyst Bruno Bettelheim, the notion of the "refrigerator mother"—a cold, rejecting mother who was unable to establish a secure bond with her child—took hold as the causal factor in autism.[9] Theories about refrigerator mothers were rooted in assumptions about dysfunctional and ineffectual parents (in this case, specifically mothers); parents who resisted these notions were dismissed as denying reality by refusing to accept the expert opinions of professionals.[10] It is worth noting that the interpretive lens of "bad mother," which explicitly offered an explanation of autism, also served implicitly to maintain racial, social class, and gender hierarchies. As Jordynn Jack explains, not only was the characterization of the refrigerator mother highly gendered (autism was not thought to be caused by cold, rejecting fathers), it was also racialized and restricted by social class; a diagnosis of autism was generally not ascribed to black children (who were more likely to receive a label of intellectual disability), and as such, refrigerator mothers were understood to be women who were white, middle to upper-middle class, and well educated.[11]

Families of children with disabilities, like all families, exist within sociopolitical environments and institutional structures. In the following sections, I discuss master narratives about parents who resist institutional discourses or question the opinions of professionals. Therefore, my framing of the oppression of families of children with disabilities as background for this chapter is intentional; I aim to situate my arguments which follow in the context of historical events in which there were profoundly negative outcomes for those who did not resist institutional pressures, those who did not question professionals' opinions. Indeed, in light of the damage wrought to families in the past as a result of unquestioned compliance with professionals' recommendations, it is remarkable that even today in cultural and institutional narratives, children with disabilities continue to be positioned as tragedy, and parents who question experts' knowledge—as the problem.

Burden, Grief, and Profound Loss: Child as Problem

Mental health professionals have long scrutinized families of children with disabilities using a medical model of disability that focuses on impairments and frames disability as a universally negative experience.[12] Master narratives on the birth of a child with a disability, rooted in the theories of mainstream psychology, center on themes of grief, loss, burden, and "tragedy." In early psychoanalytic literature, there were many references to parents' predominantly negative adjustment in response to their children's disability diagnoses.[13] Later, others like Charles Huber adapted Elizabeth Kubler-Ross' stage theory of grieving, in which she identified progressive stages of adjustment to death and dying, in their efforts to understand the ways in which parents adjusted to their disabled child.[14]

Early research on this group of families, informed by the medical model paradigm, supported the notion that the birth of a child with a disability was a traumatic event and that parents of disabled children were in a persistent state of grief.[15] In due course, the framing of the birth of a child with a disability as profound loss became a mainstay in professional discourse and practice; indeed, future professionals in the field of counseling, nursing, or social work have been explicitly indoctrinated to expect a period of mourning among parents of children with disabilities.[16]

Today, there is no dearth of research that explores the "grieving" processes of families of children with disabilities and asserts that this group of parents experience high levels of stress or negative emotions.[17] However in a body of literature that focuses on stressors for families of children with disabilities, the source of the "problem" is located *solely* in the children—more specifically, in the children's impairments. For instance, decades ago, Florence Kaslow and Bernard Cooper stated:

> Almost from the very beginning … the learning disabled (LD) child presents a problem to his parents. They are confused by their youngster's "differentness" prior to the diagnosis and often feel frustrated in their interactions with their child and annoyed at the lack of "normal" responses and behavior.[18]

This narrative has remained relatively unchanged. More recently, Gilbert Foley similarly asserted that the birth of a child with a disability "signals a potential threat to the spirit as well as to the daily and future life of the parents."[19] Here, "threat" is located in the impairment; threat is not understood as existing within the context of sociocultural attitudes that stigmatize or devalue children with disabilities, nor in the difficulties families may experience in accessing services or supports. Sara Green points out that "the majority of research on caring for children with disabilities has emphasized the emotional distress of having a child with a disability and de-emphasized both the benefits of caring and the negative consequences of stigma and socio-structural constraints."[20]

Parents who do not fit professionals' expectations in terms of their responses to their children's diagnoses are described as either "denying" their grief or as unable to "accept" the reality of caring for a child with disability.[21] Generally in medical model research on this group of families, parents' adjustment to their children's differences is decontextualized from discursive practices in society. It is also important to note that in traditional research, based on professionals' work with predominantly white, middle-class families residing in the USA, there is little room for subjectivity in interpretations of disability; alternative pathways in familial adjustment to a child with a disability are not considered and there is little acknowledgement that perceptions of a disability diagnosis are embedded in the context of sociocultural attitudes toward disability.[22] In presuming to locate the source of these parents' stress and "grief" in their children's impairments, these master narratives rely on medical discourses that pathologize disability and cast it as "tragedy," thus leaving the environment largely unquestioned.[23]

"In Denial": Parent as Problem

It is fair to say that the contexts within which families raise children with disabilities have changed drastically in recent decades. Parents are no longer routinely advised to institutionalize their children. The early psychoanalytic theories, with their focus on dysfunctional parenting, are not in favor, and the notion of "refrigerator mothers" has long been discredited. In contrast, there is growing understanding of the need for professionals to engage with families of children with disabilities. Current educational laws position parents as equal partners in educational decision making, and in many professional contexts, there is greater understanding of the need for professional–family collaboration and the importance of understanding parents' perspectives.[24]

Despite these changes, however, the early psychoanalytic theories which linked children's emotional difficulties to malignant or ineffectual parenting have left a lasting legacy, influencing the ways in which professionals understand families and shaping cultural narratives on parenthood. This is evident in good mother–bad mother binaries in most Western cultures, and among those most affected are parents of children with disabilities who have been either idealized or villianized in professional discourses—either valorized for their courage or dismissed as being "in denial" of their children's limitations.[25]

The body of literature on parents of children with disabilities in the 1960s and 1970s was situated in assumptions about negative outcomes or pathological functioning among this group.[26] For instance, Kaslow and Cooper implicated parents as contributing to the problems for children with disabilities, as a result of their "overly punitive or overly indulgent behavior," their feelings of ambivalence, rage or depression, and their overinvestment in their children.[27] In this regard, it seems that not much has changed over the past few decades; dysfunctionality continues to be the lens through which we view families of children with disabilities. The notion that parents' decisions are often compromised by their feelings of grief, guilt, shame, or by their "denial" of their children's disabilities is a pervasive theme in cultural and institutional narratives on these families.[28] In professional discourses, parents—especially those from culturally diverse or lower socioeconomic backgrounds—are often positioned as needing to be "fixed," and mothers in particular, become constructed by professionals as being too subjective and therefore needing guidance by experts.[29]

Among the most pervasive themes in master narratives on families of children with disabilities pertains to the notion that these parents may, either temporarily or for an extended period of time, be "in denial" (i.e., unable or unwilling to "accept" their children's disabilities). Indeed, in preservice literature aimed at preparing counselors, social workers, or rehabilitation professionals to work with this group of parents, we are often explicitly instructed to expect among them an initial period of "denial" of their children's disabilities.[30] Decades ago, Kaslow and Cooper, in discussing parents' reactions to a child's diagnosis of disability, stated, "First there is denial of the problem."[31] This narrative has remained largely unchanged over time; discussions about parental denial are frequently found even in more current literature that is genuinely aimed at helping professionals work more collaboratively with families. For instance, Chrissie Rogers informs us that "denial and shock in reaction to a diagnosis and the potential loss of the 'normal' are common when faced with a diagnosis at birth, but are not exclusive to early years diagnosis," and Milton Seligman and Roslyn Darling assert that, due to parents' feelings of extreme anxiety, they may "deny the reality of their child's disability."[32]

The use of the term "denial" in the context of psychological functioning is rooted in Freudian psychodynamic theory, where it is understood as a self-protecting, unconscious defense mechanism "used to resolve emotional conflict and allay anxiety by disavowing thoughts, feelings, wishes, needs, or external reality factors that are consciously intolerable."[33] In post-Freudian psychology, the deployment of the concept of denial in mental health practice has been informed by the Kubler-Ross' stage theory on the ways in which individuals come to terms with death and dying.[34] Kubler-Ross explained denial as a temporary defense against an uncomfortable and painful situation, which is soon replaced by at least a partial acceptance of the reality of the situation; she posited that all patients confronted with the news of their terminal illness exhibited denial.

Although Kubler-Ross' stage theory focused specifically on the psychological processing of death and dying, mental health professionals have used her framework to explain individuals' reactions to other forms of loss, which is to say, situations that are socioculturally understood as loss. As such, this model has been unquestioningly adapted to fit professionals' interpretations of the ways in which parents respond to a diagnosis of childhood disability.[35] For example, according to Barnett et al., grieving is typical among parents of children with disabilities and denial is a factor that hinders their acceptance of a disability diagnosis.[36]

It is important to acknowledge that the work of various scholars that I reference in this chapter is, I believe, genuinely focused on gaining a better understanding of parents' varied experiences of raising children with disabilities.[37] Their perspectives are grounded in beliefs about the value of professional–family collaborations and the imperative need for mutual trust and respect between parents and professionals; as such, they make valuable contributions to preservice literature. My intention therefore is not to discredit or undermine their work. However, I aim to draw critical attention to the ways in which scholarship aimed at strengthening professional–family relationships may be influenced by the legacies of early psychoanalytic theories, with their implicit assumptions about dysfunctionality among families and the objectivity of the clinician. These discourses reify beliefs that parents' emotional states may sometimes stand in the way of their children's best interests, and therefore they should be further unpacked. In attempting to understand claims about parental denial, perhaps it is necessary to take a closer look at the particular actions or reactions reported by parents, which are interpreted by mental health researchers or practitioners as indications of their being in denial.

In studies that explore parents' reaction after hearing a disability diagnosis, it is documented that many parents report initial feelings of shock, disbelief, or overwhelming sadness.[38] It is likely that their reported disbelief may be interpreted as indication of denial. More commonly however, parents who elect to seek a second (or third) opinion about their children's diagnoses, those who reject particular diagnostic labels, or those who "shop" for a different diagnosis are categorized as being in denial.[39] With regard to this, Kaslow and Cooper state,

> The routine of 'doctor shopping' will probably occur as the parents try to find someone who can allay their fears, but this is not possible… Then comes the moment of truth—the need to deal with the child's limitations.[40]

It is worth noting that in narratives on parental denial, positivist language which alludes to a universal nature of disability is ubiquitous; diagnoses are understood as "truth" and parents' alternative interpretations of their children's difficulties are positioned as a refusal to accept the objective opinion of professionals or a universal "reality." For example, Drotar et al. state, "Denial is the stage in which parents try to escape from the reality by disbelieving the diagnosis."[41] Similarly, Cook, Klein, and Tessier assert that "it is a professional's responsibility to help families cope with the demands of their reality."[42] In these discourses there is little acknowledgement that the phenomenon of disability is itself a sociopolitical construct; in language which positions the disability diagnosis as reality or truth, critical questions about what counts as a disability and more importantly, who gets to decide, become obscured.[43] For example, Seligman states that the parental defense mechanism (of denial) interferes with an "objective appraisal of a situation or an event."[44] Here, the "objective appraisal" is understood to be that of the professional; parents become positioned as irrational, subjective, and counterproductive, and disability labels are reified as universal.

Narratives on parental denial seem to suggest that parents should unquestioningly accept professionals' opinions; as such they validate the notion that "experts know best." Disguised in the language of "accepting a child's disability," the real expectation seems to be that parents should acquiesce to the worldviews of professionals.[45] By privileging the perspectives of those in positions of power and control, these dominant narratives fail to acknowledge the subjective meanings that parents bring to their experiences; minimize their insights and concerns, and construct restrictive meanings of normality. Ironically, since defense mechanisms are defined as operating at an unconscious level, parents' objections to being positioned as being in denial can conveniently be dismissed as their lack of conscious awareness of their own feelings, creating a powerful double-blind for parents.[46] For example, Seligman and Darling inform the practitioner that denial of the *reality* (emphasis added) of a child's disability is a defense mechanism that operates on an unconscious level; parents "fight unconsciously to keep their pain hidden from their own awareness."[47] Ironically then, any attribution of denial is a self-serving one, since by definition, it automatically privileges the opinions of those making the attribution—in this case, those in positions of power and control. Any attribution of denial works powerfully to negate and delegitimize parents' own feelings and their objections to being labeled by professionals.

In an earlier work, I highlighted that parents' resistance to particular diagnostic labels for their children or to the classification of their children for the purpose of receiving special education services in schools is sometimes interpreted as indication of their denial of their children's disabilities.[48] In unpacking this particular parental reaction to a potential disability label, it is helpful to distinguish between parents' refusal to acknowledge their children's differences versus their resistance to the labeling of their children as disabled. Beth Harry explains that when parents are in conflict with educational professionals over diagnostic or classification issues, usually they are not in disagreement about their children's difficulties in learning or developmental differences—rather, the dispute is over the naming of the problem.[49] Her study with low-income Puerto Rican mothers reveals that among this group, understandings about the parameters of normalcy were broader than would be expected in a Western psychological context; hence, while the mothers in this study acknowledged their children's learning challenges, they were opposed to the labeling of their children as having "mental retardation" (the term formerly used to refer to intellectual disabilities). Similarly, other studies indicate that although some parents may accept that their child has learning difficulties, they may reject the notion that their child is learning disabled.[50]

As noted above, the majority of the existing literature on families of children with disabilities is based on white (mostly Euro-American), middle-class families residing in North America, and uses a Western, Eurocentric psychological framework in interpreting individuals' responses to having a child with a disability. However, parents' responses to their children's differences do not exist in a sociopolitical vacuum; rather they are situated in the context of individual or collective understanding of the meaning of disability. Some researchers who have sought to explore the perspectives of parents from ethnic minority or low socioeconomic backgrounds have found that many parents' interpretations of their children's disability were embedded in their understanding of family identity—that is, labels of disability or mental illness took on greater significance for these parents because they were understood as reflecting a judgment on their entire family. For example, Steven Taylor, in his (2000) ethnographic account of the Duke family—a low-income family in which each member had a disability label—discusses the ways in which members of this family resisted collective stigma by rejecting labels of disability, and instead reframed them as mundane actions or poor choices made by individuals. Family members were described as "acting young for his age," "being a pest," or "drinks too much," instead of "mentally retarded" or "mentally ill." By dissociating individual members from the labels they had been ascribed, and by rejecting dominant parameters of normalcy, this family was able to maintain a positive social identity.[51]

The examples above speak less about denial of disability and more about families' understanding of the impact of labeling a child as disabled. Elsewhere, I have highlighted parents' concerns over the marginalization of their labeled children in schools and discussed the ways in which parents endeavor to avoid stigma by contesting particular disability labels and seeking alternative ones which they may perceive to be less stigmatizing.[52] In contrast, dominant narratives fail to contextualize parents' reactions to a disability diagnosis. For instance, Seligman and Darling state that "denial can be caused by the threat the disability presents to the family."[53] Here (similar to my earlier discussion on researchers' location of threat), the "threat" is located in the impairment rather than in sociopolitical environments in which children with disabilities are stigmatized, devalued, or marginalized.

The stigmatizing of individuals is a powerful phenomenon linked to the value placed on certain identities; it involves the social construction of difference and the consequent rejection or marginalizing of individuals or groups.[54] Erving Goffman explicates the concept of stigma as a social or psychological marking of individuals (originally it referred to the practice of physically branding or marking individuals), which serves to establish the stigmatized as fundamentally different.[55] Disability is a stigmatized identity, with some disabilities—the "discredited" ones—being more stigmatized than others.[56] Not only are disabled individuals stigmatized, their families may also experience a level of stigma and isolation; this is resonant with Goffman's notion of *courtesy stigma*—or the concern about becoming stigmatized because of ones association with stigmatized individuals.[57] As noted before, parents' resistance to certain disability labels and their seeking alternative ones may sometimes be driven by their desire to avoid stigma for their children or for the family as a whole. Historically, this was seen in the movement for the creation of a new disability category—learning disability. Christine Sleeter elucidated that, after the term "learning disability" (LD) was first coined by Samuel Kirk in 1963, parents who considered it to be a more desirable label for their children experiencing difficulties learning in schools lobbied for its adoption as a special education classification in ways that distinguished it from the label of mental retardation (currently termed "intellectual disability"). Sleeter drew critical attention to the racial and socioeconomic underpinnings of disability categories, as well as the social distribution of stigma; the parents who advocated for the creation of the LD category and for ascribing this label to their own children were overwhelmingly white and middle class and motivated by a need to dissociate with the stigma associated with the language of mental retardation when accessing services for their children in schools. The creation of an LD category therefore served to maintain race and class stratification; diagnoses of LD separated white, middle-class children who were struggling in school from minority children, and allowed for an explanation of why these children were struggling academically, in ways which did not threaten the social order.[58] In my own work with families, I explained the extent to which parents of privilege drew upon their cultural and economic capital to access certain diagnostic labels or educational classification for their children, and to avoid those which they believed would lead to low expectations from teachers and social rejection of their children.[59] Collectively, this body of literature disrupts dominant assumptions about parents who resist disability labels as passive or counterproductive, positioning them instead as agentic and strategic. Additionally, it explicates the ways in which parents' experience of having a child with a disability is not universally defined, but rather, is shaped by, and consequently shapes, the sociopolitical landscape with regard to the meaning of disability itself.

References to parents who have "unrealistic expectations" of their children with disabilities are also found in the literature. For example, "Some parents are able to provide for and love their child while holding on to the unrealistic hope that the child will make dramatic improvements… For most parents the reality of [a] child's situation becomes clearer over time."[60] Here, there is an implicit assumption that parents are initially unable to accept their children's conditions. It is also not uncommon for parents to be positioned as being in denial when they advocate for literacy education or advanced placement courses, or inclusive education for their children with disabilities.[61] Many studies document parents' "struggles" with regard to obtaining services or their "fight" to access inclusive learning environments for their children; these studies reveal the level of stress and frustration experienced by parents who engage in advocacy.[62] Parents who seek inclusive education for their children with "severe" disabilities, intellectual disabilities, or autism are sometimes dismissed as having unrealistic expectations and, by extension, being "in denial."[63] Thus, rather than problematizing traditional special education discourses and practices deeply entrenched in deficit models, parents who demand access to their children's educational rights or who have the audacity to presume competence among their children with developmental disabilities are often positioned as the problem.

In particular, parents from lower socioeconomic or ethnic minority backgrounds tend to experience many obstacles when navigating school bureaucracies and contending with school professionals. The work of Rayna Rapp and Faye Ginsberg underscores the immense amount of labor and the constant vigilance (usually on the part of mothers) required when advocating for educational services to which a child with a disability is entitled—advocacy without which services usually do not materialize.[64] In an earlier work, my colleague Chris Hale and I problematized the uneven access to inclusive learning environments for children with disabilities and the vastly different experiences of parents who sought these, based on their socioeconomic status. We argued that, within an institutional system which works against them, privileged parents of children with disabilities utilize the cultural and economic capital available to them to access the services, accommodations, and inclusive environments that they understand to be the fundamental rights of their children, while low-income parents with fewer resources, are generally less equipped to successfully advocate for their children's needs or to resist institutional pressures. Additionally, parents from cultural and linguistic minority groups often encounter biases and deficit-based judgments of their parenting from professionals (or are excluded from the special education process because professionals fail to address procedural or language related barriers).[65] As such, it needs to be acknowledged, the familial experience of having a member with disability is inextricably linked with dominant assumptions about different groups as well as the holding of privilege.

My commentary in this chapter is not intended to imply that parents do not react to their children's disability diagnoses in the ways documented in research, and neither do I mean to suggest that parents never experience shock or sadness, resist certain disability labels, or "shop for" particular diagnoses. All of these may very well be among the range of responses that parents have; indeed, they are well documented in research literature, including my own work with families.[66] I do not challenge the existence of these parental reactions—rather, I aim to question the labeling of these reactions as denial, the casting of professionals' judgment as objective truth, and the positioning of disability diagnoses as reality. Consistent with the work of many scholars who caution that the labeling of parents' reactions as denial reifies stereotypes and presents barriers to professional–family communication.[67] I problematize the common failure to recognize that there are a wide range of reactions among parents to their children's differences, and that these reactions are situated in the sociopolitical contexts within which families exist. I argue that the casting of parents' subjective meaning-making of their children's differences as pathological responses, and of children with disabilities as representing profound loss, become tools for the marginalization of some families; these institutionalized discourses privilege the perspectives of those in positions of power and control, discredit agency among families, and construct restrictive meanings of normative family life.

Future Directions: Critical Psychology and Families of Children with Disabilities

How then might researchers engage in understanding the lived experiences of families of children with disabilities? How might practitioners work collaboratively with these parents? Ferguson et al. caution us against making assumptions about families of children with disabilities, drawing attention to the wide range of outcomes and responses that exist among them.[68] Others have stressed the importance of critical research and practice with this group of families.[69] From a disability studies perspective, disability is understood as a social construct; within this framework it is imperative to include the perspectives of family members in any efforts to examine the familial experiences of having a child with a disability.[70] Rapp and Ginsberg argue that although there is much variation among families of children with disabilities, there is also a recognition of shared experiences or "a sense of existential kinship" among this group of parents across race and class; these parents are aware that they must grapple not only with the issue of accessing services for their children, but also with broader issues of nurturing the personhood of their children, and with the task of reimagining the meanings of family and humanity.[71]

In research and practice framed in the constructivist frameworks of disability studies, parents' reactions to their children's disabilities are understood as linked with the social meanings ascribed to the construct of normalcy,[72] and situated in cultural interpretations of disability labels.[73] Grounded in a social model of disability, disability studies scholarship compels us to retract our collective gaze from the impact of children's impairments on families and to focus instead on the socioculturally constructed notions of the "otherness" of children with disabilities and the marginalization of their families.[74] Elsewhere I have made a case for narrative inquiry as a critical research methodology; narrative research sheds light on subjective interpretations of disability, contributing to new understandings of the ways in which the meaning of having a child with a disability is mutually negotiated by individuals and society through discursive practices.[75]

Olkin and Pledger ask whether disability studies and psychology could possibly join hands; they point out that despite psychology's interest in diversity, people with disabilities are relegated to the periphery in psychology, and usually only studied in the field of rehabilitation psychology with its focus on individual adjustment.[76] They emphasize the urgent need for psychology to take heed of "new paradigms" in conceptualizing disability when engaging in disability-related research. Similarly, Prillitensky and Nelson remind us of the need to resist the pressure to pathologize individual families if we are to begin to seek collective solutions to problems.[77]

Perhaps in considering Olkin and Pledger's question about whether there can be a collaboration between disability studies and psychology, we might turn to the perspectives offered in critical psychology.[78] In contrast with mainstream psychology, critical psychology has little to do with the diagnoses and treatment of individual people—rather it focuses on cultural forms of alienation and it endeavors to form communities committed to social change.[79] Critical psychologists are invested in questioning mainstream psychology's role in the systematic oppression of individuals and groups.[80] Ultimately, critical psychologists aim to develop concepts and approaches that provide a means for analyzing power relationships, in order to contribute to the creation of knowledge and meaning in the search for social justice.[81] As such, the grounding premises of critical psychology are consistent with the perspectives offered in disability studies, and therefore, as Goodley asserts, perhaps there is potentially fertile ground for the emergence of a new psychology of disability.[82] Taking this a step further, one might envision a new psychology—one in which disability and normalcy are not dichotomized—thus rendering the need for a "psychology of disability" unnecessary.[83] In the quest to understand the familial experience of disability, mental health and rehabilitation professionals can be informed by critical psychology and disability studies; both are grounded in critical, constructivist frameworks and committed to the dismantling of power differentials in society.

Goodley asserts that questions need to be raised not about the disabled psyche, but the nondisabled psyche—that is, moving away from theorizing about the impact of impairment on individuals and toward examining the problematic ways in which nondisabled people view disability.[84] Extending Goodley's idea to a progressive understanding of families of children labeled with disabilities, I argue that rather than pathologizing parents' reactions to their children's disabilities, we need to challenge the oppressive narratives that marginalize some families. Rather than problematizing parents' resistance to "expert" knowledge, perhaps the institutionalized discourses and practices, rooted in ableist ideologies and cloaked in the myth of the neutrality of scientific knowledge, should to be problematized. When the objectives for research on families of children with disabilities are framed as such, then disability studies and critical psychology can indeed join hands. Collaborating with families in understanding the nature of their lived experiences, we might find the constructed parameters of normalcy challenged and in doing so, uncover new meanings of the normative family and, indeed, of the desired child.

Notes

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CHAPTER 13

Postfeminist Motherhood?: Reading a Differential Deployment of Identity in American Women's HIV Narratives

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Motherhood is central to conceptualizing domesticity. The deployment of motherhood as a centralizing identity is evident in the narratives of women living with HIV: a deployment that I argue creates a new affective landscape within which HIV can be understood. In contemporary HIV memoirs written by women, motherhood is a differentially deployed identity; as such, motherhood must be read with an attention to intersectional (racist, classist, sexist, heterosexist, and ableist) oppressions. In this chapter, I look at two memoirs that rewrite the affective landscape of HIV—Catherine Wyatt-Morley's *AIDS Memoir: Journal of an HIV+ Mother* (Kumarian Press, 1997) and Paula Peterson's *Penitent with Roses: An HIV+ Mother Reflects* (Middlebury Press, 2001)—to argue that motherhood can be deployed as a white supremacist claim to citizenship (Peterson) or as a social justice tactic for eliciting affective belonging (Wyatt-Morley).

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I contextualize two HIV memoirs written by women within HIV literature and affect theory, highlighting how motherhood upsets the current theorization of HIV literature. In order to understand the meaning of HIV, we have to contextualize the virus within what I am calling its affective landscape. Expanding Sara Ahmed's theories, I argue that an affective landscape is a constellation of ideas and values connected in and through multiple objects, in this case, images and representations of stigmatized citizens.[1] HIV is very much an affective story, intimately connected to images of gay men as promiscuous, black women as welfare queens, and drug users as warlords. Heterosexual monogamous mothers enter this landscape and upset this constellation, causing ruptures between ideas and values that constitute HIV care and prevention. Through these ruptures, Wyatt-Morley and Peterson construct a new affective landscape to justify political intervention. Prior to these monographs written by women in long-term heterosexual relationships, the affective landscape of HIV narrative was one oriented toward decline and ultimate death; motherhood upsets this orientation because it looks to the future in more normatively productive ways through procreation and childrearing, and elicits political action that bolsters the heterosexual family unit.[2]

Between 1997 and 2009, when African American women were the fastest growing HIV population in the United States, four memoirs were written by women in the United States living with HIV; two authors were white, two authors were African American.[3] Two of the four memoirs were written by women who discovered their HIV status while in heterosexual marriages and after the birth of their children. In this chapter, I look at these two memoirs, both of which co-construct a HIV experience alongside their experience of motherhood. In both memoirs, motherhood becomes the entry point through which a female-embodied HIV experience can become recognized as part of the HIV story, inciting political action.

By theorizing labor and motherhood as co-constitutive of an HIV experience, these memoirs move beyond current understandings of women's experiences with illness. In her discussion of women's health activism and advocacy, Tasha Dubriwny claims that the social justice goals of the women's health movement that took place roughly from the mid-1960s through the mid-1980s have been abandoned in favor of neoliberal and postfeminist agendas.[4] Dubriwny argues that this utilization of motherhood for the purpose of women's health advocacy is not only a simplification of the complex experience of illness, but a reification of traditional gender norms.[5] Unlike Dubriwny, I argue that the deployment of motherhood by women living with HIV is actually not a simplification of women's experience with illness, particularly if they are read for the differential deployment of identity, paying particular attention to how identity is mobilized in relation to racist, classist, sexist, heterosexist, and ableist oppression. Further, interrogating the differentiality of the motherhood identity unveils how identity can be deployed affectively, resisting essentializing gender roles and insisting on a politicized understanding of motherhood, domesticity, and disability. HIV motherhood, it turns out, is neither simple nor "postfeminist."

In what follows, I contextualize two HIV memoirs written by women within HIV literature and affect theory, highlighting how motherhood upsets the current theorization of HIV literature. I then analyze the role of motherhood and reproductive labor in these memoirs, noting the ways in which each narrative rewrites the affective landscape of HIV. Finally, I look to the material labor in and of these memoirs, questioning how motherhood is deployed differentially, at times reinforcing and at times writing against white supremacist calls for citizenship.

Gendered HIV Narratives

Jacquelyn Foertsch argues that many of the first HIV memoirs, written by gay men, can be understood through constructions of enemy, boundaries, and an ongoing apocalypse.[6] As Foertsch writes, "the conditions prevailing during the Cold War have come to characterize the AIDS era as well, so that the body remains precariously placed and susceptible as ever to immonology's depiction of it as on the defensive yet badly defended."[7] Similarly, as Priscilla Wald writes most recently of HIV in relation to other outbreak narratives, "Patient 0"—the archetypal HIV patient—was understood as "alien" from the beginning.[8]

> Patient 0' led to a diagram of and eventually to a narrative about forty ostensibly linked cases of AIDS [...] But if, as they suggest, an infectious agent causes AIDS and the disorder has a long incubation period, then everyone who gets AIDS has presumably been an asymptomatic character and then becomes an ailing transmitter. So what distinguishes 'Patient 0'?[9]

In Wald's analysis, "Patient 0" is distinguished through an absence of geography, thus always alien.[10] Wald argues that "Patient 0" was a necessary narrative construction for North Americans, particularly those in the larger population who were not approaching HIV through direct biomedical fields, in order to write HIV as an outbreak narrative, situating HIV within a North American tradition of understanding contagious illness (a tradition that she traces back to Typhoid Mary). Significant for both Foertsch and Wald is an understanding of a barrier between "me" and "not me," the healthy from the contagious. Both theorists emphasize that this narrative is one based solely on masculine sexuality. So what happens to understandings of contagion, enemies, and disease when female bodies are understood as HIV-positive?

We can understand the affective landscape of HIV, using Massumi's concept of affective threat, when we look at the first writings that emerged featuring women living with HIV.[11] These narratives actually resist understandings of external threat/threat event by focusing on motherhood as the site of illness. Through gestational motherhood, the threat of contagion is both of the mother and distinct from the mother; contagion does not come from an external threat in the way the flu is contagious but instead comes from the gestational parent's own body, which is protecting and nourishing the fetus it grows while at the same time exposing it to HIV. HIV medicine has developed so that in 2015, in utero infection is preventable but at the time Peterson and Wyatt-Morley were writing, this was not the case. So while Peterson's and Wyatt-Morley's memoirs are oriented toward a fear of death and contaminating others (children, primarily), their attention to their own reproductive labor creates a new affective landscape for HIV outside of contamination. With attention to reproductive labor, the barrier between "me" and "not me" becomes blurred.

Understanding HIV/AIDS Origin Through Motherhood

Catherine Wyatt-Morley and Paula Peterson both write from their perspective as heterosexual mothers, situating their experience with HIV within their experience as parents, which is often inseparable from their overall experience of parenthood. Additionally, both women discovered their HIV status in the context of gynecological events: Wyatt-Morley post-hysterectomy and Paula Peterson post-caesarean. As such, both women discovered their HIV as a female-bodied event co-constituted through motherhood, a strikingly different narrative than those written by (men who have sex with) men.

Catherine Wyatt-Morley wrote the first book-length memoir by a woman living with HIV, publishing with a small African-centered press in 1997.[12] Importantly, she titles her memoir, written as a collection of journal entries from her initial diagnosis in 1994 through her press contract (she reflects on this process in her latest entries), *AIDS Memoir: Journal of an HIV-Positive Mother*. The focus on motherhood remains central to the text, as does marriage (and her eventual divorce), with a formal portrait of her with her kids appearing on the front cover.

Wyatt-Morley begins her memoir with a bodily geography of reproduction. She received a diagnosis of HIV after an infection from her hysterectomy, which failed to heal as expected.[13] The reasons for the hysterectomy go unexplained (Wyatt-Morley is an African American mother of three, only 35 years old). Her motherhood remains central as she is given her diagnosis:

> But doctor, there have been no signs, no symptoms, no warning. I'm married and have been faithful to Tim," I said, as I looked at my husband whose beautiful brown eyes were filling with tears. "I have not shot any drugs. I don't understand. I don't know anything about HIV." My thoughts began to turn to my children. Suddenly, I was afraid for my babies. Oh my god, I am dying.[14]

The stigmatizing factors associated with those living with HIV are negated in Wyatt-Morley's telling of her encounter with HIV. Assembled as a series of journal entries, the memoir tells us that Wyatt-Morley's husband has been unfaithful due to a past period of alcoholism (a period and affair that were previously disclosed to Wyatt-Morley) and is HIV-positive as well.[15] This makes room for an affective resistance to identifying Wyatt-Morley with other HIV-positive people (homosexual men, drug users) who are stigmatized; by highlighting her heterosexuality and her monogamy, Wyatt-Morley gives her readers a chance to identify her as unfairly victimized at a time when other adults living with HIV were understood as responsible for their own illness. The memoir becomes one about disclosing to family the effects of HIV on children. While Wyatt-Morley chooses not to disclose to her daughter (her youngest child), she and her husband do talk with her two sons. "My sons have no idea what the discrimination and rejection associated with HIV/AIDS could do to their accepting hearts. They are so young and impressionable; this is happening to my beautiful children, too."[16] Directly following some of her journal entries, Wyatt-Morley, in a reminder of her motherhood to the reader, writes letters to her children, with advice about relationships, work, and God, as well as interspersing photographs of her children.[17] All of this works to reinforce the affective landscape of motherhood and HIV.

At the same time Wyatt-Morley is learning how to parent with HIV, she is also learning to parent as a single mother. She is divorced from her husband, who has taken up drinking, contracted several severe opportunistic infections, and refused marital counseling. Wyatt-Morley's support comes increasingly from the peer support group, WORTH (Women on Reasons to Heal), which she founded for women in Tennessee living with HIV.[18] In June 1996, without commenting on her husband's disintegrating health, she writes:

> Today my marriage of ten years came to an end. I feel like hell. Now I have to face life as an HIV-positive mother alone with three children. Divorce hearings were over in less time than it took to get there—ten years over in less than ten minutes. Tim was a no-show, as expected, and a hearing date for property settlement was scheduled.[19]

By cataloguing the process of divorce, and writing herself as proactive while her husband becomes simultaneously increasingly sick and increasingly distant from his family through alcoholism, the reader is affectively removed from Wyatt-Morley's stigmatized husband and attached to Wyatt-Morley through her motherhood. As she writes: "Though I have educated myself well and associated with many organizations, committees, universities, and hospitals, have access to protocols, and am on what seems like thousands of mailing lists, none of this changes the fact that I am HIV-positive and progressing, much too rapidly, toward AIDS."[20] This being one of her final journal entries in the book, Wyatt-Morley successfully frames herself as a responsible citizen alongside her HIV-positive status; doing so, she also emphasizes how she "represents the fastest growing group of HIV infection in the United States."[21]

By mobilizing this affective landscape and establishing cultural trust, Wyatt-Morley is able to use her journal entries as educational essays for readers who may know very little about HIV, explaining T-cells, AZT, viral loads, protease inhibitors, and the failures of sex education.[22] She is also able to hold her community leaders accountable for neglect. "Our minority families extend little support, our minority religious leaders honor silence, and our black brothers and sisters die alone. No honor is found in abandonment."[23] Even more directly, she writes, "Ministers have the power over the accepting, captive congregations that listen to 'the holy word.' When the 'holy word' is given by a minister with his or her own hidden agenda, the 'holy word' becomes something other than 'The Holy Word.'"[24] By beginning her journal entries first with lessons on the technical details of HIV, she slowly builds trust with her reader as de-stigmatized and wise. By the time she begins to look at cultural factors for HIV infection rates and turns the lens on her own community, particularly the black church, she has built an affective landscape around motherhood which changes stigmatized understandings of infection. By connecting her HIV to her motherhood, HIV becomes a disease of all people, not just drug users or gay men.

Paula Peterson published her book-length memoir, *Penitent with Roses: An HIV-Positive Mother Reflects*, in 2001, through a small literary press at Middlebury College. In it she echoes Wyatt-Morley's affective landscape of motherhood, but without Morley's pointed political interventions. Emphasizing the centrality of biological motherhood in her HIV origin story, Peterson begins her first chapter, "Caesarean," with the literal birthing of her son. "The 'pains', as they are so quaintly called, begin in earnest at midnight on November 14, 1995, which happens to be my exact due date."[25] As Peterson recounts the dinner party where her contractions began, she emphasizes motherhood as a kind of identity border-crossing, writing, "These are the last few hours that my life will really belong to me."[26] By centering literal labor, Peterson contributes to the new affective landscape of HIV. She centers her motherhood while also drawing attention to her privilege. As a white, Jewish middle-class woman, Peterson writes, she "was 35 years old, and up to that point, had led a sheltered life. Most of my suffering had been existential, which meant I had to invent reasons to torture myself. Things generally came easily to me, just in the way conception had. I awoke each morning thinking of the inviolability of my identity, and of my rights."[27] Peterson does not reveal her HIV-positive status in this first chapter, since she herself is unaware of her infection. She is given a caesarean because of an inability of her labor to "progress," not because anyone is aware of her HIV status.[28] Because of her caesarean, she feels distant from her son, ending her first chapter, "It will be months before I feel anything when I pick up my son. […] I am being forged anew. Little by little, I reinvent myself."[29] While beginning her memoir with this scene of birth, Peterson resists idealized notions of motherhood, conceptualizing motherhood and the emotions attached to it, as work, not instinct.

Peterson waits until the second chapter to give readers her diagnosis. In "Prognosis Guarded," the reader follows Peterson's own discovery of her illness. She discloses to the reader by again emphasizing her privilege. "I was thirty-six years old, had been married nearly four years and had a baby nearly eleven months old when, out of the wild blue sky, I was diagnosed with full-blown AIDS."[30] The disclosure of a full-blown AIDS diagnosis, as opposed to asymptomatic HIV, without any prior recognition of the virus, is jarring. Peterson recounts for the reader the symptoms that led to the diagnosis (extreme exhaustion, headaches, unaccountable weight loss) alongside the waiting period for the test results for her husband and baby. Again, she centers a reflection on her labor, writing:

> It turned out that the Caesarean delivery, which I had always been ashamed of, feeling that I had merely had a baby pulled out of me instead of giving birth to one, had actually been a safeguard for my child. The virus nestled in the walls of the birth canal and a fetus who did not make the treacherous passage stood a much better chance.[31]

In her retelling, the virus is "nestled" inside her, much like her baby, giving an image of the virus not as ravaging or menacing, but as infantile. At the same time, in reflecting on 11 months of breastfeeding, Peterson writes, "And now I was jolted to the realization that what I fondly imagine had been nurturing my son for many months had, in fact, been endangering his life."[32] Like the image of the virus during birth, the virus at this stage is not understood as an enemy. Instead, it is her own breast milk, the carrier of the virus—this traditional symbol of motherhood—that is understood as dangerous. Despite Peterson's apparently ambiguous relationship to the virus, she writes that it, much like motherhood, was "savagely mauling her identity."[33]

In the end, Peterson embraces her identity as a mother, further complicating the affective landscape within which her narrative unfolds and simultaneously drawing in the empathetic reader. When she finds that doctors suspect she has had the virus for at least ten years, Peterson begins the process of finding old lovers, leaving messages, recounting short conversations where her exes are sympathetic and HIV-negative.[34] Peterson never discovers exactly how she contracted the virus, admitting that she was promiscuous in her 20s, when HIV was still thought only to affect gay men; the reader is left with an ambiguous HIV origin story that Peterson re-routes back to motherhood, by the end of her second chapter. "One thing I did gain, which I could point to," Peterson writes, "I had no more ambivalent feelings about motherhood. There was nothing common or animal-like about it. Giving birth had not been a sacrifice of my higher nature, as I had once half-believed, but a redemption of that higher nature and an enhancement of it."[35] By the end of "Prognosis Guarded," she finds out that both her husband and son are HIV-negative.

The centrality of childbearing remains throughout Peterson's narrative; when she begins her chapter on attending a conference for women living with life-threatening diseases, many of whom are living with HIV, she writes:

> But when you take into account the heaviest population of infected women falls between the ages of 25–39—prime childbearing years—the statistics begin to look more frightening. The more women who are infected, the more likely they are to pass HIV along to their children, either while in uterus or through breastfeeding.[36]

For Peterson, what is notable about the growing rate of HIV among women is the threat of its effect on reproductive labor. Peterson, in attending a support group specifically for mothers while at the conference, struggles with intentional motherhood in the face of HIV (her own pregnancy occurred while she was ignorant of her status) and yet feels a connection with the women because of her status as a mother, the first time she feels a connection in the conference itself.[37] Her identity as a mother leads her to activism, when she works on behalf of the Mother's Caucus for the National Association for People with AIDS:[38]

> And suddenly, I remember why I am here: I'm white, I'm middle-class, I'm well-educated, and I look like Senator So-and-So's niece or daughter or sister-in-law. I've been chosen for my shock value. Our biggest enemy, what we came to fight, is the attitude that AIDS is happening to *other* people.[39]

Here is a clear example of Peterson's emphasis on her motherhood working in connection with her class and racial privilege. She feels at once connected with other women living with HIV and alienated from them.

Peterson writes of how this sense of simultaneously belonging and not belonging manifests in the context of policy speech-making, which she argues is largely performative, for the extension of the Ryan White CARE Act.[40] "As I speak, I begin to feel curiously divided from myself—my story is a genuinely sad one, and I can tell from the expressions on the faces of my listeners that I have delivered it convincingly, and yet after many tellings, I no longer feel an emotional connection to it."[41] Peterson is intentionally mobilizing this new affective landscape for the purpose of political advocacy. The connection with motherhood situates her within the context of other women living with HIV. Yet it is a connection that transcends the barriers of HIV and has the potential to appeal to a broader public. Motherhood elicits political action.

Peterson finishes her memoir with a lengthy letter to her son, told in segments reflecting on her own childhood, from a relationship with her babysitter/cleaning lady to her first after-school detention, leading the reader to the end of the memoir before we find out much of Peterson's early life.[42] She often speaks directly to her son in these passages, explaining mundane, perhaps nostalgic details, such as the desk arrangement in her totalitarian third-grade classroom.[43] In her conclusion, she writes, both to her son and to her broader audience,

> I stated, in the beginning of this letter, that I wanted to present myself to you because I wanted you to know something about my history. But it is possible that I have turned myself into more of an enigma than I had intended […] Yet, on closer inspection, I see that something has emerged from these vignettes after all. The whole is possibly the tale of the birth of a writer […] and the responsibility of bearing witness."[44]

With the intentional use of the word "birth," Peterson has turned her reproductive labor in on itself, emphasizing that what is produced is not more laborers, but writing and the creation of an affective landscape within which to situate HIV narratives such as her own. In her final message to her son, Peterson recounts a children's story, *Are You My Mother*, about a young bird's search for his mother, who has left the nest temporarily to find breakfast. She writes, "It is my hope after reading this you will be able to recognize […] your mother for what she is. And you will be able to claim me immediately."[45] Peterson's use of this children's story performs a few different functions for her memoir's end: first, it reinforces the child–mother relationship upon which the memoir opens; second, it closes on the idea of a search, one she begins in her second chapter in the hope of finding her HIV origin (which partner infected her?) and the one the reader, in part, expects to find with the "Patient 0" precedent constructed in the decades before she contracted the virus. Instead, the end of Peterson's search is motherhood itself.

WRITING AGAINST THE POLITICS OF DISGUST: CATHERINE WYATT-MORLEY'S AIDS MEMOIR

In Wyatt-Morley's memoir, paid labor plays a central role in how she conveys the daily experience of living with HIV in the mid-1990s (1994–1996). This centrality, in conjunction with her consistent emphasis on her motherhood, writes against a "welfare queen" representation, which took on heightened significance at the time of Wyatt-Morley's writing due to the Clinton administration's 1996 Welfare Reform Act.[46] The welfare queen representation, which is organized around hyper-fertility and laziness, leads to what Hancock terms "the politics of disgust."[47] As Hancock explains, in welfare politics, democratic attention is perverted into "ideological justification for a specific policy," which separates welfare recipients from other "worthy" Americans. This perversion of democratic attention is a key component of the politics of disgust.[48] The elite manipulate public discourse in an effort to create and enact certain policies. In the contentious decades of the 1980s and 1990s, the public identity of welfare recipients (constructed as African American single mothers—"welfare queens") interacted with a politics of disgust to produce undemocratic outcomes.[49] This is key for thinking about who gets empathetic attention in terms of HIV. Wyatt-Morley effectively writes against the welfare queen stereotype, subverting this politics of disgust and asserting herself in a democratic space, by focusing on her negotiations of labor in the context of HIV stigma and HIV-related illness.

Wyatt-Morley, writing in journal format, first discusses her negotiations of labor and illness when, after being on a three-month sick leave following surgery and subsequent HIV diagnosis, she returns to work. While Wyatt-Morley is not specific about the precise kind of work she does, we know she works at a plant and is possibly unionized.[50] In mid-July 1994, she writes, "I'm back at work but I'm really not feeling well enough to be back. Bev wanted me to stay out longer, but I had to come back because my pay has been at 60 percent since June. The company has not changed since March; neither have its people. I was not put on a job, so I sat in the cafeteria waiting for a supervisor to find a job within my restrictions."[51] Here, we see Wyatt-Morley negotiating disability accommodations within her physically demanding factory job as well as the need to work to support her family (her husband is having much more difficulty than she and is often unable to maintain hours). Her emphasis on working while not feeling well, and the lack of paid work available to her based on physical restrictions, counter stereotypes of laziness. She also emphasizes her responsibility to her family.

While Wyatt-Morley is focused on working to support her family, a few journal entries later she discusses how she begins a support group for women with HIV, WORTH.[52] WORTH develops from a support group to an advocacy organization, centering "the needs of working mothers who are sick, women as heads of households, dental care, gynecological issues, and the aloneness we all share."[53] Notably, material, economic concerns are listed before medical and emotional needs. Wyatt-Morley emphasizes her volunteer work and her ability to participate in less physically demanding paid labor while her factory employer searches for appropriate accommodations—it took two months for her supervisor to find her a "temporary placement."[54] This juxtaposition of factory work and accommodations, and her HIV coordinating and volunteer work, remains a consistent narrative technique throughout the memoir. Wyatt-Morley often discusses both in the same journal entries. The importance of material labor is highlighted throughout the memoir. As part of her class-based politics, Wyatt-Morley also consistently lets her readers know how she is making ends meet financially, letting them know when she is getting paid and when she is not. Wyatt-Morley consistently centers class in her experience of HIV, recognizing how material privilege and nonphysical labor could benefit her wellness now that her immune system is compromised.

In the midst of continuing troubles at work, including sexual harassment from her supervisor, Wyatt-Morley begins to attend national HIV conferences with her group.[55] "I'd like to work in the fight against HIV and AIDS," Wyatt-Morley writes in November 1994. "I want God's words to come from my mouth as I speak against the lack of education that has occurred among our youth or for universal healthcare for every American. We need to be educated."[56] By connecting her activism to educating youth in particular, Wyatt-Morley indirectly connects her labor with motherhood. She is also consistently demonstrating her increased professionalization in the emerging field of HIV care and advocacy:

> January 12, 1995. Went to an HIV/ADS conference in Fort Campbell, Kentucky, with my good friend, Diedre from WORTH, and a guy named Joe to hear speakers and get updated information. It was very informative. I watched and listened to medical personnel speak about patients' treatments, clinical trials and new medication.[57]

In this entry, and throughout the book, Wyatt-Morley details the information she learns at these conferences, demonstrating her knowledge and educating her readers.[58] The book itself becomes part of her educational advocacy.

As Wyatt-Morley's HIV-related conditions cause more physical problems, such as carpal tunnel and peripheral neuropathy, she begins a women and HIV media project, walking the readers through the process of learning to write grants, finding producers, conducting interviews, and promoting the project.[59] "HIV is the driving force behind me doing this video. I would be working at the plant and going on with my life if Tim and I were not infected with this virus."[60] Development of the video project weaves itself through the book, often directly preceding her medical updates.

> *March 28 1995.* Things with the video are moving slowly. There's so much to learn. I told Tim that I spend more than ten hours a day doing or thinking of things to incorporate into it.
>
> Went to the doctor today. Bev said I was doing great. I told her that I feel good, other than my hands.[61]

Here, not only does Wyatt-Morley juxtapose her video project with her physical disability that causes her problems with working at the plant, she also counts her hours working for wage labor, writing against any stereotypes of laziness.

Wyatt-Morley eventually sees the need to merge her volunteer advocacy with paid work. "Well, I have given it great thought and I think it is time for my work life and private mission to become one. I can no longer live in 'if.' It's time 'if' got a life. My work with the video has taken me many places."[62] Wyatt-Morley eventually comes out as HIV-positive at work, takes her video to film festivals, tells her own story in media outlets, and procures a book contract.[63] As Wyatt-Morley becomes increasingly disabled in the context of her paid work, she becomes a powerful HIV advocate, experiencing a change in her own understandings of power. She provides readers access to this ideological shift through a new affective landscape for HIV that emphasizes her own motherhood and details the complex material negotiations that write against the politics of disgust.

Reinforcing the Politics of Disgust: White Motherhood and Paula Peterson's Negotiations of Labor

While Wyatt-Morley writes against the politics of disgust by centering her negotiations of paid labor and HIV, Paula Peterson, a white, married Jewish mother, actually reinforces the worthy/unworthy citizenship divide. Not only is there a notable absence of economic and labor negotiations in her memoir, but the ways in which Peterson continually emphasizes her white, married, heterosexual subjectivity, in contrast with women of color and poor women who she meets in her search for community after her HIV diagnosis, perpetuates the ideological divide between those deemed worthy and unworthy of inclusion and access to the rights of citizenship. Peterson's memoir itself is a material marker of the divisions that exist among HIV-positive people in the contemporary United States. Unlike Wyatt-Morley's book, *Penitent with Roses* is marketed as a literary text and is published in conjunction with the Breadloaf Writer's Conference/University of New England Press. It is also the winner of a nonfiction creative writing prize. With her constant references to graduate school, and writing as "art" (not work), and her own writerly identity, Peterson distances herself from self-conscious activist texts like those of Wyatt-Morley, whose publisher, Kumarian Press, is marketed toward African Americans and centered on social justice work. While Wyatt-Morley writes about procuring her book contract, and the economic opportunity that contract opens for herself and her family, Peterson never mentions the material negotiations of writing a book or even pursuing an MFA in Creative Writing. In short, Peterson's memoir is one of "art"—not labor or advocacy—in which her experience with HIV is removed from other social justice concerns.

In the opening chapter of her memoir, when Peterson recounts her caesarean, she positions herself against any stereotype of hyper-fertility:

> In my twenties, I harbored a romantic notion that I was "barren." This may have been reinforced by the fact that, as a young girl, too thin and too athletic, I often went six months or more without having a period; I had also been on the Pill for many years and had been told by a doctor that the hormonal interference might make conception a lengthier process. And as a writer, I nursed a conviction, quite legitimate, that any fertility that I possessed would be manifested through my art, not my body.[64]

While Peterson does not deny sexual activity, with reference to taking birth control, she does write herself as "responsible," concerned with having children before monogamy, while also potentially so disciplined (athletic, thin) that she is actually the opposite of lazy and hyper-fertile. While simultaneously establishing herself as disciplined and responsible, she also establishes herself as an artist, writing not to make ends meet but because of some inner drive, some innate sense of self.

As Peterson recounts the process of her diagnosis following the birth of her son, she again resists the notion that there might be stigma attached to her condition; that she is in some way not deviant; that her civil rights are indisputable. “I told myself I had the advantage of having contracted a very public and political disease that instantly conferred martyrdom on its sufferers […] You could not have a more fashionable disease. In San Francisco, at least, the stigma was not as pronounced. Your civil rights were indisputable.”[65] While Peterson is not as explicit as Wyatt-Morley in the period of her diagnosis, we can understand, based on the timeline Peterson provides (referencing she probably contracted the disease in 1985 and had it for ten years when she was diagnosed), that she is experiencing her diagnosis at the same historical moment as Wyatt-Morley. Being white and middle-class herself, and living on the West Coast, experiencing HIV in proximity to white, upper-class activism left Peterson with a less-stigmatized association with her diagnosis. At the same time that she understands her HIV in proximity to whiteness, she also does not feel a part of the HIV community. “It was not ‘my’ disease. […] I did not know anybody else like myself—white, Jewish, middle-class, college-educated, and HIV-positive. I tried turning it all upside down and thinking about it in a different way. This was a more successful tactic. It was funny but I turned out to be exotic after all.”[66] Here, Peterson, in one of many iterations, emphasizes her whiteness and class privilege, as well as her education and religious/ethnic heritage. In a paradox, she does not feel the stark stigma related to HIV because of the 15 years of de-stigmatization work of white male activists in San Francisco. In yet another seemingly paradoxical moment, she comes to understand her HIV racially. It makes her “exotic,” an Other, and in the midst of mid-1990s multiculturalism, this to her seems desirable. She establishes herself as an anomaly to the HIV community (and by extension, not deserving of HIV).

In a Chapter “Who We Are,” where Peterson rehearses statistics related to women with HIV, she again emphasizes her own whiteness. “Being a white woman with HIV in the United States, a white Jewish woman at that, puts me in a unique position. It’s a lonely place to be. I discovered after my diagnosis that I had very little community, especially if I wanted to scrape together a community out of women who fit my demographic specifications. I soon abandoned that idea and began looking for women, any women.”[67] Although Peterson acknowledges that her position is a “lonely place to be” and that she has “very little community,” she seems to view her status as nothing more than “demographic specifications.”

Unlike Wyatt-Morley, who becomes more politicized after contracting HIV, Peterson does not equate her experience with larger struggles for social justice. In the same chapter, Peterson goes on to describe a retreat of women living with HIV almost as if she were an anthropologist, observing and recounting participants' life stories while also giving an hour by hour description of the retreat's activities.[68] Peterson describes the first two women with a sense of detached observation, as she does throughout the chapter:

> Two women in wheelchairs introduce themselves: Joanne, square, chinless, with tiny eyes and a flat forehead. A thug's face. She had long sparse reddish hair that an attendant, standing behind her, is combing and re-braiding. The other, Martina, is younger, smaller, and softer, with brown moist eyes that seem filmed over. Next to her chair, the paraphernalia of the oxygen deprived—tank, tubing, carrying case. Both are chain smokers, dropping their ashes on the sidewalk, directing their unflinching gaze into the middle-distance. Joanne converses with me but Martina is not as accessible.[69]

Here, Peterson describes physical details of appearance and states that Joanne converses with her, but we never get a sense of who these women are, where they come from, or their relationship to their disease. For Peterson, important markers of identity are displayed on the body but not through the person. In her observations, Peterson negatively judges these participants, describing one as having a "thug's face" and both as chain smokers, despite their reliance on oxygen. These women, in Peterson's short racially tinged reflection, are irresponsible, unhealthy, and dependent on others for care. At their meal later in the day, Peterson attributes an animal-like paranoia to Joanne and Martina, "they eat solemnly, glancing from side to side, as if they fear someone is going to cheat them of their portion."[70] Peterson also describes the food, "black-eyed peas, cornbread, meatloaf. Several of the Black women whoop with joy."[71] By describing the food and describing other participants with child-like or animal-like qualities, Peterson sets herself apart from the participants at the retreat and from the larger community of HIV survivors.

In contrast with the participants, Peterson describes their workshop leader, Eve, who is living with HIV, with positive judgment. "Hazel eyes and seamless ivory skin. A voice that is always in excellent tune. Hers is an authentic beauty: she draws from a deep well of grace within her."[72] While again Peterson focuses on the physical details of Eve, she attributes a personality trait while her physical descriptions also focus on racialized notions of whiteness. Eve's "seamless ivory skin," her voice that is "always in excellent tune," and her "authentic beauty," stand in stark contrast to Joanne who is described as, "square, chinless, with tiny eyes and a flat forehead." Eve's "deep well of grace" carries with it significantly different connotations than the direct and "unflinching gaze into the middle-distance" of Joanne and Martina. It is Eve with whom Peterson finds community, not the other women in her group. Peterson's affinity with Eve is confirmed, when she writes, "But I notice the shadows in her cheeks. The slight sunkenness. The oversized sweater probably hides the thickened waist. These are the signs by which we know one another."[73] Although Peterson seems almost to function as a detached reporter or anthropologist, her physical descriptions are coded with racial and class judgment. She understands herself as a member of the HIV community only in relationship to white workshop organizers. This juxtaposition between herself and the retreat participants reinforces a deserving/undeserving binary of HIV subjectivity.

In her chapter "Working the Line," Peterson makes an analogy comparing volunteering at a San Francisco HIV hotline with factory work. Yet for Peterson, the workplace has a sense of relaxation and comfort, not the bustling pace of an assembly line. She begins her chapter, "I settle myself into my booth with a cup of coffee, after schmoozing with my neighbor."[74] She conveys stories of hotline callers, presenting herself as knowledgeable, expert. "I force myself to ask, my heart beating rapidly, whether she has nursed her children. 'Of course, miss,' she says proudly. 'Every single one for a year.' She does not seem to understand that the virus can be transmitted from mother to child through breast milk." In the process of presenting to the reader her own knowledge and training as a hotline volunteer, she conveys her caller as ignorant, a "young African-American woman" with a "pleasant sing-song accent."[75] Here, Peterson's descriptive prose becomes tainted with racialized understandings of African Americans as uneducated performers, while she herself is the white educated savior.

The power hierarchies, which remain unacknowledged in Peterson's volunteer work, seem to exist outside of her consciousness. She ends her chapter with one of her few insights into her work life. Yet even this is self-focused: "Fondly, I imagine that thousands of men are now using condoms correctly because of my advice ('Never use an oil-based lubricant. Roll out the air bubbles. And for God's sake, check the expiration date.') That thousands of women will now buy condoms themselves and insist their partners wear them […] These airy fantasies sustain me for the week between my shifts."[76] Here, Peterson reinforces her own hotline expertise by also emphasizing that she is volunteering, one four-hour shift a week. The focus remains, as always on her own achievements and experiences. While she is equipped to offer advice about condoms, she does not provide the reader with a deeper analysis of health inequalities and economic negotiations for people living with HIV. Peterson's "working the line" stands in sharp contrast to Wyatt-Morley's work at the factory. It also stands in sharp contrast with Wyatt-Morley's own volunteer work; first with founding WORTH, an organization meant for peer support and community-building (Peterson is not interested in community-building through her hotline work); and second, Wyatt-Morley's insistence on allowing others the opportunity to tell their stories through her film project, a sharp contrast from Peterson's appropriation of others' stories for her own narrative.

In Peterson's final chapter, before she begins her closing letter to her son, she writes about her work on Capital Hill, reinforcing her ambivalence around social justice and enforcing her understanding of HIV in isolation from other inequalities:

> At the age of thirty-nine, on the brink of middle-age, I set out to save the world. I am an activist. Tentatively, I mouth these words, and by the third or fourth time I have spoken this sentence, it begins to seem credible. […] I have good reason to doubt myself because for most of my life, I have been indifferent to world affairs. It is only for the last few years I have developed a political conscience. Once, in graduate school, I got dragged into a march against apartheid, but it was only because I was on my way to the library and the marchers happened to cross my path and one of them was my advisor, who pulled me in, and I felt for the sake of my academic career, I couldn't refuse.[77]

For Peterson, genocide is simply one of many "world affairs" that does not enter her "political conscience," placing apartheid in the same category as only voting rarely in local elections. And when she is "dragged" into activism, it is only for her own narcissistic reasons. While it could be argued that HIV awakened Peterson's political consciousness, she has not demonstrated an investment in social justice work at any other place in the text. As she discusses her work in HIV advocacy on Capital Hill, she again emphasizes herself and her own whiteness. To return to a passage from earlier in the essay:

> And suddenly I remember why I am here: I'm white, I'm middle-class, I'm college-educated, and I look like Senator So-and-So's niece or daughter or sister-in-law. I've been chosen for my shock value. Our biggest enemy, what we have really come to fight, is this attitude that AIDS is a disease that happens to *other* people. Our second biggest enemy is the mistaken belief that the disease no longer poses a significant threat: that it's a sort of low-simmer illness, something you can safely leave on the backburner while you attend to other things.[78]

In this passage, Peterson reinforces this deserving/undeserving divide by emphasizing her own (privileged) position (white, middle-class, college-educated, the daughter or niece or sister-in-law of Senator So-and-So) in order to gain political attention for HIV. Because she is not an "Other," HIV warrants legislative attention. Her work on Capitol Hill is a microcosm for the book's project itself. In fact, she writes of her legislative speech as a "performance"—"a story about my story"—again framing writing as art, as opposed to an economic negotiation that addresses power inequalities.[79] She does not go into details about how "AIDS" is not a low-simmer disease, about how resource inequalities, the prison industrial complex, sexism and intimate partner violence all exacerbate the prevalence of HIV infection and one's ability to access and maintain a pharmaceutical regimen. While Wyatt-Morley does not emphasize all of these systemic contributions to HIV prevalence, her own story is one of politicization. Her memoir ends with her as the Executive Director of WOMEN (Women on Maintaining Education and Nutrition), a comprehensive organization that serves women and families "affected and infected" by/with HIV.[80] By keeping the mission and clientele (those affected by HIV) broad, Wyatt-Morley stands at the helm of an organization that can address myriad systemic issues that contribute to the HIV/AIDS epidemic.

Peterson, in contrast, reinforces this deserving/undeserving divide again when she discusses the financial negotiations of her group, the only time Peterson ever mentions finances in relation to HIV:

> All of us have been allotted a small sum of money for this trip and most of us feel the amount has been generous. Several of the women, however, have spent all of their money and have nothing left to get them from the airport to their homes. One woman has been begging money from a few other women in the group, myself included. We suspect she may be an alcoholic.[81]

In a narrative where economic negotiations are notably absent (How does Peterson make a living? How does she access/pay for her medications?), her attention to the financial details of this trip seems superfluous. In fact, she appears to highlight the economics of this trip as a means of displaying her own condescension and moralizing judgment, while again distancing herself from other women living with HIV. Her use of this financial detail does nothing to illuminate why women on the trip would need an allowance in the first place (Why are many women with HIV living in low socioeconomic conditions? Do their medication's side effects cause them to lose hourly wages, as in Wyatt-Morley's case?) Instead, the reader gets Peterson's explanation of alcoholism (irresponsibility) in contrast with Peterson's own sense of gratitude—the allowance, for Peterson, is "generous." Peterson is unable to address the social inequalities between herself and the other women in her "activist" group. Her advocacy, what she calls her activism, stops at her own whiteness and class privilege. Her story about HIV is a story that reinforces white privilege and undermines HIV social justice work.

Beyond a Postfeminist Motherhood

In this reading of these two memoirs, I have demonstrated the way in which HIV is co-constituted with motherhood; as such, women writing about HIV have created a new affective landscape oriented toward a life that disrupts earlier conceptualizations of HIV as enemy invader. At the same time that both memoirists understand their HIV as inseparable from their motherhood, their negotiations of material labor—paid labor, volunteer labor, writing labor—create strikingly different affects for each memoir. Wyatt-Morley, an African American working-class woman, continually recounts to readers how her HIV disrupts her financial security, at the same time she works as a volunteer to build community among other HIV survivors and works to provide a platform (through video documentation) for HIV survivors to tell their own stories; Peterson, in contrast, distances herself from other HIV survivors, calling consistent attention to her whiteness and class privilege, judging other survivors for their material negotiations as she continues to be a stay-at-home mother. Some scholars have argued that connecting illness to motherhood is a simplification of illness experience and a postfeminist political tactic; in the context of HIV, motherhood is differentially deployed to elicit affective responses from readers. The two memoirs highlighted here reveal two different ways in which motherhood can be deployed. Unrecognized white privilege and class status lead one memoirist to counter the progress made toward eliminating HIV stigma, reinforcing a white supremacist call for citizenship. The other memoirist situates her experience with HIV within a broader understanding of racism, classism, sexism, and heterosexism, compelling readers and scholars to resist a simplistic understanding of motherhood as postfeminist. Motherhood, it seems, can still be affectively radical.

Notes

1. Sara Ahmed writes that affect is what preserves the connection between ideas, values, and objects; additionally, an object is affective by its location and timing of appearance. I am expanding Ahmed's thinking here to an affective landscape, meaning the constellation of connections between ideas, values, and objects. Sara Ahmed, "Happy Objects" in *The Affect Theory Reader*. Eds. Melissa Gregg and Gregory J. Seigworth (Raleigh: Duke University Press, 2010): 29–51.
2. Sontag, echoing this argument and writing during the height of the HIV crisis, argues that identifying people as HIV-positive is not an identification of the ill but of "future pariahs," voicing that the social death precedes the physical one (121–122). Sontag Susan. *Illness as Metaphor and AIDS and Its Metaphors* (NY: Picador, 1989).
3. According to the CDC's most recent statistics, black women's rate of HIV infections decreased 21 percent from 2008 to 2010. Black women are still 20 times more likely to be infected than white women; in 2008, they were only 15 times more likely to be infected. So while the number of black women becoming infected with HIV is increasing now, the disparity between white and black women is also increasing. For more statistics, visit: http://www.cdc.gov/nchhstp/newsroom/docs/2012/HIV-Infections-2007-2010.pdf. For more about black women and HIV during the 1990s, see: Cohen, Cathy. *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics*. IL: University of Chicago Press. 1999. Recent HIV narratives include: Marvelyn Brown, *The Naked Truth: Young, Beautiful, and (HIV) Positive* (NY: Harper Collins. 2008); Regan Hoffman, *I Have Something to Tell You* (NY: Simon and Schuster, 2009); Paula Peterson, *Penitent with Roses: An HIV+ Mother Reflects*.

(Vermont: Middlebury Press, 2001); Catherine Wyatt-Morley, *AIDS Memoir: Journal of an HIV+ Mother* (CO: Kumarian Press, 1997).

4. By neoliberal and postfeminist, Dubriwny is referencing scholarship that understands the late twentieth century and early twenty-first century as market-driven with individual identities understood through categories of consumption; some scholars also understand this period as postfeminist; these scholars believe that the goals of the second wave feminists (the women's liberation movement of the 1960s and 1970s) have been reached and gender is no longer a salient identity of difference and oppression.
5. Tasha N. Dubriwny, *The Vulnerable Empowered Woman: Feminism, Postfeminism, and Women's Health.* (New Brunswick, NJ: Rutgers University Press, 2013): 171.
6. Jacquelyn Foertsch, *Enemies Within: The Cold War and the AIDS Crisis in Literature, Film, and Culture.* (Urbana: University of Illinois Press, 2001): 22–24.
7. Ibid., 23.
8. Priscilla Wald, *Contagious: Cultures, Carriers, and the Outbreak Narrative.* (Durham: Duke University Press, 2008): 226.
9. Ibid., 229.
10. Ibid., 229–231.
11. The affective landscape must take into account both the conditions of an object's (HIV's) arrival and its futurity. Because HIV works to break down the immune system, making room for opportunistic infections that are increasingly rare (Kaposi's sarcoma, pneumocystis pneumonia), the threat of HIV can be understood not as a threat itself, but as a threat of a threat. This corresponds with Brian Massumi's argument that even if a threat is nonexistent because it is in the future, it is real if it is felt to be real. Brian Massumi, "The Future Birth of the Affective Fact: The Political Ontology of Threat" in *The Affect Theory Reader*, 52–70. Similarly, Sontag, writing at the height of the HIV crisis, argues that identifying people as HIV-positive is not an identification of the ill but of "future pariahs," voicing that the social death precedes the physical one. Susan Sontag, *Illness as Metaphor and AIDS and Its Metaphors* (NY: Picador, 1977.1989): 121–122.
12. For more on Kumarian Press, founded in 1977, and still publishing today, see: http://www.styluspub.com/Info/aboutkp.aspx
13. Wyatt-Morley, *AIDS Memoir*, 3–4.
14. Ibid., 5.

15. Ibid., 5–18.
16. Ibid,. 22.
17. Ibid., 40, 127 and 73, 118, 139.
18. Ibid., 19, 24, 54.
19. Ibid., 167.
20. Ibid., 179.
21. Ibid.
22. Ibid., 137, 149, 183, 165.
23. Ibid., 182.
24. Ibid., 175.
25. Peterson, *Penitent with Roses,* 1.
26. Ibid., 2.
27. Ibid., 6.
28. Ibid., 7–15.
29. Ibid., 15.
30. Ibid., 16.
31. Ibid., 19.
32. Ibid.
33. Ibid., 21.
34. Ibid., 22–29.
35. Ibid., 31.
36. Ibid., 71. What Peterson describes here is no longer the case because of pharmaceutical intervention, caesarean section, and abstinence from breastfeeding.
37. Ibid., 86–89.
38. Ibid., 124–138.
39. Ibid., 130.
40. Ibid., 133. The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act Care is named after a young white boy with hemophilia who contracted HIV after a blood transfusion. According to their informational website, "The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, was enacted in 1990 and reauthorized in 1996, 2000, 2006, 2009, and 2013. It is the centerpiece of the federal government's efforts to improve the quality and availability of care for medically underserved individuals and families affected by HIV/AIDS. The Health Resources and Services Administration (HRSA) allocates funding to programs created by the CARE Act under various Parts" (http://www.ryanwhite.com/rwcareact.html, accessed June 1, 2015).

41. Ibid., 133.
42. Ibid., 139–243.
43. Ibid., 152–153.
44. Ibid., 241.
45. Ibid., 243.
46. Ange Marie Hancock, *The Politics of Disgust: The Public Identity of the Welfare Queen*. (New York University Press, 2004): 1–10.
47. Ibid., 1–25.
48. Hancock characterizes four features of the politics of disgust: the perversion of democratic attention so that not all citizens are given democratic attention; the space of deliberation is monologic, not intersubjective, meaning not all participants are represented in the deliberation of ideas; citizens succumb to representative thinking; and finally, a lack of solidarity between citizens who are a target population and citizens who are not. Politically, emotions serve to regulate power relations. Hancock, *The Politics of Disgust*, 3, 6–7.
49. Ibid., 6.
50. Wyatt-Morley references working at “the plant” several times. We get a clue to her unionized status when she writes that she is being forced to sit with others “who don’t have a job” in the company cafeteria all day while the plant tries to find her suitable workplace accommodations. *AIDS Memoir*, 101.
51. Wyatt-Morley, *AIDS Memoir*, 17.
52. Ibid., 18.
53. Ibid., 24.
54. Ibid., 27–28.
55. Ibid., 28–34.
56. Ibid., 35–36.
57. Ibid., 43.
58. Ibid., 43–45, 47–49, 85–87, 92.
59. Ibid., 52,57, 75, 76. 90–91.
60. Ibid., 54.
61. Ibid., 55.
62. Ibid., 117.
63. Ibid., 140–182.
64. Peterson, *Penitent with Roses,* 5.
65. Ibid., 28.
66. Ibid., 29.
67. Ibid., 71.

68. Ibid., 71–106.
69. Ibid., 73.
70. Ibid., 77.
71. Ibid.
72. Ibid., 78.
73. Ibid.
74. Ibid., 105.
75. Ibid., 114–115.
76. Ibid., 123.
77. Ibid., 124.
78. Ibid., 130.
79. Ibid., 133.
80. Wyatt-Morley, *AIDS Memoir*, 154.
81. Peterson, *Penitent with Roses,* 136.

CHAPTER 14

Melting Down the Family Unit: A Neuroqueer Critique of Table-Readiness

Zachary A. Richter

On a section of Autism Speaks' website titled "Autism & Your Family," two headings in bold greet the reader, the first reading "How will I deal with this diagnosis," the second saying "Stages associated with grieving." The author of the piece then lists and blurbs a series of emotions, including "Shock," "Sadness," "Anger," "Denial," and finally "Loneliness." This narration as well as Autism Speaks media emphasizing loss of eye contact proliferate the notion that Autism is a crisis in the American family. The isolation hyped by Autism Speaks and others is put forth as a crisis for the workforce and for social relationships. So, the message repeats, "Autism is a crisis." In turn, therapeutic batteries, miracle cures, specialty schools, government programs all manifest as responses to that crisis. The disabled child in the family haunts the image of a happy middle-class peaceful family. Large nonprofits as well as care providers have used the image of "the autistic child" to portray despair, the loss of domestic joy, and the destruction of the American family. Inscribed within this image of disabled child as crisis, a series of normalizing discourses offer early intervention as an option that can help to manage autism and avoid domestic collapse. In such a portrayal, autism and autistic symptoms become separated from the

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persons who are identified with them and come to imply a rising epidemic tide of interpersonal disorder.

In an attempt to challenge the erasure of more positive autistic experiences, this chapter argues that the crisis, so harped upon by charity workers, behavioral psychologists, and educational personnel, is in actuality a scene of conflict between the repressive ideology of the normal family and the resistant practices of autistic subjectivity. The codification of expectations of attentiveness, eye contact, and conversational reciprocity as gateways to normative functioning within curative, medical, and psychological epistemologies obscures the contestation of neurotypical and able-bodied social norms and conventions by autistic and other neurodivergent people.[1] As autistic people who would otherwise be institutionalized have grown up in the family home, those families that have raised them have not always been able to fully prevent a set of changes consistent with their presence. As one might also say, certain nondisabled families can explain away the changes brought by their autistic members, but they cannot always understand those members advocacy of a new type of social relations for the family unit.

To argue that the site of the family is a scene of conflict between autistic subjectivity and familial heteropatriarchal normativity is not to imply that the forces on each side of such a conflict are equal. Instead, the forces of familial normativity are backed by a mass of institutional power and funding, and those that support autistic and neurodivergent changes to the family unit are relatively small (but growing) and minimally supported, financially or otherwise. Bernard Rimland formed one of the first autism-focused nonprofits in the United States, the Autism Society of America, in 1965 to combat autistic behavioral interruptions to his own family life.[2] Autism Speaks, founded in February 2005 by Suzanne and Bob Wright, self-stated grandparents of autistic children, is now one of the biggest and most well-funded nonprofit organizations in the United States. Like Rimland, the Wrights founded the organization to amend, and upend, autistic disruptions into family life.[3] Organizations such as those founded by the Wrights and Rimland work to find a cure for autism, a project that cannot avoid its interior meaning of normalizing the life of the disabled child and in turn renormalizing familial life. The embrace of heteronormative values regarding how autistic children should be included within families by major publically and privately owned organizations has given rise to a countermovement among disability studies scholars who consider themselves “crip/queer theorists” to investigate the site of the family as a site of normalizing intervention.[4]

Crip/queer theory, as it has been articulated in the works of Robert McRuer, Allison Kafer, and others, will be enlisted in this chapter’s rereading of two major clinical and curative ideas about how autistic people relate to families. First, the blaming of autistic children or adolescents’ atypical behavior for the divorce of their parents as propagated in some psychology, social work, and other medical research.[5] Second, the representation and ideology of table-readiness or regulated communicative and bodily presence, as maintained and reproduced by psychological, occupational therapist, physical therapist, speech therapist, and other medical or pseudo-medical personnel. In addressing the above problematic conceptualizations, neurodivergent analyses and counternarratives will be offered. In response to the claim of autistic behavior as destructive, the failed project of cure will be indicted. To critique the ideology of table-readiness, an alternative neurodivergent model of sociality and familial relations centered upon fixations and sensitivities will be offered. The contrast between normative ideals and structures for familial interaction and autistic experiences and structures will be emphasized in a crip/queer criticism of the unassumed neurological and familial norm. But before the broader implications of this chapter’s argument unfold, we will need to consider how the singling out of autistic children as disruptive and as candidates for alteration begins with a focus on and idealization of the image of the child symbolically.

Queer theory proposes that legal, political, and moral images of childhood are a primary area of reproduction for a normative heterosexual cultural grammar or what is described as heteronormativity.[6] Within a heteronormative matrix of intelligibility, the image of the child comes into being as an embodied justification and confirmation of the rightness and productivity of heterosexual reproduction. The couple form, or the pairing of male/female, is then concretized and reified as a primary pairing and an exemplary structure for a broader set of social relations, the most obvious one being the family unit, in which gendered reciprocity is a thematic and performative requirement. Scholars in the area of Family Studies have also remarked on the couple-form structure, but through reference to the nuclear family.[7] As will be illustrated, the nuclear family may be understood as the superstructural outgrowth that emanates from the epistemic core of the heteronormative couple.

What is usually called “Family Studies” comes together as a mix of sociological, anthropological, psychological, and therapeutic conceptualizations of the organization of family structure and how family members relate to one another. Family studies scholars argue that sociological and anthropological analyses have helped to codify and institutionalize the concept of a nuclear family as an ideal type.[8] This idea is confirmed by family therapists, who regard anthropological claims about the dyadic family unit as a basis for how a family with stable boundaries is organized and place interparental relations as formative of how relations with children and broader intergenerational kinship relations are carried out.[9] A goal in this chapter will be to reconceptualize the ideal type of nuclear family through the use of the table metaphor read through a crip/queer lens, as well as the communicative resistance of neurodivergent activists and scholars.

In queer theorist Sara Ahmed’s *Queer Phenomenology* (2006), the nuclear family is understood as a spatial and social collective object, manifested through the device of the dining table, that orients how bodies “inhabit space … [and] how we apprehend this world of shared inhabitance, as well as “who” or “what” we direct our energy and attention toward.”[10] As will be explained in the following paragraph, table interactions manifest the repressive demand to conform to the closed-off dyadic form of the nuclear family structure and in turn condition the limits and paths of intimacy within that closed scheme. The phenomenological presumptions inherent in Ahmed’s work make attention to a founding concept for conceiving how the table enacts socially the rules and mandates of the nuclear family unit. Attention to phenomenon is limited and produced by acts of relegation to the background. To perceive a thing demands that other things not be perceived. In turn, orienting devices limit attention. In the work of Maurice Merleau-Ponty, attention and attentiveness are the principal resources for understanding the world and are limited by the temporariness of consciousness as well as the limited range of the human senses.[11] Based on such theories, the phenomenological form of the family unit in terms of attentiveness and the contextualization of family in terms of its form are parsed as a crucial background for considerations of how disability might disturb and rewire familial relations.

Within Ahmed’s thought on the dining table as an orienting device, vertical lines show the blood ties and horizontal lines represent the epistemic pairing of the sexes; these lines of intimacy provide a basis for the compulsive normative realignment of deviant embodiments and ways of being.[12] If we envision the "traditional" nuclear family seated around their dining table, we see the father at the head of the table, the mother at the opposite end of the table, and the brother and sister seated on either side of the table. Buttressing the extension of the vertical line of blood ties into history and in anticipation of a normatively reproduced patriarchal future, the necessary logic of the nuclear family can be understood as a power scheme of distribution by proximity to masculinity. This ideological reverence and identification in the name of the father provides a guide to the extension or intrusion of the table into deviant or estranged subjects of it.[13] Membership within the defining confines of the heteronormative table is then patriarchally granted; for there to be a place at the table, one must look up to the father at the head of the table. The crisis in the family unit occurs when the chain of signifiers becomes untied or in the event of uneven attention across such horizontal and vertical axes. As argued by family therapists Falicov and Brudner-White, "triangular shapings" of the nuclear family are inherently unstable because of the uneven distribution of attention—speaking not only to disability, but also to the patriarchal desire to have more than one child, ideally representing each sex.[14]

Balance is a key word, not only in terms of physics and geometry, but also family, the good life, and health. For a table to rest firmly on the ground, the legs must be balanced. Similarly, professionals put forth the word balance to explain how parents should simultaneously make efforts to normalize their children and to participate in familial intimacies. A series of studies that have come out since the advent of deinstitutionalization in areas like Pediatric Nursing put forth the idea that parents must find a balance between the role of being a teacher to their child and the role of supplying spousal intimacy.[15] In this figuration of the family, repeated by those in the health professions and modeled, according to Sociologist Gil Eyal at Columbia, on the efforts of autism parent-researcher-advocate celebrities such as Bernard Rimland and Lorna Wing, the energies of familial effort must be redirected from its former role of offering supportive sociality to a role of clinical social and bodily rehabilitation and normalization or educational and medical preparation for an ableist world.[16] Such doctrines of "balance" presuppose and assume the necessity of parental participation in almost ritualistic scientifically unsound therapeutic efforts to reward "normal" behavior and punish autistic symptoms.[17] The talk of balance additionally anticipates the question of events that cause loss of balance and the symmetry demanded in attention required by therapeutic discourses of "table-readiness." But before the heteronormative expression of "table-readiness" will face critique, we must investigate the inflammatory claim of autistic people causing the disillusion of families and the divorces of their parents through disability studies scholar Alison Kafer's conceptualization of curative time.[18]

Hartley et al.'s (2010) study entitled "The Relative Risk and Timing of Divorce in Families of Children with Autism" cloaks its dangerous hypothesis blaming familial collapse on burdensome autistic behavior through psychology-based discourses that claim as a veritable fact that autistic embodiment is always disruptive.[19] Underlying these claims that situate autistic symptoms as most difficult to live with in the period just before adolescence is a timeline imposed upon Autistic bodies by medical and other professionals that locates the last chance to "save" autistic people from the dangers of permanent symptoms at that same period. The justification for the intensive behavioral programs in Lovaas-inspired behavior modifications, such as Applied Behavioral Analysis (ABA), can be said to assume a shrinking window; that is, if behavioral programs are initiated at an early age, "improvement" is expected by ages 7–9, the exact moment, preadolescence, in which families are expected to be most vulnerable to collapse.[20] What appears here is an argument that the demise of the family unit is ushered in, not by an unruly autistic child, but by the imposition of hyper-normalizing temporal criteria onto that autistic embodiment from within the family unit. Kafer's concept of curative time helps to explain how the production of a curative futurity for the autistic subject is what loosens social relations; in expecting an impossible future, the present of the family is shattered.[21]

The curative calendar for autistic children, first introduced by Ole Ivaar Lovaas and advanced by the works of Seltzer and others, suggests that with appropriate commitment early on in the life of the child, improvements will occur prior to adolescence. Kafer writes of curative time as "future…framed in curative terms" and as a temporal trajectory that renders disabled embodiment a tolerable obstacle only so far as it is on the way to elimination, integration, and ultimately normativity.[22] We may consider how the translation of diagnostic authority from clinicians to parents also implies a transmission of curative responsibility. Parents are stretched by compulsory able-bodiedness, a system that disability studies scholar Robert McRuer argues, "assumes in advance that we all agree: able-bodied identities, able-bodied perspectives are preferable," into positions of affection and normalizing responsibility by the expectation that they provide extra training to their children.[23] Parent bodies are taught and led to expect an end to such a stretch in the finalizing moment of the cure. When the curative estimate is impossible, when its manifestation turns out to be a false prophecy, the delay system snaps and the normatively mandated gaps in affection become realized as the new reality. It is this simultaneous failure of affection and failure of curative time that may be the trigger identified in Hartley et al.[24] Instead of preadolescent behavior being a hump that parents have to be able to put up with (or get over), it is the inevitability and acceptance of autistic difference that is the true—and according to some researchers insurmountable—hump. While in early childhood, curative futurisms leave a normal adulthood in place. In preadolescence, the chronic nature of "the condition" becomes fully clear; the curative clock stops and the pressure built up by the anticipation of a future free of autism leads to a familial meltdown.

The purpose thus far has been to illustrate how claims about the collapse of families with autistic children may be reread in light of disability studies theories and through the transfer of jurisdiction over autistic children from institutions to a network of unassuming therapists, educators, and clinicians, as well as parents. In choosing to regard the therapeutic dictate of balance as a factor that causes the stretching of parental efforts so far across normalizing and affectionate roles, the intention is to illustrate how it is the requirement of habilitation by parents that has ruptured the family unit, not the autistic child. But habilitation cannot rupture the family unless it is in competition with affection as a key resource in interpersonal and perceptive engagement. This may be why the phenomenological building block of attention is so important in this chapter. To conceive of the limits of the dining table as an orienting device, we must recognize that the table places members of the familial complex on differing sides and we must be able to imagine an impossibility of awareness of all sides at once. The shape of the dining table directs attention to the sides shared by the beholder. When this order is disrupted, as it is by the presence of disabled embodiments, the old ways of discipline (that punish speaking out of turn) are brought back, often through ideologically violent means.

In the clinical developmental disability literature, aimed primarily at parents and practitioners, "table-readiness" is codified as a condition of socio-spatial normative docility in communication and the receipt of familial roles.[25] The "table ready" disabled child must comply with familial instructions while making eye contact, keeping their hands and body quiet (not rocking their body or flapping their hands, doing what practitioners call self-stimulatory behavior) and self-regulating their emotional response to the situation (not tantrumming). Expanding on Ahmed and Carsten's work on the table as an object of kinship used to organize and stabilize the family structure, it may be useful to consider how the attachments that are constitutive of table-readiness aim to transform the overexpressive and overemotional, self-stimulatory, autistic subject into a reflection of the reciprocity and geometric boundedness of the couple form.

One of the earliest usages of the concept of "table-readiness" (that this researcher could find) comes from Koegel et al.'s (1988) self-help-oriented article "How to teach pivotal behaviors to children with autism."[26] In Koegel's manual, a successful message is sent between mother and child only when the two of their bodies face each other and the mother can request, using touch and eye contact, that the child put forks on the table in their proper places. Koegel distinguishes this form of communication from the situation in which the mother calls from the kitchen into the dining room to ask the child if the table is ready. While Koegel's manual highlights the instance of calling across several rooms as being problematic mainly because the instructions are unclear for the disabled child, his paragraph on why calling across the room is a bad choice begins with noting that the mother is not sure that her child is paying attention. In Koegel's formulation of clarity and attention as an ideal, attention is only achieved in a bodily parallelism akin to that of the table—returning the gaze and keeping the body facing another body are prioritized.

Using Foucault and disability studies theorists, we can analyze how the mechanistic dictates for the body, as well as the molding of self-consciousness about the shame of impaired embodiment operate concurrently. It will not be difficult to find a parallelism in this narrow concept of attention to Foucault's notion of docility. Foucault (1977) writes of docility in *Discipline and Punish*:

> …it was a question not of treating the body, en-masse…but of working it retail…of obtaining hold upon it at the level of the mechanism itself—movements, gestures, attitudes, rapidity: an infinitesimal power over the active body. Then there was the object of the control: it was…the economy, the efficiency of movements, their internal organization; constraint bears upon the forces rather than upon the signs… it implies an uninterrupted, constant coercion, supervising the processes of the activity…[27]

Foucault's theorization on the strategy of docility's work upon the body may easily be made more concrete with theorist of ableism, Fiona Kumari Campbell's (2009) retheorization of disability oppression as beliefs and practices that generate and assume a specific sense of body and self that is projected upon the entirety of the community as a standard for humanness.[28] One can then think about the attention aspect of table-readiness as a set of mechanistic adjustments to autistic bodies intended to recertify the presumption of ableness in the family unit itself.

In that the discipline of table-readiness transforms the flesh, it replaces the expressions that were previously native to it with an austerity of expressiveness. What makes autistic bodies in their undeveloped form so much a threat to ableness is their overexpression. In a blog titled "Quiet Hands," Julia Bascom writes, "When I was a little girl, they held my hands down in tacky glue." Her title "Quiet Hands" is repeated throughout the piece. "Quiet Hands!" they insist over and over.[29] In the physical gripping of flapping or stimming hands, in the mantra-like repetition of the instruction to quiet one's hands, there is an intention of pruning to maintain the geometric stability of the social whole.

The table, we might remember has an origin and end. It places on the exterior of its social zone, the people who must labor to create it. Emotions, nonnormative expressions, excitements, obsessions, bodies are left out. The sides of the table, created as reactions reflect each other and meet in an objective parallelism that becomes destabilized and teeters when its legs or sides have extraneous material (in the form of disability) added to them. Autistics and their allies know the flapping of hands and other nonverbal tics may not speak to the rigid confines of the table, but they detail otherwise hidden traumas and excitements. Great importance is placed upon the attentiveness of the table-ready autistic subject, but this is not attentiveness to emotional and sensory information. It is attentiveness to the ongoing expectation and presentation of social neutrality and openness to specific types of human-created communication.

The restrictions of attentiveness require a body that is acting only in response to social directives and does not respond to inner or outer, environmental stimuli. One may understand these restrictions as strategies through which the emotionality of the intervened upon subject—the autistic child—is fixed in subjection and mimicry of social norms. In the clinical literature, a meltdown is a tantrum, a loss of control over emotions. Sometimes meltdowns are understood as resulting from sensory or social phenomenon. Table-readiness ascribes a social performance that excludes inner and environmental stimuli, except in cases in which the environmental disruption is something viewed as problematic to neurotypical participants. Attention is placed on the authorities within the family structure and on the social designation of the setting. In that the therapeutic goal of attention implies only interpersonal attention, it becomes an austerity of embodiment, canceling out all ways of interacting or being with the exception of narrow notions of interpersonal familialism.

"Table-readiness," the performative mask of bodily docility, of subjection to or perhaps oneness with the set of practices that normatively construct the family is as much a fantasy as the table itself. These are illusions that bodies ache to construct. The autistic must deaden their senses. The parent must become a tool of schooling, not an ally of a child's own way in the world. In the deployment of words like balance, professionals recompose and condition parental intimacies to curve around instrumentalist goals for body performativity. The discipline of the domestic is carried out through discourses of the autism epidemic, focusing on the autistic child. The types of discipline and order instilled in these practices are fantastic because they purport to arrange matter and family life according to strict rules. The inconvenience of the day-to-day cannot be made orderly. No matter how carefully familial existence is regulated, there will always be sources of leakage. Order is an illusion brought about through daily micro-violences. The wider affects of table-readiness on autistic adults are dangerous but unspoken.

The implicit devaluation of autistic ways of being occurs in the mechanistic shaping of action and self-conception that takes place as a child. Campbell (2009) discusses internalized ableism as a concept of selfhood that is permanently dissociated from impairment (or what the social model of disability called the material or medical aspect of disability) and the body.[30] In that regimes of table-readiness suppress disabled ways of being and only grant value to abled sociality, they train adult autistics to readily accept their lack of ownership over their bodies and to be repelled by their senses and needs for expression. This is an internalized structure for self-hatred, wherein the body itself is set against the demands by society for a self that is not disabled in its self-description. As long as the self of the disabled person is placed as separate from the characteristics of impairment, the disabled self will be fractured. As I anticipated earlier in this chapter, the owning of the self and the creation of neurodivergent forms of sociality within and outside the family structure will be crucial to disabling domesticity by altering this legacy of devaluation.

Jim Sinclair's (2010) article "Being Autistic Together" offers some bases for an alternative type of social and familial relations, starting with attentiveness that is not oriented toward a couple-form relation, but whose intimacy is a function of inner and outer sensory and emotive environments. Like the early childhood classroom activity of Show and Tell, Sinclair's model of sociality around fixation provides a mode for sociality based not around parallel reciprocity between self and other, but channels communication around an intermediary, existing in content and form that redirects social relations.[31] This may be why it is useful to consider this a neurodivergent sociality, even if Sinclair himself claims it as an autistic social element. The word "neurodivergent" has been coined to describe alternative neurology, usually implying either diagnosed or undiagnosed developmental disability or mental illness.[32] But if we enter neurodivergence into a phenomenological concept of sociality, it takes on a spatial meaning, indicating how socializing with an unusual neurology often requires taking diverging or deviant routes to community. Socializing around an object of sensory excitement is a major path of neurodivergent sociality. In the autism world, examples of this include props that are brought by individuals or special interests that divert attention from the regulation of social hierarchies. Such as in the children's activity of Show and Tell, a third or fourth object to interact around offers a destabilization of the perceptive hierarchies present in top-down patriarchal relations. Objects of sensory excitement function as alternative orienting devices to the structures of family and capital machinery. Sinclair's discussion of socializing revolves around the triggering of excitements, such as fixations on certain colors.[33] While a neuronormative ableist model of socializing would condemn flapping hands at the sight of specific colors, a social style built around attention to an intermediary object allows for those overexpressions and extra-perceptivities to be an active part of the social familial process.

We can thus imagine the possibility of the reformulation of the social space of the table, in the hope that collective social spaces can diverge from the need merely to reflect and to refract as in the couple form and instead coalesce around an alternative and more inclusive basis for social grouping. As noted above, the organizational styles pioneered by Jim Sinclair in their writing point to a way for alternative social forms to develop. The use of social technologies that help to divert attention according to user needs help in this endeavor. Furthermore, the pioneering of cultures not reliant on a set of normative greeting rituals but more willing to accept rants as social orienting devices does offer promises for what can be adopted by the mainstream culture. However, it would be no easy task to alter how the heteronormative ableist majority converses. Perhaps the most that

Sinclair's suggestions could aspire to is a series of guidelines for social groups whose aim is to be inclusive. This may mean a recognition of the obsession or the special interest as a way of deflecting social pressures; it may also imply the use of some of the social devices mentioned by Sinclair among populations not privy to the precision of "being autistic together." Then, the reformulation of social grouping offered by Sinclair can only aspire to adding a new suggestion to the mercurial hybrid world where so many contradictory forms of social life present themselves.

Notes

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6. Berlant and Warner. "Sex in Public," 49; Edelman, *No Future*.
7. Jon Bernardes, *Family Studies: An Introduction*. (Psychology Press, 1997); Celia Jaes Falicov and Lilyan Brudner-White. "The Shifting Family Triangle: The Issue of Cultural and Contextual Relativity." *Cultural Perspectives in Family Therapy* (1983): 51–67.

8. Bernardes, *Family Studies.*
9. See, for example: Falicov and Brudner-White. “The Shifting Family Triangle.”
10. Ahmed, *Queer Phenomenology*, 3.
11. Maurice Merleau-Ponty, and Colin Smith. *Phenomenology of Perception* (Motilal Banarsidass Publisher, 1996).
12. Ahmed, *Queer Phenomenology*, 83.
13. Ahmed, 74.
14. Falicov and Brudner-White. “The Shifting Family Triangle.”
15. Seltzer, et al. “Trajectory of development…”; Hartley et al., “The Relative Risk and Timing of Divorce…”; Koegel, “How to Teach Pivotal Behaviors…”
16. Eyal, “For a Sociology of Expertise.”
17. The Lovaas method entails a series of prompts to the autistic child and then either positive or negative reinforcement, depending on how the autistic child reacts. O. Ivar Lovaas, “Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children.” *Journal of Consulting and Clinical Psychology* 55, 1 (1987): 3.
18. Alison Kafer, *Feminist, Queer, Crip*. (Bloomington: Indiana University Press, 2013).
19. Hartley et al., “The Relative Risk and Timing of Divorce…,” 449.
20. Hartley et al., “The Relative Risk and Timing of Divorce…”.
21. Kafer, *Feminist, Queer, Crip*, 47, 149.
22. Kafer, *Feminist, Queer, Crip*, 27.
23. Robert McRuer, *Crip Theory: Cultural Signs of Queerness and Disability*. (New York University Press, 2006): 9.
24. Hartley et al., “The Relative Risk and Timing of Divorce…”.
25. Koegel, “How to Teach Pivotal Behaviors…”; Grindle and Remington, 2004.
26. Koegel, “How to Teach Pivotal Behaviors…”.
27. Michel Foucault, *Discipline and Punish: The Birth of the Prison*. (Random House LLC, 1977): 137.
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29. Julia Bascom, “Quiet Hands.” http://juststimming.wordpress.com/2011/10/05/quiet-hands/ (Accessed: October 5th 2011).
30. Campbell, *Contours of Ableism*, 26.

31. Jim Sinclair, “Being Autistic Together,” *Disability Studies Quarterly* 30, 1 (2009).
32. firewingedlion, May 31st 2015 Tumblr page of user noting the origin of “neurodivergence” term.
33. Sinclair, “Being Autistic Together.”

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