

Christine Kelly

# DISABILITY POLITICS AND CARE

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**The Challenge of Direct Funding**



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# DISABILITY POLITICS AND CARE



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## Introduction

### The Tensions of Care

Jennifer has lived in an array of long-term care settings in Ontario, including in a hospital-like residential centre, where she was institutionalized as a child, and presently in her own home, where she receives cash to directly hire attendants to support her. This range of experiences shapes Jennifer's political views and gives her a unique perspective from which to comment on long-term care for people with disabilities in Ontario. When describing the residential centre from her childhood, Jennifer explained that the staff members knew each of the fifty-two children with physical disabilities who lived there, yet they decided to institute hospital bracelets for identification. Jennifer and the other children resisted the bracelets, seeing them as impractical and demeaning, but the staff insisted they were necessary. Jennifer recounts:

We cut them off. And the kids who couldn't cut it off themselves, we helped them cut it off. And kids would chew them off. Every day they were replacing these bracelets with us. They just gave up. So we wore them down. We won that battle.

Jennifer and the other children resented the bracelets that stood for the medicalization of their bodies and the complete control of their lives, and literally chewed them off their bodies to make a dramatic statement about life in a large institution.

"I offer an apology to the men, women and children of Ontario who were failed by a model of institutional care for people with developmental disabilities."

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In December 2013, Ontario premier Kathleen Wynne delivered this historic public apology, acknowledging the harms and “deeply flawed” approach of government-funded regional centres for people with developmental disabilities, which ran in parallel to the hospitals for children with physical disabilities, such as the one where Jennifer lived as a child.<sup>1</sup> The litany of harms include physical, emotional, and sexual abuse; ineffective “therapies”; human degradation through social isolation; and complete control over the lives of individuals who lived in the centres, all of which took place under the guise of “care” for disabled populations. The premier characterized the regional centres as a painful chapter in the history of the province of Ontario. This apology followed the closing of all regional centres in 2009, and was part of a class-action settlement against the Ontario government led by former residents.

Mass institutionalization of disabled people, like other forms of systematic oppression, cannot be contained to a specific historic period. The harms, abuses, and human degradation associated with social segregation and the material effects of this exclusion continue to haunt institutional survivors and their families and friends, as well as, more broadly, people with disabilities who do not have direct experience living in institutions. Models of institutional care continue to structure other care arrangements for people with all types of impairments, even if services are delivered in smaller settings that are designed to be home-like and endorse community-oriented frameworks. Paternalistic and “caring” approaches to disability pervade popular perceptions and shape individual encounters between nondisabled and disabled people. In short, this history is not a history. The effects of these models of care cannot be erased by glossing over or tangibly repurposing former institutional sites (Abbas and Voronka 2014).

Jennifer also recounted challenges she faced in every single support arrangement that she lived in over the years after leaving the residential centre, many

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<sup>1</sup> Many authors explore questions of terminology in their work on disability (e.g., Shakespeare 2006; Siebers 2008; Titchkosky 2003). These discussions explore the extent to which disability is socially constructed, the power of naming, and whether disability is central or marginal to personal identity. There are some regional and generational elements to this discussion, that is, generally people in the United Kingdom and people coming from a cultural framework use the term “disabled people,” whereas some people in North America and established leaders tend to use “people with disabilities.” In my experience, this debate also occurs in disability-related organizations and among individuals with disabilities, including participants in this study (see also Watson 2002). Since there is no consensus regionally, within disability movements, or within academia, I use both of the most widely accepted terms, that is, “people with disabilities” and “disabled people.”

of which were positioned as alternatives to medical, institutional, and caring approaches to disability. She reflects, “Wherever they are, people want choice. They want autonomy, they want more control over where they are.” Lack of choice over major and minor life decisions, from relationships and employment to what to wear and eat, is one of the most pervasive and perhaps subtle violences of institutionalization. Enabling choice for all disabled people became the crux of Jennifer’s activism over her lifetime and reflects the broader framework of the Independent Living movement.

The recent history of mass institutionalization, the caring mentalities and attitudes that continue to undergird support for people with disabilities, and the political efforts to contain institutionalization to a specific historic period all forge a difficult backdrop for present-day attendant services. Part of this challenge is to bring the critiques of institutional care to the many researchers, practitioners, activists, and students from varied backgrounds who work in care-related fields. Care is arguably a foundational orientation and pivotal goal of many health and social sciences fields and policy discussions and, for many, a motivating force for the work they do. To complicate things further, “care” is a common word, often deployed in business names and mandates, extending far beyond the worlds of disability movements and health and social policies. The ubiquitous presence of care, however, does not imply a lack of controversy, as demonstrated by both Jennifer’s life story and the apology from Premier Wynne.

Independent Living movements, disability activists, and disabled individuals worldwide proclaim, “We do not need care.” This statement comes from even those with profound physical and intellectual impairments, some of whom require comprehensive, ongoing assistance with daily activities that might otherwise be described as care. Disability movements do not intend to eliminate the provision of daily physical assistance, so which meanings and practices of care *are* rejected in this sentiment? *Disability Politics and Care* aims to interrogate the foundational concept of care and to consider the implications of taking seriously the rejection of care presented by disability movements and individuals with disabilities. That is, the book explores what it might mean to acknowledge the disability critiques and to incorporate a rejection of care into the core of theorizing, research, practices, and policies of care.

The central objective of *Disability Politics and Care* is thus to document contemporary practices and conceptualizations of care within a program that explicitly rejects it: Ontario’s Direct Funding Program, the same program Jennifer uses. The program is administered by a nonprofit organization affiliated with international Independent Living movements. Independent Living has a vibrant history that includes rejecting caring approaches to disability while

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redefining independence. Independent Living is a (sometimes) effective social and political placeholder that offers valuable commentary on care. It is also a fragile social movement managing to survive in hostile neoliberal and austerity policy climates. Academic debates about care build on Independent Living critiques, and occur most often and directly between disability scholars and activists on the one hand, and feminist care researchers aiming to revalue gendered forms of labour on the other. Rather than seeking common ground between the disability and feminist perspectives, this book instead defines care as a tension. I argue that the tensions and competing meanings are integral to common, and uncommon, understandings of care.

*Disability Politics and Care* considers this tension from the perspectives of the individuals at the centre of the debates – that is, through reporting on fifty-four qualitative, in-depth interviews with people with disabilities, attendants, informal supports, and key informants from varied sectors related to Ontario’s Direct Funding Program. Through these conversations, I found that direct-funding mechanisms and the connections to disability movements rhetorically remove care but do not eliminate it. Rather, care is moved and contained to specific meanings, transforming our understandings and practices in the process. I term this process “removing care” or the “removal of care.” *Disability Politics and Care* has implications that extend beyond the specific program to resonate in parallel policy spheres and throughout Canadian and international disability movements.

The tensions of care and the related academic debates take place in the context of attendant services for people with disabilities. According to the Attendant Services Advisory Committee (ASAC), attendant services primarily serve people with physical disabilities. As ASAC describes: “Consumers direct their attendants to perform the activities of daily living (ADL) they require to get on with their day-to-day lives. Attendant services include: bathing and washing, transferring, toileting, dressing, skin care, essential communications, and meal preparation. The consumer is responsible for the decisions and training involved in his/her own services” (OCSA 2008).<sup>2</sup> Attendant services can also include help with cleaning, household maintenance, errands, and

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<sup>2</sup> In material influenced by Independent Living philosophy, people with disabilities are commonly referred to as “consumers” in an effort to position disability-related programs as services and disabled people in charge of these services. There are issues with this term and ongoing discussions in the community about it. “Consumer” makes concessions to a mass-produced culture, may overvalue individualism and choice, and implies options when none may be available. Thus, because of these debates and since it is less widely used than the phrases discussed in the preceding note, I do not use this term other than in a direct quotation.

sometimes child care. Attendant services are rooted in the Independent Living movement and are premised on the notion of consumer direction, which shifts control of the services to people with disabilities. Attendant services influenced by Independent Living often include an explicit rejection of the concept of care. Language is a primary indicator of this approach and is reflected not only in the aversion to the term “care” but also in the choosing of terms such as “self-manager” and “consumer” when referring to people with disabilities using the services, and “attendant” (in Ontario) and “personal assistant” (most common in the United States and the United Kingdom) when referring to the person providing the service.<sup>3</sup>

Perhaps the culmination of Independent Living attendant services that is clearly linked to an adamant rejection of care is directly-funded service delivery.<sup>4</sup> “Direct funding” refers to providing public funds to disabled people, nonprofit organizations, and, in some cases, family members or guardians to hire individuals to provide assistance with daily needs. In direct-funding arrangements, people with disabilities become the employers (in varying respects) of their attendants and are often required to take on administrative duties previously in the purview of service-provision organizations or governments. Disability movements and related organizations pushed for this style of service delivery in the United Kingdom, in various US states, and throughout Canada because of the associated flexibility, empowerment, and user control it provides for disabled people (Mladenov 2012). The push for direct funding has transformed into advocacy and pilot programs for individualized or personalized budgets that expand the eligible activities beyond attendant services and aim to account for the diverse needs and services of a wider range of disabled people. There are sixteen documented direct-funding programs among the ten Canadian provinces (none in the territories or on First Nations reserves), plus an option through the Veterans Independence Program, a service of Veterans Affairs Canada (Spalding, Watkins, and Williams 2006). The Ontario version is the only Canadian example that was developed and piloted, and continues to be administered, by an Independent Living organization. Canada has a national network of Independent Living organizations with strong connections to disability movements in North America, and at times, this network is characterized as a movement itself (Lord 2010).

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<sup>3</sup> “Self-manager” is the term used in Ontario’s Direct Funding Program materials and is used in this book.

<sup>4</sup> The term “self-managed (home) care” has some currency in Canada, though “direct funding” is the most popular term in Ontario.

The Self-Managed Attendant Services in Ontario Direct Funding Program – known more simply as the Direct Funding Program – is administered by the Centre for Independent Living in Toronto (CILT). The program, piloted in 1995–96, was established as a permanent program in 1998 and is funded through the Ontario Ministry of Health and Long-Term Care (Parker et al. 2000). In 2011, when the study this book is based on was conducted, 676 people were using Direct Funding, out of the approximately 6,000 people who were documented in 2008 as using attendant services in Ontario (Katherine Janicki, Direct Funding clerk at CILT, pers. comm.; OCSA 2008). To demonstrate the relative size of attendant services and Direct Funding, Bannerjee (2009) documents 70,100 long-term care beds in Ontario in 2004; this number includes supportive housing (as does the 6,000 count) but does not include attendant outreach services or Direct Funding recipients.<sup>5</sup> Taking into consideration the ambiguity of the figures, the number of people using Direct Funding in Ontario makes up less than 1 percent of long-term care service users and roughly 11.6 percent of attendant-service users. This percentage is similar to direct-funding use elsewhere, with the exception of increases in the uptake of Direct Payments in the United Kingdom in the mid-2000s (Hall 2011).<sup>6</sup> Despite its small scope, the Ontario program is the largest direct-funding program in Canada in terms of the number of people assuming the full responsibilities of being an employer and receiving cash transfers (Spalding, Watkins, and Williams 2006). The program is by far the most independent model of attendant services in the Ontario landscape, and in 2011 had a four-year waiting list, with approximately four hundred people on it. In January 2014, Deb Matthews, the Ontario minister of Health and Long-Term Care, announced that the Direct Funding Program would receive an injection of capital that would enable approximately three hundred more people to become self-managers and reduce the waiting list from four years to two, signifying increased political support for this program (CILT 2014). In a broader context, the Ontario government will fund self-directed and directly funded home-care pilot projects for older Canadians in the fall of 2015. The cultural messages inextricably tied to the history and the current information on the Direct Funding Program declare that people with disabilities do not need

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<sup>5</sup> Attendant outreach services are prescheduled, at-home/at-work personal support provided through Community Support Services. People with disabilities may be involved in the administration of these programs, but on a day-to-day basis, individuals using the program do not directly choose who will be supporting them and may have to compromise the time of service based on the needs of others using the program.

<sup>6</sup> Direct funding is known as “Direct Payments” in the United Kingdom.



care and can collectively and individually manage disability-related services. Access to quality attendant services is framed as a right that enables people with disabilities to fully participate in society, making the Direct Funding Program an interesting case study with which to explore care.

This book highlights the strengths of the program and makes tentative recommendations for improvements where appropriate; however, the primary aim is to enter into theoretical discussions of care. Specifically, this book enters into the debates and conversations between feminist care researchers and disability perspectives and explores the broader policy and movement effects of these discussions. The Direct Funding Program can be characterized as embracing a disability perspective that explicitly rejects the concept of care. As is discussed throughout *Disability Politics and Care*, there are wide-reaching implications of the messages conveyed through this small program. This argument begins by exploring the program within the context of social and political factors in Ontario. Considering the position of the Direct Funding Program among disability movements, the Ontario policy landscape, shifts in social policy and medicine, and globalized care patterns, it is clear that the program guidelines, those who administer it, and those who use it are remarkable examples of social movement activity in a highly constrained context.

### **Direct Funding among Disability Movements**

Ontario's Direct Funding Program builds on numerous historical precedents and can be situated within disability movements in the United States, the United Kingdom, and Canada. Direct-funding models of support can be linked to the deinstitutionalization movement from the 1950s onwards, which seeks to transition people with disabilities and mental health concerns physically out of large-scale institutes and metaphorically out of institutionalized approaches to disability (Ben-Moshe, Chapman, and Carey 2014; Gardner and Glanville 2005; Stroman 2003). The ongoing deinstitutionalization movement is largely led by parent advocates, people with intellectual disabilities, and people with mental health concerns. As briefly mentioned at the outset of this chapter, in March 2009, Ontario closed the final three large-scale institutions, namely the Huronia Regional Centre, the Rideau Regional Centre, and the Southwestern Regional Centre. Institutionalized approaches, however, continue to structure the lives of many people with intellectual impairments living in group homes and long-term care homes throughout Ontario and other parts of Canada (Ben-Moshe, Chapman, and Carey 2014; Canadian Association for Community Living and People First of Canada 2011). Following the closures, former residents of the

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Hurononia Regional Centre, located in Orillia, Ontario, launched a class-action lawsuit alleging that the Ontario government “failed to properly care and protect the people who lived at Huronia” and “that residents of Huronia were emotionally, physically, and psychologically traumatized by their experiences at Huronia” (Crawford Class Action Services 2014). The suit resulted in a \$35 million settlement for people who lived at the centre between 1945 and 2009 and a formal apology from Ontario premier Kathleen Wynne; it was then followed by two related settlements for former residents of the Rideau Regional Centre and the Southwestern Regional Centre (Institutional Survivors 2014; Ontario Ministry of Community and Social Services 2013). The historical and political significance of these settlements is a salient backdrop to the ongoing history of direct funding. Deinstitutionalization activities highlight the often deplorable living conditions in segregated residences, as well as the cultural messages about disability conveyed through social isolation, medicalization, lack of choice, routinization of life, and inhumane treatment. The deinstitutionalization movement demands that people with disabilities live in community settings, and the Direct Funding Program is a potential mechanism for making this possible. At least two participants in this study lived in large-scale institutions as children, reflecting strong links between the Direct Funding Program and deinstitutionalization. Unlike programs in five other provinces, the Ontario example does not serve people with intellectual disabilities or mental health issues unless a physical impairment is also present and the individual can demonstrate the ability to self-direct (Spalding, Watkins, and Williams 2006). The relationship of Direct Funding to intellectual disability is taken up throughout this book.

Elements of the social model of disability also resonate with the Direct Funding Program. As most commonly described, the social model refers to the concept articulated by Paul Hunt of the British organization Union of the Physically Impaired against Segregation in the early 1970s and refined with a materialist lens by Mike Oliver (1990). The social model argues that disability is a social construction: people are disabled primarily by societal structures and attitudes and not by their biological impairments (Campbell and Oliver 1996; K. Davis 1993). The social model is often cited as the basis for disability organizing in the United Kingdom (Campbell and Oliver 1996), though it has undergone substantive critique in academic spheres (e.g., Shakespeare and Watson 2002; Corker 1999) and does not exemplify the intricate theorizing and scholarship that now characterizes the field of disability studies. However, the more complex theoretical scholarship is not necessarily as accessible to, or visible within, community organizations and activist efforts related to disability

(with some exceptions), whereas to an extent, the social model has managed to permeate common parlance in these arenas. Like the Direct Funding Program, the social model draws attention to the environment of disability and promotes the removal of barriers and the provision of supports in order to mediate the effects of impairments. As is found at a few points in this study, the availability of reliable, respectful, and sufficient attendant services makes living with a disability in an ableist society easier, and “mediates citizenship” by creating the conditions for diverse participation (Krogh 2004, 139).

Most significantly, the Direct Funding Program can be interpreted as the quintessential manifestation of the Independent Living movement. Direct-funding schemes build on the legacy of disability leader Ed Roberts and a group of students with disabilities who named themselves the Rolling Quads. In the 1970s, this group was forced to live in a hospital while attending the University of California, Berkeley, because of physically inaccessible residences. Initially, the Rolling Quads focused on living independently yet integrated in the community, and the group founded the first of many Independent Living centres in the United States (Longmore 2003). Like deinstitutionalization, Independent Living is a philosophical commitment. “Independent Living philosophy,” as it is termed on websites and community newsletters, values disability as a social role, emphasizes rights discourse and consumer control, redefines independence in terms of decision making, and is a central orientation of many direct-funding programs.

Disability movements emerged in Canada in the early 1980s and can be distinguished from American and British movements in numerous ways. Scholars note that Canadian disability activists and organizations played an integral role in establishing an international disability rights movement (Driedger 1989) and have a long history within the nonprofit sector (Neufeldt 2003). These organizations and activists work closely with Canadian governments and are often characterized as employing nonconfrontational tactics (Chivers 2007; Valentine 1996). The Canadian Independent Living movement in particular has an emphasis on individual advocacy rather than on collective action, in contrast to the approach of its American counterparts (Lord 2010; Valentine 1994).

In many ways, Ontario’s Direct Funding Program is a seamless fit with the goals, history, and approach of disability movements in North America and the United Kingdom – that is, it’s a seamless fit with the movement histories that are well documented. Some of the most oft-cited historical events in Canada could be easily replaced by the Direct Funding history. For example, accounts

of how people with disabilities garnered inclusion in the Canadian Charter of Rights and Freedoms (Peters 2003) present a seemingly unanimous, policy-focused, nonconfrontational, consultation-based achievement that resonates with the establishment of the Direct Funding Program. As is explored further in Chapter 6, there are other, less well-recorded elements and factions of Canadian disability organizing that do not fit as well.

Disability movements in the United Kingdom and the United States have also pushed for direct-funding models of service delivery, setting precedents for the Ontario example. Overwhelmingly, these programs are evaluated as highly successful, cost-effective, and empowering (Blyth and Gardner 2007; Caldwell and Heller 2007; Stainton and Boyce 2004; Carmichael and Brown 2002; Leece 2000; Askheim 1999), and this can be said of the Ontario example also (Parker et al. 2000; Roehrer Institute 1997). In Ontario, community organizations and advocates participated in writing the policy and continue to administer the program, raising interesting questions for the future roles of disability movements (Yoshida et al. 2000). This may indicate that if individuals or disability organizations take issue with the administration of the program, they are in the uncomfortable situation of having to direct efforts at a fellow disability organization. Most of the advocacy of the program and attendant services more broadly is targeted at the Ontario Ministry of Health and Long-Term Care. For example, the Attendant Services Advisory Committee (which includes representatives from CILT) recommends attendant-service waiting lists be added to the Provincial Wait List Strategy, funding be increased to the sector, and additional individualizing funding options be made available (OCSA 2008). Also in Ontario, community advocate Scott Allardyce proposed draft legislation called the Consumer Attendant Support Services Protection Act, which would provide a venue for attendant service users to report abuse and includes recommendations for a consumer advocate office, reduced wait times, and mechanisms for dispute resolution (draft legislation; Scott Allardyce, pers. comm.). Citizens with Disabilities – Ontario (CWDO) formally declared support for Allardyce’s proposed legislation, advocated that the Ontario Ministry of Health and Long-Term Care reduce the Direct Funding waiting list, and hosted webinars with practical advice on managing attendants. CWDO’s position paper on attendant services also includes an explicit rejection of care. Indeed, most of the current advocacy of Direct Funding is consistent and cooperative, systems focused, and directed at the provincial ministry.

There is one notable exception to the seeming consensus in attendant service advocacy in Ontario: a small, radical group with little publicity or formal or-

ganization called DAMN (Disability Action Movement Now) 2025 (DAMN 2025 2008; Henderson 2007). Some of DAMN's efforts regarding Direct Funding are aimed at CILT. While still rejecting care, members of DAMN 2025 claim that the way CILT administers the program is "blatantly discriminatory against people who are illiterate. Many, many people with disabilities fit this description because of being segregated into institutions and 'special schools' where their abilities (both mental and physical) are underestimated and discouraged" (Ann Abbot, pers. comm.). The agendas of many other disability organizations include poverty, but DAMN consistently integrates a class analysis, keeping it at the forefront of radical disability politics and thus echoing the new wave of disability justice politics (Mingus 2011). The significance of DAMN's critiques is incongruous with documented disability movements in Ontario and the rest of Canada – that is, with histories that document a generally unified approach to Direct Funding.

There are parallel activities in Ontario led primarily by parent advocates regarding the Special Services at Home (SSAH) program, established in 1982, which was formerly available for children with any type of impairment and for adults with developmental disabilities. In 2012, adult funding was separated into the Passport program, designed for people with developmental disabilities who are eighteen years and older. SSAH is run through the Ontario Ministry of Children and Youth Services, whereas Passport funding is administered by the Ontario Ministry of Community and Social Services. Both programs provide funds to facilitate community participation, and the eligible expenses are much broader than those allowed by the Direct Funding Program. There is a long history of community-based advocacy aimed at the Ontario government, which includes asking for reduced waiting lists, increased funding, and, at one point, expanding eligibility of SSAH to children with physical disabilities (SSAH Provincial Coalition 2011). More recently, efforts have transitioned towards requests for a holistic individualized funding model to serve these constituencies (Individualized Funding Coalition for Ontario 2008) and for continuity between child and adult services. This does not suggest there is a unified approach to Direct Funding in Ontario, since the parent advocates do not push CILT or the Ministry of Health and Long Term Care to expand eligibility criteria for the Direct Funding program to include children or adults with intellectual disabilities. However, it does signify the popularity of direct and individualized funding options within disability spheres in Ontario, these options having a history that predates the pilot of Ontario's Direct Funding Program (SSAH Provincial Coalition 2011).

## The Policy Landscape: From Neoliberalism to Austerity

In policy and in official state rhetoric, the Global North shifted to a neoliberal framework from the early 1990s onwards (Harvey 2005). In the most rudimentary sense, neoliberalism is a governing framework that privileges free markets and leads to the privatization of services. This results in smaller governments, at least rhetorically, since in practice neoliberal governance is characterized by increased surveillance of both citizens and noncitizens (Dobrowolsky 2008; Bhandar 2004; Stasiulis 2004). Ideologically, neoliberalism includes an emphasis on individual responsibility and exalts the value of choice for worker- and consumer-citizens (Mol 2006; Breitreuz 2005; Larner 2000). Of relevance to disability movements with a long history in the nonprofit sector, neoliberal agendas are also linked to a co-optation of the third sector through a shift from core-funding arrangements to project-based competitions that are directly linked to government priorities (Incite! Women of Color against Violence 2007; M. Smith 2005; Hall and Banting 2000) and through the removal of gender from policy agendas (Brodie 2008). This period is also characterized by a transition away from full-time secure employment arrangements to more precarious forms of temporary, contractual, and part-time employment, which is reflected in the nature of attendant work under Direct Funding (Vosko 2000). Against the backdrop of these more localized trends is increased immigration and the exploitation of labour in the Global South to support the globalized economy (Encalada, Fuchs, and Paz 2008).

The neoliberal regime is accelerating and transforming in the wake of the 2008 global recession, which resulted in high unemployment that particularly affected young people in North America and Europe, and in damages to middle-class retirement savings, thus contributing to the aging workforce and delayed retirements. Government agendas refocused to bail out major industries, stimulate the economy, and implement austerity measures that would curb government spending by reducing social and health services. There were grassroots protests to these decisions, including the amorphous and largely misunderstood Occupy Wall Street movement that began in July 2011 and spread throughout the United States and into Canada over the summer and fall of that year (Chappell 2011).

In the United Kingdom and Greece, students filled the streets to protest specific austerity measures and demand access to education and employment. After the mass protest outside the Conservative Party conference on October 3, 2010, in Birmingham, England, the group Disabled People against Cuts, or DPAC, formed (2014). DPAC engages in a range of political tactics, from direct

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action to producing research and policy papers. DPAC has renewed disabled activism in the United Kingdom, and its work and popularity highlight how austerity policy frameworks disproportionately affect disabled people. Ellen Clifford(2014), a vocal leader within DPAC, reports that disabled people are nine times more likely to be directly affected by austerity measures than are nondisabled people, and that that number raises to nineteen times in relation to the most profoundly disabled and sick people. Further, Clifford emphasizes how cuts and dubiously applied policy changes result in the death, including by suicide, of disabled people. DPAC has mobilized a movement with over forty-five hundred formal members and a much broader base of support (Clifford 2014). DPAC garnered mainstream media attention during the 2012 Paralympic Games held in London by protesting the sponsorship involvement of Atos, a company contracted by the UK government to implement a harsh austerity measure, the Work Capability Assessment. This process claimed to determine whether people were fit for work and eligible for benefits, though DPAC discovered that the process was intended to reduce the overall provision of benefits and even included weekly quotas to ensure fewer people received support (Clifford 2014). Unfortunately, recommendations from the 2012 report by the Commission for the Review of Social Assistance in Ontario echo austerity trends in the United Kingdom, and it remains to be seen how these recommendations will play out in the Ontario context (Lankin and Sheikh 2012).<sup>7</sup> The ongoing visibility and presence of DPAC in the United Kingdom underscore the dire outcomes of austerity budgets for disabled and sick persons, and also the ability of disabled people to push back.

The shift to austerity has a varied effect on direct-funding schemes in the United Kingdom, which has an expansive Direct Payment program that is open to a wide variety of applicants, including older people, people with developmental disabilities, children with disabilities, people with mental health concerns, and adults with physical disabilities. The program, begun in 1997, expanded in 2003 when it became mandatory for all local councils to offer this option. Despite increases in enrolment in the early 2000s, interest in receiving

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<sup>7</sup> For example, the report recommends that the province should “more vigorously pursue medical reviews of ODSP [Ontario Disability Support Program] recipients, and develop a strategy to deal with the backlog of reviews as a priority” (Lankin and Sheikh 2012, 103). If this strategy is taken up, the vigorous emphasis on medical reviews will perpetuate long-standing stereotypes about people with disabilities cheating the government support system and will likely result in ODSP recipients losing benefits in erratic and unfair ways, similar to what is happening in the United Kingdom.

Direct Payments remains lower than expected (Hall 2011). In addition to Direct Payments, a national Independent Living Fund (ILF) was set up by the Department of Social Security in 1988 to provide supplementary income with which people with disabilities could hire personal assistants. The ILF could be used in combination with Direct Payments or home care programs. Like Ontario's Direct Funding Program, the ILF and Direct Payments are tied to a history of Independent Living movements and activism, and the activist rationale for direct-payment schemes centred on cost-effectiveness, quality, and rights (Evans 2003).

In March 2014, the Tory-led coalition government announced the closure of the ILF, which at the time was funding approximately nineteen thousand disabled people. The government had previously attempted to close the fund in 2012 but was delayed after a protracted legal battle (Eady 2014). Disability activists are concerned this closure will mean less funding available to individual disabled people and result in more residential care options. The elimination of the ILF may signify an attempt to erase the connection to the Independent Living movement by removing the phrase "Independent Living" and by folding disabled people in with all other care recipients. In many ways, the cost-effectiveness and individualized focus of direct-funding schemes is a favourable policy option within an austerity framework, and yet simultaneously there is a deliberate erasure of the social movement history and social justice potential.

In this climate, direct-funding initiatives contribute to enduring neoliberal government priorities since they are extreme forms of downshifting service provision to individual citizens. Instead of provision of services by government-regulated and -owned institutions, care homes, or home care, money is transferred to the nonprofit sector (in the Ontario case), which administers the funds and, in turn, further shifts the services to individuals. It is the individual who becomes responsible for hiring and training other individuals to provide the personal support he or she requires. Disability movements in Ontario and elsewhere advocate strongly for the adoption of direct-funding mechanisms, thereby supporting the argument that social movements are agents in the enactment of neoliberal governmentality (Larner 2000). While direct-funding models of support may greatly benefit individuals with disabilities in a day-to-day sense, endorsing the neoliberal approach undermines other disability supports, changes the agendas of disability organizations, and contributes to the hostile environment for social movement activity.

Home care in Ontario and elsewhere in Canada has also been transformed by neoliberalism and austerity, through varied incremental processes that Hugh



Armstrong (2001) terms “privatization by stealth.”<sup>8</sup> Aronson, Denton, and Zeytinoglu (2004) identify a “contractual approach” to home care in Ontario that promotes privatization linked to the landmark Commission on the Future of Health Care in Canada – colloquially known as the Romanow Commission (Health Canada 2009). Aronson and colleagues note that the commission made a “relatively weak and permissive recommendation[,] once again leaving supportive home care to the discretion of the provinces,” and thus contributing to the privatized, contractual shift in home care and cementing the move to regionalization across all provinces (Aronson, Denton, and Zeytinoglu 2004, 113; see also Shapiro 2003; Jenson and Phillips 2000).

One development in health care reform in Ontario affecting attendant services is the 2005 adoption of the Local Health Integration Networks, or LHINs, following a similar approach in other provinces (Ronson 2006). There are fourteen LHINs in Ontario, delineated by geography, whose primary activity is to streamline health care services by making funding decisions for various health-related organizations (Ronson 2006). The ministry moved “from a system manager to a system planning and oversight role” (Ronson 2006, 47) – another example of the changing role of governments in the neoliberal context. This is a system-wide shift in health care administration; yet, despite being funded by the same ministry, until 2011, the Direct Funding Program managed to bypass this mechanism because of its provincial scope – one of its most lauded features – as well as because of the relatively small number of people it serves. The program is now under the LHINs system, but incorporating it required a change to accommodate programs with a provincial scope. Furthermore, during this shift, CILT confirmed program materials (which reject “care”) and maintained control over the administration of the funds. The Direct Funding Program clearly fits within broader trends of neoliberalism and austerity, yet it uniquely manages to maintain a semblance of autonomy and philosophical commitments to Independent Living, unlike developments in the United Kingdom.

From this brief review, it is clear that local to global policy landscapes are constantly changing, with frequent adjustments to political positions, policy

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<sup>8</sup> In principle, CILT seeks to distance Ontario’s Direct Funding Program from other forms of home care and long-term care, instead presenting the idea of attendant services. In practice, the distance may not be so great; many self-managers previously used other services and, in the case of home care, some access it simultaneously or intermittently while receiving direct funding. Furthermore, the Ministry of Health and Long-Term Care funds the entire system and categorizes Direct Funding as a form of long-term care.

responses, and budgetary priorities, regardless of which government is elected to power or which international body is in discussion. Disabled people, like other marginalized and abject populations, are approached as a special-interest group to be catered to, consulted with in prescribed formats, or ignored, depending on the potential votes or perceived political ramifications of these actions. On a provincial level, attendant services and other forms of support become one more budget line and policy-briefing topic to be considered and continually deferred, while the experiences of the services are often inadequate, especially for those on waiting lists. Political attention and seeming gains, such as the 2014 injection of capital into the Direct Funding Program or the budgetary announcement of a wage increase for personal support workers (Sousa 2014), follow prolonged periods where people are in crisis, waiting on wait lists, or dealing with high worker turnover because of low wages.<sup>9</sup> Titchkosky (2011, 93) comments: “An abiding concern is how, under bureaucratic governance including legislative or procedural change, disability remains more or less represented as an unexpected participant.” The presence of disabled people and discussions of social supports for people with disabilities in political arenas is not only unexpected but often optional for politicians. In this context, Titchkosky makes a compelling argument that “disability is managed as a potentially excludable phenomenon since it is present as a not-yet” (109). In the “not yet” time of disability, bodily difference is submerged into a liberal (and timeless) notion of a universal public body while, at the same time, the specifics of disability are never important or present enough to be a pressing political priority. Titchkosky argues that this erasure happens even in bureaucratic responses that are specifically about disability, such as the Accessibility for Ontarians with Disabilities Act (AODA), which notably does not promise an accessible Ontario “now” but twenty years from its establishment, in 2025. The policies, consultations, and detailed measurements legislated into law attempt to usher in social inclusion and publicly signify “action” by political leaders, while disabled people remain literally absent from positions of power and even from mundane (but meaningful) activities of daily life. As governments change and budgets are announced, minor adjustments may be made to policies and programs that

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<sup>9</sup> The wage increase initially excluded attendants working under Direct Funding, Special Services at Home, and Passport. Setting attendant services apart from other forms of care has the potential to be a politically and culturally salient strategy, yet it can also have material consequences when direct-funding options are excluded from broader policy developments.

dramatically shape the lives of disabled people, but disability and care remains “not yet” a priority.

## **Shifts in Social Policy and Medicine**

There are parallel moves among governments to adopt direct-funding options or to use voucher systems instead of providing services in social policy and health spheres. Voucher systems have been implemented in childcare systems (e.g., Warner and Gradus 2011; Adams, Rohacek, and Snyder 2008) and education (e.g., Witte 2000; King, Orazem, and Wohlgenuth 1999). For example, Martin Carnoy (1998, 335) finds mixed results from education vouchers, arguing they do not achieve what the supporters claim but also do not signify the “catastrophic decline in public education claimed by its opponents.” Carnoy further notes that the national voucher systems he explores are tied to political agendas and linked to an overall decrease in educational contributions from governments, which also resonates with the low-cost argument linked to direct-funding programs for people with disabilities.

Another important related development is the increasing emphasis on “patient-centred,” “patient-directed,” “person-centred,” “client-centred,” or “consumer-directed” care in medical fields and in some educational approaches to disability (e.g., Macleod and McPherson 2007; Turner-Stokes 2007; Davis et al. 2005; Nolin and Killackey 2004). Although difficult to define precisely, patient-centred care includes an implicit critique of the power and control given to medical professionals through the current organization of medical systems. Patient-centred care attempts to level power imbalances by providing information to enable patients to make their own health care decisions (with the added incentive for medical practitioners to pass on the liability for those decisions). Evidence shows that patient-centred approaches lead to more satisfactory experiences with medical systems and, theoretically, to better care (Sidani 2008).

Patient-centred care requires a change in values and assumptions, and conflicts with the more dominant trend of evidence-based medicine (Bensing 2000). According to Lewis (2009), the shift requires understanding patients as a type of consumer, and health care as the provision of services. This resonates with the ideas behind the concept of attendant services. Despite the emphasis on the “good of the patient,” patient-centred approaches also intend to decrease physician and practitioner liability, decrease health care costs, and in some respects, maintain an aura of paternalism, as the professionals must counsel

and encourage self-determination and self-care among the patients, who are presumed to lack these skills.

Patient-centred medical approaches may not be as popular as evidence-based ones, particularly in practice, and may have more complex intentions than first appear; nevertheless, it is a notable trend that demonstrates a hospitable climate for direct-funding models of attendant services. The emphasis on decision making and patient knowledge, and the occasional drift into market-based consumer terminology, make direct-funding options appear to be a patient-centred approach to long-term home care. Patient-centred care emphasizes individual needs and specific localized contexts; however, care policies and work are also valuable commodities in a globalized world.

## **Globalization and Care**

Care work is globalized in ways that include the physical migration of workers to care-related fields and, more conceptually, the exchange of social and health policy frameworks across borders and political contexts. The latter can be seen in multinational, comparative academic studies of direct funding (e.g., Adams, Rohacek, and Snyder 2008; Ungerson and Yeandle 2007; Carnoy 1998), and it would be inaccurate to claim that Ontario's Direct Funding Program emerged without reference to these other contexts. Since the majority of migrants are now women entering gendered forms of work, the trend of migrating workers is of great interest to feminist researchers (Parreñas 2008; Zimmerman, Litt, and Bose 2006). The migration of women to perform service and care work often signifies an inequality among the women in receiving countries, the migrant women, and, even more pronounced, the women who stay behind to perform care duties in the home countries. The demand for care workers in receiving countries "also speaks of women's oppressions in neoliberal states and the failure of states to meet the needs of women who choose to enter the labor force" (Parreñas 2008, 137).

In Canada, which is considered a receiving country, there is a federal initiative known as the Live-in Caregiver Program designed to attract foreign domestic workers to support children, older people, and sometimes people with physical disabilities (Tumolva and Tomeldan 2004; Stasiulis and Bakan 1997; Bakan and Stasiulis 1994). The Direct Funding Program operates independently of this program, and the number of temporary or new Canadians employed through Direct Funding is not well documented. The only available demographic information on attendants is from the 1997 evaluation of the Direct Funding pilot. The 1995–96 pilot version of the program served 102 self-managers from

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across Ontario and documents 16 percent of self-managers' main attendants as being visible minorities, and 10 percent as being people who did not speak French or English as a first language (with a likely overlap in those percentages); it does not provide information on country of birth (Roeher Institute 1997). Further, the financial administrative start-up package published by CILT allows for the hiring of people with temporary work permits (CILT 2008, 4). Ontario's Direct Funding Program has globalized connections conceptually and more concretely through the individual histories of the attendants, though this remains an important area for further inquiry.

Among these various trends – the developments in disability movements in Canada and elsewhere; the influence of neoliberalism, austerity, and health care reform; shifts towards voucher and direct-funding services and patient-centred care; and the globalization of care policy and work – the Direct Funding Program in many ways fits in. It might at first appear unremarkable that disability advocates in Ontario were able to secure and maintain funding for this program. However, what is remarkable is that community advocates and an organization with a social movement history were able to set the terms and continue to maintain a significant degree of control over the program. Material on the Direct Funding Program includes strong cultural messages about disability, care, and empowerment that might not otherwise appear if the program were administered in a more distanced, “objective” fashion by a government ministry or even by a nonprofit organization with a less political history. There will be an opportunity to explore parallel examples that do not have this history in the coming years as the Ontario government pilots programs for seniors. The Direct Funding Program does not represent a concession or a straightforward manifestation of neoliberal ideologies, which often serve to dismantle social movements (M. Smith 2005). Rather, the program helps set the agenda for, and stands out as a unique example among, broad trends that can seem unruly at times.

### **Organization of *Disability Politics and Care***

Throughout this book, I make the case that the rejection of care in public rhetoric related to Ontario's Direct Funding Program, and in other similar programs and advocacy efforts worldwide, is only part of the story. The rejection of care does not eliminate it but moves it to appropriate realms, thus limiting its oppressive and invasive potentials. It may be disconcerting to some to define “care” as *also* a form of oppression, but this book aims to thoroughly engage with the critique raised by people with disabilities and disability scholars, and

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explore what it might mean to incorporate this critique into discussions and practices of care.

Part 1 provides theoretical and methodological tools for understanding care and direct funding. Chapter 1 uses elements of autoethnography to theorize an informal support relationship between me and “Killian,” a friend with a physical disability who uses direct funding. Given my experience in our particular “friend-tendant” relationship, I argue that the common scholarly orientations towards care do not adequately explain our situation. Starting from the conversations between feminist and disability perspectives on care, I develop the theoretical framework of *accessible care*. Accessible care takes a critical, engaged approach that moves beyond understanding accessibility as merely concrete solutions, to create more inclusive forms of care. Care, in this context, is positioned as an unstable tension among competing definitions, including that it is a complex form of oppression. Accessible care draws on feminist disability perspectives and feminist political ethics of care to build bridges in four areas: from daily experiences of disability and support to theoretical discussions; across feminist care research and disability perspectives; across divisions and anxieties within disability communities; and from the local to transnational applications. These bridges do not aim to resolve debates but allow us to travel back and forth between differing perspectives and demonstrate the tenuous possibility of accessible practices and conceptualizations of care.

Chapter 2 considers qualitative research as a form of care, one that requires us to be constantly aware of the potential to slide towards coercion. The specific examples from this study can also inform a broader discussion about research dynamics. I argue that the interpersonal dilemmas faced in qualitative research are not isolated occurrences but are reflective of a powerful research industry that includes a history of oppression and ongoing social inequalities.

Part 2 addresses the initial aim of this study, that is, to sketch contemporary forms of care by exploring Ontario’s Direct Funding Program. Generally, this study finds that care is not what happens “here” within the program or within attendant services more broadly. Distinct concepts are used to describe the interactions between disabled people and their attendants. However, the subsequent chapter reveals the “authentic times to care,” the meanings and practices that remain classified as care amid this passionate rejection.

Chapter 3 focuses on what care is *not*, based on the interview and contextual material. I first present the material demonstrating that attendant services are not care, as care encompasses too much and not enough to describe what is happening under Direct Funding. I then sketch aspects of the daily interactions between attendants and self-managers in order to create a reference for “non-care.”

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The attendants fulfill multiple roles in the lives of the self-managers and their work is described both as concrete “arms and legs” activities and in relational terms. The concrete tasks of attendant services are done under the direction of the self-manager, thereby easing the attendants’ sense of responsibility during interactions, while relational ties simultaneously raise attendants’ sense of responsibility off-hours to ensure they do not miss shifts. The relational aspects are a mandatory part of attendant work and are distinguished from notions of care, despite emotional and empathetic descriptors. Specific examples of interpersonal techniques deployed by self-managers and attendants show that relational ontologies are formed within attendant services.

Even though the majority of participants in this study reject the term “care” in some way, Chapter 4 argues that this rejection does not mean that care completely disappears. Very few of the participants avoid the term entirely, and some imply that there are places where care belongs. Care emerges as an ambiguous set of actions and attitudes that we all have to tolerate at some points in our lives. I explore four key areas that still count as care. (1) Care is an intricate form of oppression; (2) it is linked to medical and social professionals; (3) it is a necessary set of actions during times of illness, for specialized medical treatments, and for highly intimate needs; and finally, (4) it is an approach to supporting people with intellectual disabilities and others who cannot self-direct.

The meanings of care are refined and contained in the Direct Funding Program, and doing so challenges theoretical debates among feminist and disability scholars. The findings challenge the polemic of independence/attendant services and interdependence/care by demonstrating that there are still places in which care belongs. Removing care from Independent Living attendant services does not erase it, but changes the meanings and practices associated with it.

Part 3 turns to the tangible implications of the removal of care. Although the theoretical contributions to care scholarship matter in the realm of cultural meaning making, there are also more concrete consequences of this process in the broader policy landscape. Chapter 5 highlights the policy connections related to the removal of care. The chapter argues that removing care can obfuscate the limitations of the program, the basic provision of disability supports, and transnational issues. Yet the critiques of care from Independent Living have a unique potential to intervene in other policy topics by bringing forth rights-based and alternative perspectives on health. For example, there is a distancing and even rejection of professionalization for Direct Funding attendants, but a respect for the necessary role of health professionals in the lives of the self-managers. This creates an intricate and at times ambiguous relationship to

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professionals that is not often acknowledged in provincial conversations about education and regulation of Personal Support Workers. Efforts to critique and reject care may not always be considered in policy discussions, but they do hold the potential to (and sometimes do) challenge and intervene with critically embodied and politicized insights.

Chapter 6 explores the implications of a nonprofit organization affiliated with the Independent Living movement administering a government-funded program. The cultural critiques of care and other aspects of the Independent Living movement do not evolve in administrative documents, which are accountable to ministry oversight. As such, the removal of care from attendant services diverges from evolving approaches to disability policy, as well as from a new generation of activists. Although, practically, Direct Funding fits among a number of policy trends, as identified earlier, it appears incongruous with recent developments in the disability sector, such as the Ontario-based transformation of developmental services, and the motivations behind the UN Convention on the Rights of Persons with Disabilities. Outside the policy realm, the rejection of care and the administrative role of Independent Living does not align with the approaches of an emerging generation of disability activists engaging in disability justice work (Mingus 2011). I detail a parallel project, the Youth Activist Forum, to demonstrate that new leaders exist but that the Independent Living model does not always make room for the issues and approaches they represent.

To conclude the book, I explore removing care amid a “care crisis” for older people that dominates popular and policy discourses. Directly-funded home care is often cited as a potential solution to this crisis, yet it further entrenches neoliberal frameworks and worldviews, complete with other crises of austerity. The Direct Funding Program changes the experiences of support in Ontario and challenges common understandings of care. And yet, the program cannot be interpreted as a simple success story, as it has notable limitations, including creating highly precarious forms of labour for the attendants. The removal of care and endorsement of direct-funding policy approaches does not resolve all oppressive practices of care and the adamant distancing from care may not resonate with evolving disability movements in Canada and elsewhere.