Re/Moving care: Making care accessible through the

Ontario Direct Funding program

by

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Abstract

Through exploring current conceptualizations of 'care' in the Ontario Direct Funding program, I enter into conversations among disability scholars and activists who reject care as oppressive, and feminist care researchers who highlight care as a gendered form of work and an alternative moral framework.

'Direct funding' refers to disabled people or representative organizations receiving public funds in order to hire individuals to assist with daily needs. Direct funding is advocated for by Independent Living movements for the associated flexibility and increased user-control. The Ontario example fits within a number of contextual trends while it is uniquely administered by the Centre for Independent Living in Toronto.

Drawing on insights from feminist disability studies and the feminist political ethic of care, I propose the conceptual framework of *accessible care* founded on a critical engagement with 'accessibility' and understanding care as a tension among competing definitions, including care as a form of oppression. Accessible care bridges: experience and theory; feminist and disability literatures; divides within disability communities; and the local and transnational.

I employed a self-reflexive, interdisciplinary methodology to conduct 54 qualitative interviews with self-managers, attendants, informal supports, and key informants as well as a discourse analysis of written material. My approach includes access to insider perspectives from personal involvement with disability organizations,

pre-established relationships with some of the participants, and a relational stance on analysis.

The material reveals a process whereby care is removed from Direct Funding, but it is not eliminated. Rather, it is *moved* and transformed into arenas where it is deemed "authentic" and appropriate. This process alters the theoretical debates between feminist and disability scholars, as it is no longer about independence versus interdependence. The re/moving care process also influences a variety of policy issues as it obscures program limitations and the availability of services, conveys a nuanced message that short circuits discussions about worker regulation and health/social distinctions, and diverges from developments around intellectual disability. The Direct Funding program, and the re/moving care process it represents, suggest that Independent Living organizations and movements may have difficulty incorporating emerging intersectional, cultural approaches to disability represented by youth leadership.

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List of acronyms

AODA	Accessibility for Ontarians with Disabilities Act (2005)
ASAC	Attendant Services Advisory Committee
CACL	Canadian Association for Community Living
CCD	Council of Canadians with Disabilities
CHT	Canada Health Transfer (since 2004)
CHST	Canada Health and Social Transfer (1996-97 to 2004-05)
CST	Canada Social Transfer (since 2004)
CILT	Centre for Independent Living in Toronto
CWDO	Citizens with Disabilities-Ontario
DSW	Developmental support worker
DAMN 2025	Disability Action Movement Now
IFCO	Individualized Funding Coalition for Ontario
IL	Independent Living
ILRC	Independent Living Resource Centre
LHINs	Local Health Integration Networks
MCSS	Ministry of Community and Social Services (Ontario)
MOHLTC	Ministry of Health and Long Term Care (Ontario)
OCSA	Ontario Community Support Association
PACE	Personal Attendant Community Education
PSW	Personal support worker
SSAH	Special Services at Home
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities

Chapter One

Introduction: Situating the Ontario Direct Funding program

> Attendant services do NOT include: professional services such as nursing care, physiotherapy, occupational therapy, respite care, physician services, "care" or taking responsibility for the person with a disability. ("Centre for Independent Living in Toronto," 2010, emphasis in original)
>
> And any time they said the word "caring for us," I would just get, I would just be furious, just be furious. Then one day, the government person who was coordinating the committee...said to me, she turned around and she said, "Aren't we allowed to care about you, even with a small 'c'?" She really took me aback, you know? – Audrey King, community advocate and self-manager
>
> I think I like better somebody who care[s] than somebody who doesn't [laugh]. - Hélène, self-manager
>
> Well, it is care though. Personal assisted care. Um. Taking care of me. That's all there is to it. – Cheryl, self-manager

The meanings of common words seem obvious, yet when pressed to articulate definitions, it can prove to be a difficult process often with ambiguous and complex results. 'Care,' for example, has multiple, seemingly competing meanings in everyday vernacular, academic theorizing, social and health policy discussions, medical spheres, and social movements including women's movements and disability movements. Perhaps the most pronounced example can be found in academic literature documenting tensions between disability activists on the one hand and scholars and feminist care researchers on the other, who use the concept of care in very different ways. The pliability of care, however, does not necessarily require a quest for the most

accurate definition but rather draws attention to how care works in these various spheres and how its meanings change and reverberate in unexpected ways. It is the interplay between varied definitions that yield generative spaces and conversations about the role of terminology in our daily practices and discourses.

One arena ripe for exploring the fluid meanings of care is attendant services for people with disabilities,[1] which, according to the Attendant Service Advisory Committee (ASAC), primarily serve people with physical disabilities. ASAC describes attendant services:

> 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)[2]

While not mentioned in this description, attendant services also typically include help with cleaning, household maintenance, errands, and sometimes childcare. Attendant services are rooted in the Independent Living (IL) movement, described below, and are

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[1] Many authors explore questions of terminology in their work on disability (e.g., Erickson, 2007; Hillyer, 1993; 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 rough regional and generational elements to this discussion, that is, generally speaking people in the United Kingdom and younger people coming from a cultural framework tend to use "disabled people" while people in North America and established leaders tend to use "people with disabilities." From my own 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."

[2] In material influenced by Independent Living philosophy, it is common to refer to people with disabilities as "consumers" in an effort to position disability-related programs as *services* and disabled people in charge of these services. There are some issues with this term and there are ongoing discussions in the community around it. 'Consumer' makes concessions to a mass-produced culture, may over-value 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 note 1, I do not use this term unless in a direct quotation, such as the example above.

premised on the notion of *consumer-direction* that represents a dramatic shift as people

with disabilities are in control of the services. Attendant services influenced by

Independent Living often include an explicit rejection of the concept of care, for

example, in the first introductory quotation. Language is a primary indicator of this

approach, reflected not only in the aversion to the term 'care' but also in choosing to

use phrases such as 'consumer' and 'self-manager' when referring to people with

disabilities using the services, and 'attendant' (in Ontario) and 'personal assistant' (more

common in the United States and the United Kingdom) when referring to the person

providing the service.

Perhaps the paramount manifestation of attendant services, as defined above,

with the most adamant rejection of care is direct funding.[3] Direct funding[4] refers to

disabled people, representative organizations and in some cases family members or

guardians, receiving public funds in order to hire individuals to provide assistance with

daily needs. In direct funding arrangements, people with disabilities become employers

(in varying respects) of their attendants, and are often required to take on

administrative duties traditionally in the purview of service provision organizations or

governments. Disability movements and related organizations have pushed for this style

of service delivery in the United Kingdom, various states in the US and throughout

Canada because of the associated flexibility, empowerment and user-control it provides

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[3] The term 'self-managed (home) care' also has some currency in Canada, although 'Direct Funding' is the most popular term in Ontario.
[4] When referring to the Ontario program specifically, I capitalize "Direct Funding." I use lower case letters when referring to 'direct funding' as a model of service delivery.

for disabled people (Ungerson & Yeandle, 2007). There are 16 documented "self-managed home care programs" in all 10 Canadian provinces (none in the territories or on First Nations reserves), plus an option through the Veterans Independence Program housed in the Department of Veterans Affairs (Spalding, Watkins, & Williams, 2006). The Ontario version is the only Canadian example that was developed, piloted and continues to be administered by an IL organization. In Canada, there is a national network of IL organizations with strong connections to disability movements in North America and at times, this network is characterized as a movement itself (Lord, 2010).

The Ontario Self-managed Attendant Services–Direct Funding program, or colloquially the "Direct Funding program"[5] is administered by the Centre for Independent Living in Toronto (CILT), and is an ideal location for exploring the changing meanings of care. The Direct Funding program was piloted in 1995-6, established as a permanent program in 1998, and is funded through the Ontario Ministry of Health and Long Term Care (Parker, Self, Willi, & O'Leary, 2000). In 2011, there are 676[6] people using Direct Funding, out of approximately 6000 people documented in 2008 who use attendant services in Ontario (personal communication with Katherine Janicki, Direct Funding Clerk from CILT, July 18, 2011; OCSA, 2008). To demonstrate the relative size of attendant services and Direct Funding, it is noteworthy that Bannerjee (2009)

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[5] In this dissertation, I will refer to the program as the "Direct Funding program" or the "Ontario Direct Funding program" to reflect the terminology of service users and administrators as well as for brevity.

[6] In fall 2011 it was announced that the Direct Funding program will receive an injection of capital that will enable up to 50 more individuals to become self-managers (personal communication with Katherine Janicki, Direct Funding Clerk from CILT, November 15, 2011).

documents 70 100 long-term care beds in Ontario in 2004; this number includes supportive housing (and so does the 6000 count), but does not include Attendant Outreach Services[7] or Direct Funding recipients. In either case, the number of people using Direct Funding in Ontario make up less than 1% of long-term care service users and roughly 11.6% of attendant service users. 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 et al., 2006). The Direct Funding program is by far the most independent model of attendant services in the Ontario landscape[8] and has a 4-5 year waiting list with approximately 400 people on it, which CILT is unable to address due to a fixed budget (personal communication, see above). There are cultural messages inextricably tied to the history and current information on the Direct Funding program that declare people with disabilities do not need care and can collectively and individually manage disability-related services. Access to quality attendant services is framed as a right and a means for full inclusion of people with disabilities, making the Ontario Direct Funding program an interesting case study to explore care.

There have been other academic and community-based studies on the Ontario Direct Funding program. These studies: document the establishment of the program, largely successful due to the dedication of leaders with disabilities (Yoshida, Willi,

[7] Attendant Outreach Services are pre-scheduled, at-home/at-work personal support arranged by local Community Care Access Centres.

[8] For more information on other attendant service arrangements available in Ontario, see OCSA & Attendant Service Advisory Committee (2008).

Parker, & Locker, 2004); evaluate the pilot program with overall positive results (The

Roeher Institute, 1997); document the satisfaction of current self-managers (Parker et

al., 2000); and highlight its innovative nature (Lord & Hutchison, 2007). This study,

however, sets out with a different agenda. Throughout this dissertation, I highlight the

strengths of the program and make some tentative recommendations for improvements

where appropriate; however, my primary aim is to enter into theoretical discussions

around care. Specifically, I aim to enter the debates and conversations between feminist

care researchers and disability perspectives and explore the broader policy and

movement implications of these discussions. Thus, I chose a program that can be

categorized as embracing a disability perspective, one that definitively rejects the

concept of care. I explore some current conceptualizations of care through qualitative

interviews with Direct Funding self-managers, their attendants, and informal supports,

and bolster and contrast these messages with interviews with government policy

makers, community advocates and program administrators, as well as related

contextual information from CILT, Ontario ministries, disability-related listservs and

organizations, and academic literature. As will be discussed throughout this dissertation,

there are substantial, wide-reaching implications of the messages conveyed through this

small program.

The remainder of this chapter includes a brief note on language, an attempt to

situate the Ontario program within a number of trends, demonstrating both how it fits

yet maintains some unique features. I consider the Direct Funding program in the

context of: disability movements, specifically Independent Living movements; the

neoliberal Ontario policy landscape with attention to health care reform; shifts in social

policy toward vouchers or funding in lieu of service delivery as well as shifts in medical

fields towards *patient-centred care*; and the global exchange of care policy and care

workers. I conclude with an outline of the remaining chapters.

Note on language

While the sheer number of terms in the care field can be confusing to researchers and

practitioners (Bannerjee, 2009; Church, Diamond, & Voronka, 2004), it is important to

recognize it is not "mere semantics." In fact, for disability movements it is often *about*

language. I undertake a more detailed discussion of terminology elsewhere (Kelly,

2011), and throughout this dissertation I attempt to briefly justify my choice of terms. It

is important to respect the terminology asserted by disability organizations that aim to

achieve certain ends through the language they employ. Public and consistent use of

terms like 'consumer,' 'attendant,', 'self-manager,' 'attendant services,' is part of a

larger effort to change the meanings of disability and the presumed societal roles of

disabled people. Women's movements and feminist care scholars also use language in

transformative ways. For example, and of relevance to this study, many feminist care

researchers position care as a visible, essential labour through the phrase "care work"

(e.g., Armstrong & Armstrong, 2002; England, 2005; Parreñas, 2009). Unfortunately,

these efforts can underscore tension linked to the strong rejection of care and care-

related terms from disability perspectives. While the perspectives of attendants and contributions of feminist scholars are considered throughout this dissertation, I generally concede to the terminology preferences of people with disabilities and their allies who conceived of, developed, use, and administer the Ontario Direct Funding program (i.e., 'self-managers' and 'attendants'). These are the preferred terms, with some minor variations, of the majority of participants *including* the attendants, while terms suggested by feminist academics such as 'care work' and 'care worker' were not used at all.

Context and background

The Ontario Direct Funding program fits within a number of trends, while also representing some distinct features among: disability movements throughout the global north, particularly Independent Living; Ontario health care reform and policy landscapes; shifts in medical spheres and approaches to social policy; and global care developments.

Direct Funding among disability movements

The Ontario Direct Funding program, administered by the Centre for Independent Living in Toronto, fits within disability and Independent Living movements. While it is out of the scope of this chapter to detail the histories of disability movements in the United

States, United Kingdom and Canada,[9] the push for the Ontario Direct Funding program

clearly builds on a number of historical precedents and ideological commitments

expressed through these efforts. For example, direct funding models of support can be

linked to the deinstitutionalization movement from the 1950s onward, which seeks to

transition people with disabilities and mental health concerns physically out of large-

scale institutes and more metaphorically out of institutionalized approaches to disability

(Gardner & Glanville, 2005; Stroman, 2003; Townsend, 1962). The ongoing

deinstitutionalization movement is led largely by parent-advocates, people with

intellectual disabilities, and people with mental health concerns. Ontario only closed the

last large-scale institution in March 2009, but institutionalized approaches continue to

structure the lives of many people with intellectual impairments living in long-term care

homes throughout Ontario and Canada (Canadian Association for Community Living &

People First of Canada, 2011). This movement highlights the sometimes deplorable

living conditions in segregated residences as well as the cultural message about

disability conveyed through social isolation, medicalization, lack of choice, routinization

of life, and inhumane treatment (Townsend, 1962).[10] The deinstitutionalization

movement demands people with disabilities live in community settings, and the Direct

Funding program is a potential mechanism for making this possible. It is noteworthy

that at least two participants in this study lived in large-scale institutions as children,

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[9] Some scholars explore disability movements in global south, which often have distinct approaches and different issues from the movements in the global north (e.g., see Charlton, 2000; Meekosha, 2011; Wehbi, 2011).

[10] For a discussion of the psychological effects of the 'total institution' see Goffman (1961).

making strong links between the Direct Funding program and deinstitutionalization. Unlike programs in five other provinces, however, 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 et al., 2006).

Elements of the United Kingdom's "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 Oliver (1990). The social model argues disability is a social construction; people are disabled primarily by societal structures and attitudes and not by their biological impairments (Campbell & Oliver, 1996; Davis, 1993). The social model is often cited as the basis for disability organizing in the UK (Campbell & Oliver, 1996), although it has undergone substantive critique in academic spheres (e.g., Corker, 1999; Shakespeare & Watson, 2002). 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 will be 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, p. 139).

Most significantly, and as will be explored in the conclusion, the Direct Funding program can be interpreted as the quintessential manifestation of the Independent Living movement and philosophy. Direct funding programs build on the legacy of Ed Roberts and the Rolling Quads from the University of California at Berkeley who were forced to live in a hospital while attending college due to 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 also a philosophical commitment. IL philosophy, as it is termed in the community, 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 a number of ways. Scholars note Canadian disability activists and organizations: played an integral role in establishing an international disability rights movement (Driedger, 1989); have an amicable relationship with Canadian governments (Valentine, 1996); utilize non-confrontational tactics (Chivers, 2007); and have a long history of formal organizations in the non-profit sector (Neufeldt, 2003). The Canadian IL movement in particular has an emphasis on individual advocacy rather than collective action, in contrast to the approach of its American counterparts (Lord, 2010; Valentine, 1994).

In many ways, the Ontario 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, 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) represent a seemingly unanimous, policy-focused, non-confrontational, consultation-based achievement that resonates with the establishment of the Direct Funding program. As will be explored further in the concluding chapter, there are other, less well-recorded elements and factions of the disability organizing that do not fit so well.

Disability movements in the United Kingdom and United States have also pushed for Direct Funded models of service delivery, setting precedents for the Ontario example. Overwhelmingly these programs are evaluated as highly successful, cost-effective and empowering (Askheim, 1999; Blyth & Gardner, 2007; Caldwell & Heller, 2007; Carmichael & Brown, 2002; Leece, 2000; Stainton & Boyce, 2004). It is noteworthy that in Ontario, community organizations and advocates participated in *writing* the policy and continue to administer it, raising interesting questions for the future of disability movements. This may indicate that when 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. As a result, most recent advocacy around the program is targeted at the Ontario Ministry of Health and

Long Term Care. For example, the Attendant Service Advisory Committee (which

includes representatives from CILT) recommends attendant service waiting lists should

be added to the Provincial Wait List Strategy, funding should be increased to the sector,

and additional individualizing funding options should 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 ensure "that

Consumers of attendant support services are protected and have the right to be

involved with decisions regarding their own attendant support services" and includes

recommendations for a Consumer Advocate Office, reduced wait times and mechanisms

for dispute resolution (Draft legislation, ongoing personal communication with Scott

Allardyce 2010-2011). Citizens with Disabilities-Ontario (CWDO)[11] formally declared

support for Scott Allardyce's proposed legislation, advocated to the MOHLTC to 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 around Direct Funding is

consistent and co-operative, systems focused, and directed at the government and

Ontario Ministry of Health and Long Term Care.

There is one notable exception: a small, radical group with little publicity or

formal organization called DAMN 2025 (Disability Action Movement Now) (DAMN 2025,

2008; Henderson, 2007). Informally, through personal communication and meeting with

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[11] I am a volunteer board member for this group, although I initially limited, and later declined, involvement in the Service Quality Committee to avoid potential conflicts of interest.

members of this group, I learned that some of DAMN's efforts around Direct Funding

are aimed at CILT. While still rejecting the concept of care, members of DAMN 2025

claim that the way CILT administers the program is

> blatantly discriminatory against people who are iliterat [sic]. Many, many people
> with disabilities fit this description because of being segregated into institutions
> and "special schools" where their abilities (both mental & physical) are
> underestimated and discouraged. (Personal communication, Ann Abbot, July 31,
> 2011)

DAMN 2025 is based in anti-poverty activism around the Ontario Disability Support

Program. 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. The significance of DAMN's critiques is incongruent with documented disability

movements in Ontario and Canada, that is, histories that document a generally unified

approach to Direct Funding, and will be further discussed in the concluding chapter.

There are parallel, yet distinct, activities led primarily by parent advocates

around the Special Services at Home (SSAH) program, established in 1982. SSAH is run

through the Ontario Ministry of Community and Social Services and gives small amounts

of funds to families with children with any disabilities and adults with intellectual

disabilities. There is a long community-based advocacy history aimed at the Ontario

government asking to reduce waiting lists, increase funding, and, at one point, expand

eligibility 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).

This does not suggest there is a unified approach to Direct Funding since the parent

advocates do not push CILT or MOHLTC to expand eligibility criteria for the Direct

Funding program to include children or adults with intellectual disabilities; however, it

does demonstrate the popularity of direct and individualized funding options within

disability spheres in Ontario, with a history that, in fact, pre-dates the pilot of the

Ontario Direct Funding program (SSAH Provincial Coalition, 2011). With few exceptions,

the push for Direct Funding in Ontario fits within a variety of historic and contemporary

efforts and disability movement values, yet also maintains some unique features and

autonomy.

The Ontario policy landscape

It is well documented that countries in the global north have taken a neoliberal turn

since the early 1990s (Harvey, 2005). This turn includes a number of policy trends as

well as ideological commitments, including: an emphasis on individual responsibility and

the primacy of choice, thus framing citizens as consumers and workers (Breitkreuz,

2005; Larner, 2000); a preference for the "free-hand" of the market and the

privatization of services; "small" governments, which are more accurately transitioning

to surveillance roles, particularly after the events of September 11, 2001 (Bhandar,

2004; Dobrowolsky, 2008; Stasiulis, 2004); co-optation of the non-profit sector through

project-based funding tied to specific priorities (Hall & Banting, 2000; Incite! Women of

Color Against Violence, 2007; M. Smith, 2005); erasure of gender from policy agendas

(Brodie, 2008); erosion of full-time secure employment and the corresponding rise of

temporary, contractual and/or part-time "precarious" forms of employment (Vosko, 2000); and a hyper- globalized economy predicated on immigration and the exploitation of labour in the global south (Encalada, Fuchs, & Paz, 2008). The current regime may be accelerating or completely transforming (Jenson, 2008) in the context of the global recessions.

In this climate, direct funding initiatives in multiple policy arenas contribute to neoliberal government priorities in the global north as extreme forms of downshifting service provision to individual citizens. Instead of provision of services through government regulated and owned institutions, care homes, or home care, money is transferred to the non-profit sector (in the Ontario case), which administers the funds and, in turn, further shifts the arrangement and provision of services to individuals. It is the individual who becomes responsible for hiring and training other individuals to provide the personal support he/she requires. Neoliberalism in progressive scholarly circles is generally critiqued for the features described above, particularly the implications for marginalized groups and social movements. Disability movements in the Ontario case and elsewhere advocate strongly for the adoption of these mechanisms, adding some support to the argument that social movements are agents in the enactment of neoliberal governmentality (Larner, 2000). That is, while direct funding models of support may 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.

In Ontario, the neoliberal turn resonates throughout the home care sector. It is noteworthy that, in principle, CILT seeks to distance the Ontario Direct Funding program from other forms of home care and long-term care, instead presenting the idea discussed above 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.

Home care in Canada and Ontario has also been transformed by neoliberalism, through varied incremental processes that Armstrong (2001) terms "privatization by stealth." In research exploring the closure of a non-profit, unionized Hamilton-based home care agency in 2002, Aronson, Dentone and Zeytinoglu (2004) identify a "contractual approach" to home care in Ontario that promotes privatization. This is linked to the landmark Commission on the Future of Health Care in Canada, colloquially the "Romanow Commission." In 2001, the Romanow Commission formed in order "to review Medicare - Canada's universally accessible, publicly funded health care system - and recommend policies and measures to improve the system and its long-term sustainability" (Health Canada, 2009). Aronson and colleagues note the commission made a "relatively weak and permissive recommendation once again leaving supportive

home care to the discretion of the provinces" contributing to the privatized, contractual shift in home care and cementing the move to regionalization across all provinces (Aronson et al., 2004, p. 113; see also Jenson & Phillips, 2000; Shapiro, 2003).

One recent development in health care reform affecting Ontario attendant services is the adoption of the Local Health Integration Networks, or LHINs, in 2005, following a similar yet distinct approach to other Canadian provinces (Ronson, 2006). There are 14 "geographically defined" LHINs in Ontario whose primary activity is to streamline health care services by making funding decisions and "integration decisions" for a wide variety of health-related organizations (Ronson, 2006). MOHLTC moves "from a system manager to a system planning and oversight role," another example of the changing role of governments in the current context (Ronson, 2006, p. 47). This is a system-wide shift in health care administration; yet, despite being funded through MOHLTC, the Ontario Direct Funding program has largely managed to bypass this mechanism likely because of its provincial scope, one of its most lauded features, as well as the relatively small number of people it serves. Maintaining some distance from the LHIN's system keeps the Direct Funding program free from substantial review, revisions and cut-backs, which could be interpreted as both a benefit and drawback. Again, the Ontario Direct Funding program clearly fits within broader trends, neoliberalism in this case, yet uniquely manages to maintain a semblance of autonomy and philosophical commitments to Independent Living as seen through the example of the LHINs.

Shifts in social policy and medicine

The Direct Funding program can also be situated within shifts in social policy and medical approaches. In other social policy arenas, there are parallel moves among governments to adopt direct funding options, or more often to use "voucher" systems instead of providing services. For example, Warner and Gradus (2011) review the implications of voucher childcare systems in the United States, the Netherlands and Australia (see also Adams, Rohacek, & Snyder, 2008). They suggest "governmental support for market approaches, as well as enthusiasm for parental choice, drove the decision to shift away from government provision toward market delivery," although access to the voucher systems varies demographically in all three contexts (Warner & Gradus, 2011, p. 571). Warner and Gradus (2011) find voucher systems increase demand for services, but do not necessarily stimulate an adequate supply response, concluding that governments should play a substantive coordinating role.

There have been similar initiatives around other vital policy issues. In the late 1990s and early 2000s, there was much discussion around voucher systems in education intended to provide publically funded vouchers for use in private education facilities (e.g., King, Orazem, & Wohlgemuth, 1999; Witte, 2000). For example, Carnoy (1998) explores the success of voucher programs in Chile and Sweden, attributing the original idea to economist Milton Friedman. He finds "national voucher systems fail to do what their proponents claim" but also do not signify the "catastrophic decline in public education claimed by its opponents" (Carnoy, 1998, p. 335). Carnoy (1998) 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. The Direct Funding program represents one example in a global trend towards market-based voucher or cash service delivery.

Another important related development is the increasing emphasis on 'patient-centred,' 'patient-directed,' 'person-centred' or consumer-directed/centred care in medical fields and in some educational approaches to disability (e.g., Davis, Cornman, Lane, & Patton, 2005; Macleod & McPherson, 2007; Nolin & Killackey, 2004; Turner-Stokes, 2007). While 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 through providing information so that patients can make their own health care decisions (and, of course, also take on liability for those decisions). Patient-centred care values the patients' individual experiences and points of view. There is some evidence that patient-centred approaches lead to more satisfactory experiences with medical systems, and in theory, better care. In an operationalized study of patient-centred care, Sidani (2008) did find increased self-care ability and satisfaction with care, but no significant impact on the functional, physical status of patients.

When exploring another trend in health research and practice, that is, the rise of "evidence-based medicine," Bensing (2000) notes a spike in patient-centred terminology

and approaches in the early 1990s, with a steady increase onward. Bensing (2000)

explores the relationship between these two trends, asking "How patient-centered is

evidence based medicine? And, how evidence-based is patient-centered medicine?"

(pp. 17-18). He argues evidence-based approaches emphasize randomized, clinical trials,

representing a "doctor-centered approach" that echoes the values and practices of

historical, "objective" medicine. Patient-centred care, on the other hand, seems to

belong to a separate world that values patients' "unique knowledge and experience" (p.

19). Bensing helps ground claims about the ubiquity of patient-centred approaches by

highlighting the number and differing values of evidence-based approaches.

Lewis (2009) emphasizes the change in values and assumptions required by

patient-centred care. Lewis notes how the shift requires understanding patients as a

type of consumer (although he seeks to distinguish patient-centred care from

consumer-centred care) and health care as the provision of services. This sounds very

similar to the terms and ideas behind the concept of attendant services. Lewis (2009)

comments "one concept fundamental to the commercial world is relevant to health

care: the customer is always right" (p. 2). The customer, of course, is not always right,

particularly when there is technical medical expertise involved. Lewis highlights the

South-Central Foundation in Alaska as a successful example of the patient-centred

approach. He comments:

> The goal is to wean the patients from system dependency and increase their
> capacity to self-manage and otherwise participate in their health. This focus on
> [patient-centred care] achieved a decline not only in the use of specialists and
> acute care; it also reduced by 20% the number of primary care visits. (p. 9)

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 self-

determination and self-care among the patients.

While patient-centred medical approaches may not be as popular as evidence-

based, particularly in practice, and may have more complex intentions than first appear,

it is a notable trend that demonstrates a hospitable climate for direct funding models of

attendant services, which reflect many of the values of patient-centred care. The

emphasis on decision-making, 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.

Globalization and care

A final trend worth noting is the globalization of care work that includes the physical

migration of workers to care-related fields, and, conceptually, the free flowing exchange

of social and health policy frameworks across a diverse array of countries. The latter can

be seen in multi-national, comparative academic studies (e.g., Adams et al., 2008;

Carnoy, 1998; Ungerson & Yeandle, 2007), and it would be inaccurate to claim the

Ontario Direct Funding program emerged without reference to other contexts. In key

informant interviews and historical accounts of the program, references were made to

precedents in other provinces and countries, as well as ongoing international interest in

the Ontario program. As the majority of migrant workers are now women, the former

trend is of great interest to feminist researchers, who note "the globalization of service

work generates unequal relationships between women across nation-states" (Parreñas,

2009, p. 137; see also Zimmerman, Litt, & Bose, 2006). That is, the migration of women

to perform service and care work signifies an inequality between 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. Across
> nations, caring for the family remains a private and not a public responsibility,
> but more precisely a private responsibility designated to women. (Parreñas,
> 2009, p. 137)

Misra, Woodring and Merz (2006) find that economic restructuring associated with

neoliberalism creates "pull" conditions in the global north while structural adjustment in

countries in the global south create "push" factors for women. In an interesting play on

public/private responsibility and push/pull factors, direct funding programs provide

public funds for individuals to privately arrange support.

In Canada, which can be considered a receiving country, there is an established

federal initiative termed the "Live-in Caregiver Program" geared at attracting foreign

domestic workers for children, older people and sometimes people with physical

disabilities (Bakan & Stasiulis, 1994; Stasiulis & Bakan, 1997; Tumolva & Tomeldan,

2004). The Direct Funding program operates independently from this program, and

there is little documentation of the number of temporary or new Canadians employed through Direct Funding. The only available demographic information on attendants is from the 1997 evaluation of the Direct Funding pilot. The 1995 and 1996 pilot version of the program served 102 self-managers from across Ontario and documents 16% of self-managers' main attendants as being visible minorities and 10% whose "first language [is] neither English nor French" (with a likely overlap in those percentages), with no information on country of birth (The Roeher Institute, 1997). Further, the *Financial administrative start-up package* published by CILT outlines limitations on hiring: "You must ensure that anyone you hire is legally allowed to work in Canada" including people with "temporary work permit[s]" (CILT, 2008, p. 4). There are important global, conceptual links to the Ontario Direct Funding program, and allusions to more concrete connections through the individual histories of the attendants, although this remains an important area for further inquiry as I note in the concluding chapter.

Among these various trends, that is, developments in disability movements in Canada and elsewhere, influence of neoliberalism and health care reform, shifts towards voucher/direct funding services and patient-centred care, and the globalization of care policy and work, it seems that the Ontario Direct Funding program, in many ways, fits in. It might at first appear unremarkable that disability advocates in Ontario were able to secure support and funding for this program. However, what is remarkable about this example is that community advocates and an organization clearly affiliated with a social movement were able to set the terms and continue to maintain a

significant degree of control over the program. Material around the Ontario 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 a non-profit

organization with a less political history. The Ontario Direct Funding program does not

represent a concession or a straightforward manifestation of neoliberal ideologies that

often serve to dismantle social movements (M. Smith, 2005). Rather the program helps

set the agenda for, and exercise agency among, broad trends that can seem unruly at

times. To expand on the unique features of the program as well as points of connection

to other trends, I now outline the subsequent chapters of the dissertation.

Chapter outline

Throughout this dissertation, I make the case that the rejection of care in public rhetoric

related to the Ontario 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.

In Chapter Two, I explore common frameworks found in academic literature on

care, that is: disability perspectives on care; empirical feminist care research and the

more theoretical ethic of care; and the few sources that can be identified as

"conversations" among these perspectives. I introduce a close friend of mine, Killian,

who was involved in the research from the beginning. Through reference to Killian, I attempt to pull useful features of these frameworks to account for the unique relationships and conditions of the Direct Funding program, while also highlighting unanswered questions. Using insights from feminist disability studies and the feminist political ethic of care, I propose the concept of *accessible care* founded on a critical engagement with 'accessibility' and understanding care as a tension among competing ideas. Accessible care builds bridges in four key areas: from lived experience to theoretical; between feminist and disability perspectives; across divisions within disability movements; and from local to transnational discussions. The concept of accessible care is the theoretical centerpiece for the dissertation.

In Chapter Three, again referencing my relationship with Killian, I document the iterative, qualitative research process while practicing feminist reflexivity. I present the interdisciplinary research design and recount the process of data collection. I attempt to sort out some of the ethical dilemmas that emerged early and frequently, including my role as a researcher and issues of analysis and representation. I reframe the concept of 'key informant' to account for individuals with a self-identified, ongoing and deep interest in the research, such as Killian. I further suggest a flexible position on friendship in the research process and promote *relational standpoints* in the discussion of both researcher/participant relationships and during analysis.

The fourth and fifth chapters report the findings of the study and build the central argument. In the fourth chapter, I begin with the insistence echoed throughout

the interviews and data that attendant services are firmly 'not care.' I move on to explore what 'not care' consists of, finding descriptions of 'arms and legs' tasks consistent with Independent Living frameworks, a mandatory form of relational work, that does not necessitate friendship and is distinct from emotional labour, and a deference towards one another proclaimed by both attendants and self-managers, revealing relational ontologies and epistemologies. These elements represent the removal of care, and are only the first part of the process.

Chapter Five explores the less documented narratives about where care *remains*. In this study, there are areas where care is deemed appropriate; namely, in reference to: an oppressive outlook on disability; certain professional designations; periods of illness or injury, medical procedures and highly personal needs; and support required by people with intellectual disabilities. In light of Chapter Four, it becomes apparent that the Ontario Direct Funding program and the political, cultural rejections of care it represents do not eliminate care, but move it to specific locations. Through this process, the meanings of care are transformed, potentially limiting the oppressive potentials. This process may also occur in other public rejections of care found in disability movement activity throughout the global north. This has substantial ramifications for theoretical debates between feminists and disability scholars, changing the terms from independence *versus* interdependence to a nuanced approach that takes disability critiques of care as the starting point and considers the implications for the arenas where care remains.

In Chapter Six I explore the broader implications of the process of re/moving care. I find elements of the re/moving care process obscure policy issues such as the limitations of the program and the availability of services. I also present examples where the complex messages of the process short-circuit the policy landscape, in reference to the potential regulation of Personal Support Workers in Ontario, ministerial placement and the upcoming renegotiation of the Canada Health Transfer and the Canada Social Transfer. Finally, I demonstrate how the re/moving process diverges from new efforts around intellectual disability. I argue in spite of its small scope, the Ontario Direct Funding program, in particular the process of re/moving care it represents, has wide reaching, complex implications in multiple policy arenas.

In the concluding chapter, I outline the key methodological, empirical, and theoretical contributions as well as the implications for policy and practice. I review the central findings of the dissertation and make connections to the bridges built by accessible care as introduced in Chapter Two. I move on to explore the ramifications for Independent Living as a network of non-profit organizations and a social movement. I use the example of a recent initiative in which I was involved, the Youth Activist Forum, to demonstrate that the Ontario Direct Funding program and Independent Living movement may be constrained by their histories and the current policy landscape in ways that exclude more culturally-based, intersectional approaches to activism represented by many youth leaders. I conclude by identifying areas for future inquiry and providing some closing thoughts.

Chapter Two

Towards accessible care

With the background information mapped and the research questions outlined, I would now like to introduce myself, and Killian, two central actors in this dissertation. Killian is a good friend, a man with a physical disability, and a self-manager under the Ontario Direct Funding program. I identify as a woman, and a non-disabled ally. Awkwardly but naturally, and without too much discussion, it came to pass that I occasionally help him eat or use the washroom. This is mostly informally, as a friend, but sporadically Killian pays me to assist him. Even when the arrangement is more formal, Killian articulates that he is uncomfortable calling me his 'attendant' and insists 'friend' is more appropriate. We joke that 'Frien-tendant' is perhaps the most accurate.

Outside of our relationship, I am continually fascinated by the process whereby Killian's attendants (sometimes) become his friends, his friends become attendants or people around him gradually and increasingly lend a hand in tasks not normally associated with friendship. While these evolving relationships and the blurred distinction between in/formal are fascinating, even more compelling is Killian's mastery in dealing with human interactions.

While I had previous interests and experience with disability and support, thinking about Killian and his relationships with his attendants helped crystallize my dissertation topic and pervades both the methodology and the findings. He was my first

and most eager research participant, and significantly for this chapter, influenced my

interpretation of the literature. I found our specific relationship did not quite fit in most

accounts of care or personal assistance. This is not to claim our in/formal interactions

are the standard, but rather to reveal cracks in existing literature and serve as an entry

point to discuss broader issues relating to direct funding, including independence, care

and citizenship. However, I do not claim to speak for Killian; my account of our

relationship is partial, with details escaping, or becoming idealized on the page. This

partiality, however, does not mean irrelevance.

In this chapter, I explore disability perspectives on care, feminist approaches to

care, and the conversations between the two in order to highlight how they speak to (or

do not speak to) the relationship between Killian and myself. Through this process, I

build a case for making care *accessible*, inspired by concepts found in feminist disability

theory and the feminist political ethic of care. I choose the concept of 'accessibility'

reluctantly, but with intention as its meaning has been transformed by various disability

campaigns and expanded into a powerful policy and activist tool. 'Accessibility' in

legislation and increasingly in cultural parlance refers to adapting physical and social

environments in ways that account for disabled people, as represented in legislation

such as the Americans Disabilities Act (1990) and the Accessibility for Ontarians with

Disabilities Act (2005). Despite the specific measurements and guidelines detailed in

these acts, when done properly, accessibility is not mere logistics. The risk, however, is

that accessibility may inadvertently transform disability into a fixable problem, rather

than a complex cultural category or identity.

In recent work, Titchkosky (2011) explores the question of access in the

university setting. She argues access is not "merely a substance to be measured for its

presence or absence" but is "an interpretative relation between bodies" (Titchkosky,

2011, p. 13; p. 3). Further, for Titchkosky, access does not stand in for "justice":

> Justice, then, is not a synonym for access. Or, access can, at most, be only part of what justice means. The fight for access is the beginning of living more intimately with the interpretive material reality which has perpetuated so much exclusion; therefore, access initiatives come with the uncomfortable task of needing to ask, "What does inclusion mean?" (p. 28)

Political and legal demands for increased accessibility can lead to more abstract work

around social construction, or the analysis can stop once the benchmarks are achieved.

The most radical, critical forms of accessibility must be handled *with care*. Accessibility is

not inherently linked to disability studies or even disability movements; it can easily fall

away from critical reflection into bureaucratic checklists addressing "complaints" or

challenging design puzzles for engineers and other professionals. Careful approaches to

access and accessibility, then, can help us explore the constant evolution of the

meanings of varied embodiments. This careful approach to accessibility enables tangible

environmental changes *and* facilitates critical reflection on how built environments and

operating policies reflect underlying social assumptions about disability, and how these

assumptions come to be unquestioned. Accessibility can act as a link, or a bridge,

between social representations and embodied, visceral experiences, demonstrating that

"representations have real consequences for real people" (Titchkosky, 2003, p. 134; see also Titchkosky, 2007).

Accessible care continues this work by updating the concept of care to reflect the lived instability implied by disabled embodiment (Davis, 2002b). Accessible care builds bridges, which are not necessarily intended to dwell on the "common ground" between disparate perspectives, as some recent scholars argue (Kröger, 2009, p. 400), but to allow us to travel back and forth and leave some of the tensions standing. These bridges span four main areas:

i.   From daily experiences of disability and care to theoretical discussions

Accessible care seeks connections between experiential, intersectional and complex support relationships and the more theoretical discussions of care.

ii.   Across feminist care research and disability perspectives

Perhaps the most important bridge, this bridge is built on definitions of care that account for disability critiques. It includes acknowledging oppressive histories that were once thought of as "caring" and the constant potential for coercive manifestations of care while still leaving room for research that does not do this accounting.

iii.   Across divisions and anxieties within disability communities

Independent Living perspectives on care, arguably the most vocal critics of care, can be difficult to apply to people with intellectual disabilities. There is an ongoing tension between movements comprised primarily of people with physical disabilities and those comprised primarily of people with intellectual impairments and their allies. Accessible

care holds these tensions steady, even when resolutions are not possible, and seeks

ways of adapting care and support to be more inclusive.

iv.   From the local to transnational applications

Feminist political ethic of care scholars demonstrate daily care interactions can form the

foundation of civic and political values in national and transnational arenas (Robinson,

1999, 2006, 2011). But if care is an unstable tension, accessible care demands we bring

tension and instability to the centre of seemingly stable policies, international

relationships and discussions. In order to understand the bridges built by accessible

care, I now sketch the established care scholarship.

Perspectives on care

Support for people with disabilities has been, or still is, referred to as care, care work,

caregiving, caretaking, home care, nursing, body work (Twigg, 2000), tending (Parker,

1981), helping (Shakespeare, 2000), and more recently in disability circles, support

work, attendant care, personal support and personal assistance. The sheer volume of

terminology is confusing in the least, and can create substantive barriers for researchers

(Bannerjee, 2009; Church et al., 2004). The ever-cycling terminology signals broader

debates that can be roughly charted as five bodies of literature. There are a growing

number of empirical studies throughout the global north on the experiences of people

with disabilities who require 'support' or 'assistance' (certainly not 'care') from disability

studies perspectives. Secondly, the interdisciplinary field of disability studies includes a

related theoretical exploration of the disempowering messages conveyed by care, the

people who research it and the bureaucratic structures that administer it, often leading

to an outright rejection of the term. Thirdly, there are numerous feminist, empirical

studies that document the experiences of different types of care workers or conduct

policy analyses of care delivery systems. There is a fourth (sometimes) related body of

literature attempting to theorize care and a feminist ethic of care. Both feminist

literatures are largely unconnected to the disability studies work. Finally, there are the

conversations among these groups that are at times hostile and, more recently,

sympathetic to varied perspectives on care. I will survey these five perspectives to

unearth what they have to offer to Killian and me as well as what they leave

unanswered.

Documenting the unique(?) experiences of Independent Living

Killian uses the Ontario Direct Funding program, which, as mentioned in Chapter One, is

uniquely administered through an Independent Living (IL) organization. Perhaps then,

the emerging work from disability studies provides an adequate framework for

understanding our relationship. The divide between theoretical and empirical is less

pronounced in this literature than will be seen in feminist work. The first body of

literature, empirical studies of direct funding from disability studies perspectives, often

includes implicit theoretical assumptions about care, which are made visible through

certain signposts, for example, references to Independent Living and/or disability

movements, avoiding the word 'care,' and using terms like 'personal assistance.' These

strategies reflect the perspective of the IL movement that adamantly and often

exclusively calls for a re-orientation of the care industry around the concepts of *choice*

and *consumer control*, where the person with a disability is in charge of his or her

personal support (e.g., see the approaches of "ADAPT Free our people!," 2009; Centre

for Independent Living in Toronto," 2010). The IL movement redefines independence in

terms of self-determination (instead of physical action) and asserts that disabled people

have a right to make decisions about their lives. The IL movement creates an

employer/employee relationship through promoting direct funding. There is a surge of

studies on direct funding programs, with the results overwhelmingly reporting that the

programs are empowering and satisfying for service-users (Beatty, Richmond, Tepper, &

DeJong, 1998; Blyth & Gardner, 2007; Caldwell & Heller, 2003; Centre for Independent

Living in Toronto, 2010; Leece, 2000; Stainton & Boyce, 2004; Williams et al., 2003; Zarb

& Nadash, 1994). Some studies, however, note that user-empowerment can vary

substantially based on location or policy framework (Askheim, 2005; Barnes, 2007;

Pearson, 2000; Ungerson, 2004; Ungerson & Yeandle, 2007).

Direct funding programs and Independent Living can be liberating and flexible for

the service users, and seeing Killian in diverse settings attests to this. Yet some of the

rhetoric does not resonate with my experiences. In particular, Killian does not always act

as a professional, powerful boss, directing me or his attendants as merely his 'arms and

legs.' Some studies find formal relationships endorsed rhetorically by the community do

not always manifest in practice, where people with disabilities and their attendants form close relationships (Aronson & Neysmith, 1996; Watson, McKie, Hughes, Hopkins, & Gregory, 2004). The empowering intentions of Independent Living can sometimes backfire as the mutual *caring* relationships that inevitably develop are interpreted as inappropriate, an impediment to the goals of Independent Living, or even dangerous. Disabled people and their attendants are then left to negotiate their relationships privately, away from public conversations about personal support (Kelly, 2010b; Yamaki & Yamazaki, 2004). It is also significant that IL and disability movements have been criticized for a lack of diversity, further suggesting limitations of these approaches (Bell, 2006; Morris, 1991a; O'Toole, 2004; Vernon, 1999). Perhaps the underlying theoretical assumptions implicit in direct funding studies, and found elsewhere in disability studies literature, have something to add.

Theorizing care from a disability perspective: Dismantling the institution

The next grouping of literature, closely related to the first, is broader theoretical work from disability studies perspectives, which can be useful in explaining aspects of the example of Killian and myself. This work suggests that care is oppressive and often leads to an outright rejection of care. In essence, this body of work contains layered critiques of the concept and practices of care (now termed "disability critiques") with three main components. First, disability activists and scholars demand we acknowledge what Fine

(2007) terms the "dark side"[1] of care, that is, the potential for abuse (p. 4).[2] Between

common, romanticized understandings of care and efforts of some feminist scholars to

revalue care work, the potential for abuse is largely hidden. Yet, people with disabilities

are at a high risk for physical, sexual and emotional abuse in personal support

interactions (Matthias & Benjamin, 2003; Saxton et al., 2001). Further, the abusive side

of care can be more subtle, referring to control and coercion (Priestley, 1999; Saxton et

al., 2001). This subtle aspect of the critique can become convoluted as some individuals

require forms of "supervision and/or cueing" ("ADAPT Free our people!," 2009) and may

lack the capacity to express agency in typical ways. Indeed, it can be difficult for

individuals who need support making decisions to relate to Independent Living with its

emphasis on self-determination, or in some cases, to actually qualify for direct funding

programs (Williams, Ponting, & Ford, 2009). This critique is generally one-way as the

literature rarely acknowledges the potential for attendants to experience abuse, the risk

of which is heightened in the ambiguous and unregulated settings of home care

(Cranford, 2005; Ungerson, 2004).

Secondly, the disability critiques remind us that care is haunted by the spectres

of institutionalization, medicalization and paternalistic charities, which, in varying

degrees past and present, systematically devalue and marginalize people with

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[1] Using 'dark' to convey negative or violent connotations may have racialized elements; thus I only use this phrase when directly quoting Fine. Otherwise, I refer to the 'potential for abuse' or the 'abusive side of care.'

[2] Fine's (2007) use of the 'dark side' of care is distinct from how Olena Hankivsky (2011) uses it in reference to the connections between sex trafficking and care-based motivations pushing women to migrate.

disabilities. This can be seen as an underlying orientation of the disability studies

literature. Take for example this quote from Lennard Davis' (1995) *Enforcing Normalcy*,

a foundational disability studies text: "The previous discourse [prior to disability

studies], heavily medicalized and oriented toward care and treatment, served its

institutional purposes well" (p. 2; for other examples, see Linton, 1998; Longmore, 2003;

Oliver, 1983; Shakespeare, 2000; Zola, 1982). While some progress has been made

largely as a result of disability movements, literal and figurative institutions still exist

worldwide and oppressive ideologies continue to operate in policy and organizational

systems under the guise of "caring for" people with disabilities. In the name of "caring

for" individuals or society at large, people with disabilities have been subjected to

multiple forms of oppression, including forced sterilization, painful and ineffective

physical therapies, physical and emotional abuse, and of course, institutionalization.

Arguably, as we will explore shortly, feminist scholars also recognize oppressive sides of

care by highlighting the ways women are limited through care responsibilities and

gendered assumptions about care; however, feminist work aims to separate care from

oppression by exposing the broader social structures at play and recognizing the value

of care work. Indeed, disability critiques reject feminist conceptualizations of care

because they move past these legacies and applications, choosing instead to revalue

care. We cannot deny that care includes the alarming history of institutionalization and

ongoing dangerous potentials. Like all human atrocities, we must never forget the

continuing and historic oppressive legacies of care.

Finally, the disability movement famously declares "Nothing about us without us!" (Charlton, 1998), and disability critiques of care demand space for the person in need of support to express agency. Specifically, disability studies endorse firsthand accounts in research and theorizing (e.g., Clare, 1999; Linton, 1998; Mairs, 1996). This is the bulk of the critique directed specifically at feminist care scholars, who often literally exclude people with disabilities from their studies and examples. It can also apply to the symbolic exclusion of disability perspectives. A disturbing trend is the way in which feminist studies and theoretical explorations of care are seemingly unaware, or at times intentionally disregard disability perspectives. While Kröger (2009) briefly commends Marian Barnes' (2006) approach to care and social justice, and Barnes does acknowledge disability perspectives in her work, I find some of her interpretations dismissive. For example, Barnes (2006) declares:

> We need to rescue the concept and practice of care both from the impact of those who regard it as something that is carried out as a natural part of women's natures as wives, mothers and daughters, and thus not a matter for public regard, or as a menial task that can be allocated to those in no position to demand a decent wage, *as well as from those who equate care with practices that are controlling, smothering and disempowering* (143, emphasis added)

Barnes deftly lumps together gendered and essentialist perspectives on care, common stereotypes that devalue care providers *with* the perspectives of disability activists. Barnes inadvertently trivializes the hard-earned successes of disability activists and effectively dismisses the disability critiques of care as unimportant and unfounded. Further Barnes does not include the people who actually require support in her study of *Caring and Social Justice*, raising the question, social justice for whom?

The disability critiques seek to distance personal assistance from all facets of care, particularly the medical, charitable and professional connotations, as seen in the activist slogan, "We're not sick, we're disabled." As we will see in the findings of this study, care for people with intellectual disabilities, elderly people and people who are ill, is seen as *something else* than what happens under Direct Funding even though the actions may be identical. In some ways, this move positions the work of attendants as non-professional, and perhaps maintains attendant services as a devalued type of work. Trying to make direct funding work for certain groups of people is a common theme among empirical studies (Blyth & Gardner, 2007; Caldwell, 2007; Caldwell & Heller, 2003; Clark & Spafford, 2001; Lord, Zupko, & Hutchison, 2000; Maglajlic, Brandon, & Given, 2000; Tilly, Weiner, & Cueller, 2000; Williams et al., 2003). This trend, however, fails to critique the values of independence, rational thinking and presumptions of stability and health (Wendell, 2001) on which direct funding models of support and Independent Living draw.

It is uncomfortable and difficult to reflect on how the disability critiques of care are relevant to my relationship with Killian, but it is also important and, in some ways, more useful than the simple empowerment framework endorsed in empirical studies of direct funding. While there is no abuse in our relationship, the idea of coercion and control haunts our interactions. Killian is ever-aware of not "asking too much" while I constantly question when it is acceptable to make suggestions and when to follow instructions. As will be seen in accounts of participants in this study, more overt forms

of abuse loom in the background and do take place in support provision interactions, no matter how empowering the service delivery model. It is also likely our relationship is only possible because of the demands from disability movements to listen to disabled people regarding their personal needs. Let us now turn to feminist scholarship on care, which has greatly advanced the concept and value of care work. Perhaps this vibrant body of literature can help explain the Ontario Direct Funding program and my relationship with Killian in particular.

Documenting care work

Largely unrelated to disability work on direct funding, the third major body of work includes numerous empirical studies documenting the different facets of care work and typically focuses on the perspectives of the workers. Generally, this scholarship looks at either formal care workers with varying degrees of professionalization, such as domestic workers (e.g., Stasiulis & Bakan, 1997; Tumolva & Tomeldan, 2004), nurses (e.g., studies in *Journal of Advanced Nursing)*, home care workers (e.g., Lilly, 2008; Neysmith & Aronson, 1997), and childcare providers (e.g., Macdonald & Merrill, 2002) or informal care workers, mostly focusing on parents (e.g., Collins, 1994; Gottlieb, 2002) and those who provide support to aging relatives (e.g., Aronson, 1992; Gaynor, 1990). Empirical studies of care work may or may not blur into more theoretical explorations on the meaning of care (a noteworthy exception is the recent collection edited by Mahon &

Robinson, 2011). There are two significant trends in this literature: understanding care

as gendered work and the tendency towards "universalizing" (Williams, 2001).

Primarily, this literature focuses on the gendered and unequal nature of care

work, which includes intentionally naming the actions 'work', including the "emotional

labour" involved (Hochschild, 1983; Steinberg & Figart, 1999; Wharton, 2009). Care

work is then further divided into formal or informal, in order to distinguish the work

mothers do, for example, from the work nurses do. Significantly, through cross-national,

comparative studies some scholars complicate the in/formal distinction by

demonstrating formality has multiple manifestations, that is, it is influenced by the

presence/absence of reimbursement, nature of relationship (e.g., immediate family

member, stranger, friend), level and type of regulation, and, perhaps added by disability

perspectives, approach to daily interactions (e.g., professional business model, family

model) (Lyon & Glucksmann, 2008; Ungerson, 2004). Particularly when formal care

takes place in the informal home setting as is the case for home care and direct funding,

attendants can become "part of the family" (Aronson & Neysmith, 1996, p. 66), or at

times, actual family members or friends can be hired as formal caregivers (Matthias &

Benjamin, 2008; Ungerson, 2004; Whitlatch & Feinberg, 2006), or, migrant workers can

informally provide a paid version of home support (Gori & Da Roit, 2007), further

complicating the distinction. More specifically, Lyon and Glucksmann (2008) observe

that "the distinction between paid and unpaid is not coterminous with that of formal

and informal" (p. 114). In the example of Killian and myself it is at times impossible to

distinguish what we do for each other as friends and what we do as self-manager/attendant. Arguably, home care and the Direct Funding program still do not fit neatly on the continuum in/formal regardless of the criteria used and may require the development of new categories to account for the unique ambiguity posed by these arrangements.

In addition to exploring formality, feminist care scholarship defines care as *work*, in particular, gendered work. Cranford, Vosko and Zukewich (2003) explain gendering:

> To speak of the "gendering" of a phenomenon is to focus attention on the processes whereby sex differences become social inequalities. To argue that a phenomenon is gendered is to emphasize that gender shapes social relations in key institutions that organize society, such as the labour market, the state or the family. (p. 455)

Care and personal assistance are gendered, and further, racialized and classed, and this analysis is often missing from Independent Living perspectives. Many empirical studies on care work rest on this understanding resulting in a focus on the perspective of the care workers (who are often women) by tangibly only including care workers as research participants or through a more implicit bias demonstrated by a dismissal or unawareness of the disability critiques of care. That is, while willing to highlight and challenge the oppression of care workers, these studies typically do not highlight how care can and has oppressed the "objects of care." There are some notable exceptions to this that will be discussed later in the conversations section.

In regards to the emotional components of care work, Twigg (2000) argues in her study of community care and bathing that care work does not necessarily involve

exploitative "emotional labor" as originally conceptualized by Hochschild (1983). Many

care workers consider personal attachments a *rewarding* aspect of their work, and

studies of attendants working under direct funding have similar findings (Clark,

Hagglund, & Stout, 2004; The Roeher Institute, 1993). How the experiences of the

Ontario Direct Funding program align with the concept of emotional labour will be

explored more in depth in Chapter Four. Relating and interacting with Killian is by no

means a labour for me, although perhaps attendants who are more regularly involved

would have a differing perspective. The feminist characterization of care as work is

highly relevant to personal assistance and is reflected in the emphasis on personal

support as a service rather than a charitable gift. As we will see in Chapter Four, self-

managers must also work in terms of administrative duties and relational engagement

with attendants. In sum, some of the common tools of care scholarship, that is, the use

of the formal/informal distinctions, even more complex formulations, and identifying

"emotional labour," do not always fit in home care examples.

A related trend in this literature is the assumption that circumstances of care can

be collapsed. The presumption is that the similarity of the actions (e.g., helping

someone eat, use the washroom) required in nursing settings, childcare settings, and

home settings override differences in the identities of the people in need of assistance.

It becomes possible to talk about an encompassing category of care while focusing a

particular study on a subset of that category. This tendency is a point of contention from

a disability perspective that, at times, overtly asserts personal assistance as distinct from

all other forms of care. There is a related trend to increasingly include more professions

under the rubric of care. For example, Armstrong, Armstrong and Scott-Dixon (2008)

make a compelling case to include auxiliary health workers as care workers, and Duffy

(2005) challenges us to broaden definitions of care work to ensure women of color and

the lowest paid workers are included.

What is unique about Killian's situation? What distinguishes personal assistance

from other forms of care? This is further confounded with the popularity of the phrase

'Independent Living' and the emphasis on choice and consumer-control seeping into

many aspects of North American culture (Stein, 2001). There are political and social

potentials for considering varied categories of care together, yet this process also risks

offending adults by grouping them next to children, and glossing over the substantive

differences in the support required for those experiencing dementia, or for people with

intellectual disabilities who may not require any physical support at all. While efforts of

disability movements to distinguish personal assistance from other forms of care may be

moving too far in one direction, the insistence on difference opens some intriguing

possibilities.

Feminists mapping the parameters of care

Scholarship exploring what counts as care work bridges into a fourth region of literature,

that is theoretical work, including the ethics of care, that seeks to map out the

parameters of care and may or may not include empirical elements. The conceptual

muddiness of care is often the starting point for theoretical work. Generally, care

theorists understand care as both a relational value (i.e., caring about) and a skilled

practice (i.e., caring for), which in many ways reflects common uses of the term (Finch &

Groves, 1983; Grant et al., 2004; Held, 2005; Tronto, 1993). Others endorse broader

conceptualizations of care; for example, Daly and Lewis (2000) see care as a "meta

concept" essential for understanding contemporary welfare states (p. 286). Tronto

(1993) famously defines care as "a species activity that includes everything that we do

to maintain, continue, and repair our 'world' so that we can live in it as well as possible"

(p. 103). Thomas (1993) takes an opposing view: "I would argue that care is not a

theoretical category. It exists at the level of everyday familial and political discourse. To

put it crudely, there is no such thing as 'care' in theoretical terms" (p. 666).

Thomas' "crude" statement is primarily directed at those writing from an ethics

of care perspective who position care as a moral framework grounded in daily

experiences of providing care, most often to children. Chodorow (1978) and Ruddick

(1980; arguments expanded in 1989) are sometimes considered forerunners, with

Gilligan (1982) and Noddings (1984) most consistently cited as laying the foundations for

the field. In her 1982 book *In a Different Voice*, Gilligan observes the field of psychology

was seemingly premised on men's experiences of the world. In particular, as girls were

(eventually) included in trials of Kohlberg's (1981) model of moral development their

responses to the moral dilemmas typically scored at level three out of six on a

progressive trajectory. Gilligan argued it was not the moral capacities of the female

participants that were flawed, but Kohlberg's model and set out to map an alternative

framework based on women's experiences. The ethics of care emerged as a relational,

concrete, and active set of decision-making tools as opposed to the abstract, rule-based

ethics of justice that dominates the field of moral philosophy as well as common

systems of morality. Relationships between these two ethics would later become the

subject for many of the debates in this area (e.g., Clement, 1996; Kroeger-Mappes,

1994; Manning, 1992).

Noddings' (1984) version of the ethic of care argues we have an obligation to

care, and that obligation is greater for those with whom we are already in a relationship

or with whom there is a potential future relationship. Noddings strongly resists the idea

of abstract ethical rules, arguing moral decisions must be made in context, thus

contributing to the development of a flexible and difficult to teach "rationality of caring"

(Waerness, 1996). There is a very specific focus on the daily, relational elements of care

and a rejection of care as a political concept as demonstrated when Noddings (1984)

declares "no institution or nation can be ethical" (p. 103).

The foundation of this literature did not stand for long as many critiques

surfaced, particularly stemming from Noddings' early work. For example, in an oft-cited

article resonating with some of the disability critiques of care, Card (1990) argues

Noddings' approach risks valorizing abusive relationships. A further critique of Noddings

comes from Manning (1992): "The claim that one must withdraw from the public sphere

and retreat to the private when neglecting those to whom one is already related strikes me as classic defence of the stereotypical role of the housewife" (p. 72).

In more recent work, Noddings (2006) responds to some critiques through exploring care as a social policy tool (see also Hamington & Miller, 2006). She suggests we examine life in "ideal homes" as a starting point. She continues her critique of principles, although strangely offers a number of strong recommendations and universals, including advocating for the termination of potentially disabled fetuses. Noddings (2006) argues the only common element of ideal homes is that every member can count on the response "I am here" when in need.

It seems much of the theoretical care literature does not fully engage with the idea that care is a relationship. Many of the examples are written from the perspective of the "one-caring," to use Noddings' terms, and easily assign the power to this person as the moral decision-maker; if possible the "cared-for" is encouraged to amicably receive the actions of the "one-caring" to make her job more palatable. It is these examples that seem the furthest from my experiences with Killian and consumer-directed models proposed by Independent Living movements. As will be seen in the findings of this study, some attendants do not want to be "moral decision-makers" and enjoy the freedom from liability associated with following directions.

More recently, the ethics of care literature has developed in two main directions, one towards what Williams (2001) terms a feminist political ethics of care that pulls care away from everyday moral decision-making to a political framework and secondly, work

on dependency. The feminist political ethic of care asserts care should become a central civic value (Engster, 2007; Harrington, 2000; Held, 2005; Lawson, 2007; Mahon & Robinson, 2011; Robinson, 1999, 2006; Sevenhuijsen, 1998; Tronto, 1993). The implications of endorsing such a position are ripe with potential benefits for disabled people and will be further explored in the final section of this chapter.

Another development in ethics of care literature is work around dependency, led by Eva Feder Kittay, a feminist philosopher who draws on her experiences as a mother of a daughter with profound intellectual and physical disabilities. For Kittay (1999), care is an inherently unequal relationship that maintains the "foundational myths," as Fineman (2004) puts it, of our contemporary society by masking the inevitable dependencies of life. Kittay (1999, 2002) proposes the notion of *doulia*, or caring for dependency-workers, as a way forward.

It is noteworthy, and at times troubling, that Kittay specifically uses the word 'dependency' over 'interdependency.' While meanings of 'dependency' have shifted over the course of history it currently retains highly racialized, gendered and classed connotations often linked to welfare-recipients (Fine & Glendinning, 2005; Fraser & Gordon, 1994). Kittay uses the term 'dependent' to refer to those who require assistance and suggests dependents are "the charge" of care workers, which leaves little room for any expression of agency on behalf of those receiving help. She explains her rationale: "I mean to emphasize both the responsibility that the role of dependency worker entails and the ways in which the well-being of the dependent person requires

another to act in her best interests" (Kittay, 1999, p. 31). While this may apply to some

disabled people who communicate in non-verbal ways and/or require assistance to

make decisions, it does not account for people who need daily assistance and are able

to make decisions about their lives. In particular, this does not apply to Killian. It would

be simply offensive and demeaning to refer to Killian as a "dependent" or my "charge."

Significantly, Wong and Millard (1992) demonstrate there is often a disparity between

what attendants think is in the best interest of people with disabilities and what they

themselves think. Kittay (1999) emphasizes that the "dependency relationship does not

authorize the exercise of power except for the benefit of the charge," yet there will

inevitably be occasional or even frequent moments of impasse when the desires and

opinions of attendants and disabled people conflict, and one person will need to assert

a form of power over the other (p. 33). When we label one person in the relationship a

"dependent" who is "the charge" of the other, it is clear which perspective these

impasses will tend to favor.

Nonetheless, Kittay's contribution to both feminist and disability care research is

substantial. In particular, Kittay helps to demonstrate the degrees and varieties of

in/ter/dependency by starting from people who are so often excluded from other

frameworks, like her daughter. Her work presents a powerful and necessary challenge

to others working in these fields.

Moving away from ethics of care literature, Fine's (2007) review of care and care

policy concludes a singular definition of care will always remain elusive. Instead, Fine

(2007) sets forth a complex definition that can speak to multiple situations. It is worth quoting Fine's definition at length as it concludes with one particularly interesting component:

> care is a complex, contested, multilayered concept that refers not just to actions and activities, but to relationships and to values and attitudes about our responsibility for others and for our own being in the world. It is at once an activity or form of work, as a system of social relationships that extends from the intimate and personal to a broader set of ties acknowledging our mutual dependency, and an ethical position that involves an approach to the self and a commitment to others. By extension, care can also be understood as an open and supportive orientation to strangers, to the community, to society at large (both national and global) and to the natural world. In viewing care, however, what might be thought of as the negative or dark side of care, the enforced dependency of care-givers and the potential for harm to the recipient need to be recognized alongside the more positive attributes. (p. 4)

The idea of a "dark side" of care resonates with disability critiques of care, yet indeed, remains underexplored in feminist work on care.

Fine's complex definition of care is, in many ways, the most accurate. Care cannot be reduced to a simple definition, and most significantly, the abusive side of care cannot be removed from academic and public understandings. Further, as the disability critiques of care demonstrate, the potential for abusive care is much deeper than alluded to in Fine's definition. While there are some exceptions (notably Twigg, 2003; Williams, 2001; 2009), countless recently published articles and books launch into complex discussions of the many facets of "care work" without acknowledging the agency of those receiving support nor the history of the terminology being used (e.g., Duffy, 2005; Lynch, Baker, & Lyons, 2009; Stone, 2000). Taking Fine's definition a step further, and in a more succinct manner, I would suggest care, in particular *accessible*

care, is an unstable tension between emotions, actions, and values, simultaneously pulled towards both empowerment and coercion. Care is a paradox (Douglas, 2010a) that includes a long history of institutionalization, a deep emotion between individuals in various relationships with one another, a policy arena, a motivating perspective on the world, a tendency to control other people, a form of gendered work, and so on. To distinguish this definition of care from our common usages requires the critical concept of access, which as Titchkosky (2011) argues is "an interpretative relation between bodies" that reveals the links between discourse, material environments and social inequalities (p. 3). Accessibility, like care, is never fully achieved, but requires constant evaluation and evolution of our practices and shared discourses around disability. Pairing (critical) accessibility with the idea of care as a tension introduces a new approach to, and new applications of, care. This seemingly unwieldy definition captures the complexity of care, and includes multiple perspectives in meaningful ways. Understanding care as a tension is a prerequisite for accessible care and poses interesting questions if one also argues for care as a central civic value (Williams, 2001). The implications of holding an unstable tension at the centre paves the way for accessible care, and will be mapped out in the concluding section of this chapter.

Conversations

The final body of literature is comprised of the few conversations among the bodies of work, which represent other 'Killians,' that is, voices that demonstrate dominant

approaches to care have some substantial gaps. These conversations fluctuate between

hostility, glaring silence to more recent sympathy. There are three main trends in this

literature: the earliest conversations between feminists and disability scholars (often

also feminists) characterized by silence on the part of the former, or hostility on both

parts; work that engages with disability perspectives, but concludes feminist and

cultural approaches are superior; and finally, efforts to work with both perspectives in

order to build bridges and form the foundation for something new. This final, and

perhaps most difficult, strategy is required for accessible care.

Disability scholars, or arguably feminist disability scholars, first critiqued care

researchers and theorists for not only ignoring the perspective of people with

disabilities, but for further disabling people through oppressive representations in their

work. For example, in an oft-cited article, Silvers (1997) makes a compelling argument

against an ethics of care: "So modeling morality on being cared-for and caring appears

to make such self-sacrificially compliant behavior obligatory for persons with disabilities,

and this is morally counter-intuitive" (p. 33). Instead, Silvers argues for a system of

morality based on a historically "counter-factualized" notion of equality, such as the

version found in the Americans with Disabilities Act. For Silvers, the ethics of care is

irredeemable as a moral framework since it does not address the past and present ways

people with disabilities are marginalized and devalued through discourses of

dependency and care. Unlike an ethics of care, Silvers' proposed alternative demands

only inclusion and equal opportunity in the current system, although perhaps

meaningful inclusion of disabled bodies is in some ways radical as she notes "individuals with disabilities customarily are conceptualized as irremediably unequal" (Silvers, 1997, p. 27).

In her early work, Jenny Morris notes "for feminists writing and researching on carers, the category 'women' does not generally include those who need physical assistance," thus creating a false distinction between women who care and genderless and passive objects of care, which resonates with my own reading of this literature (Morris, 1991a, p. 154; see also Morris, 2001; 2004). This statement was in direct response to some feminists who concluded residential care was the "only realistic alternative [to community care], though the quality of care in residential settings would need to be much improved" (Thomas, 2007, p. 110, regarding Janet Finch). Outside of published material, Thomas (2007) recounts several confrontations that took place at academic conferences, including some scholars dismissing disability perspectives as "minority" and "radical" viewpoints that were not practical or important. After witnessing such overt hostility, Thomas (2007) concludes in her recent analysis of the disability/care debate: "the disciplinary divide remains wide and deep on questions of care and dependency: the social oppression and social deviance paradigms clash irreconcilably" (p. 119).

The second theme in these conversations is scholars engaging with both disability and feminist perspectives, but concluding feminist approaches to care are the most adequate (Barnes, 2006; Beckett, 2007; Hillyer, 1993a; Kittay, 2002; Little & Levy,

2010). There are also a few scholars writing from a cultural theory perspective who, again, end up abandoning Independent Living perspectives on care (e.g., Fritsch, 2010; Gibson, 2006; Price & Shildrick, 2002). While in some respects this work is promising for acknowledging the disability critiques of care exist, it still ends up dismissing this perspective, sometimes more thoroughly and carefully than others. What this work does bring, however, are critiques of Independent Living and occasionally, direct funding, concepts that are largely undisputed in disability circles. Indeed, Kittay (1999) argues independence, even a reformulated version that emphasizes decision-making, still excludes people like her daughter who do not communicate in traditional ways (see also Hillyer, 1993). In a series of studies and theoretical musings, Ungerson (1997, 1999, 2004; Ungerson & Yeandle, 2007) explores cash-for-care (i.e., direct funding) schemes, arguably the hallmark of Independent Living, in many different countries. Ungerson includes people who receive the services, thus acknowledging aspects of the disability critiques of care, and importantly, discovers empowerment does not automatically accompany this style of service delivery, particularly for the care workers (Ungerson, 2004). There are also some empirical studies of direct funding from an Independent Living perspective in which scholars include both users and attendants as research participants (Earle, 1999; Helgoy, Ravneberg, & Solvang, 2003), and a few studies that include family members as participants (Aronson & Neysmith, 2003), although this appears to be more common in studies of people with intellectual disabilities (Caldwell,

2007; Williams et al., 2003). However, these studies do not usually directly engage with feminist work.

The final conversation is more recent, with Wendell (1996) representing an early example. In this limited conversation, scholars engage with both disability and feminist perspectives and attempt to salvage and protect each viewpoint in order to build bridges and lay the foundations for new approaches (brief section in Garland-Thomson, 2002; Hughes, McKie, Hopkins, & Watson, 2005; Kröger, 2009; Shakespeare, 2006; Watson et al., 2004; Williams, 2001; 2009) and this perspective is trickling into empirical studies (Gibson, Brooks, DeMatteo, & King, 2009). Importantly, this work highlights how "disabled people and their assistants do not experience personal assistance in purely contractual, unemotional and instrumental terms," suggesting the IL model does not fully account for the relationships that form under direct funding as explored previously (Watson et al., 2004, p. 338; see also Brooks, Gibson, & DeMatteo, 2008). This seemingly small detail represents a significant opportunity for bridging the independence/interdependence divide, similar to feminist work on relational autonomy (e.g., Clement, 1996). It is also noteworthy that this conversation draws on the "feminist voice in disability studies" demonstrating that disability scholarship includes more than just Independent Living (Hughes et al., 2005). These authors make room for both/and instead of either/or, for example, Shakespeare (2006) argues

> for a pluralist approach to care and support, recognizing that diversity of disabled people's lives and preferences. Independent living has transformed the choices for thousands of disabled people, but it's not the only approach to solving the problem of meeting physical and other needs. If autonomy and

> choice are regarded as the only desirable ends, then personal assistance schemes will always come out on top. But other disabled people may value other goals. (p. 151)

The most encouraging work in this conversation, from my perspective, comes from

Fiona Williams. As will be discussed shortly, Williams (2001) maps the parameters of a

feminist political ethic of care. Aside from the important theoretical ramifications of this

approach, it is remarkable that Williams incorporates disability critiques of care within

her work. Notably, Williams' work is not specifically about direct funding or Independent

Living, and serves as an example of a feminist care theorist contributing to accessible

versions of care. Indeed, in light of these developments and in contrast to Thomas'

(2007) assessment, Kröger (2009) asserts "The fundamental conceptual antagonism

between care research and disability studies seems to have become diluted recently" (p.

406).

Accessible care: Building bridges

The final theme in the final body of literature aims to incorporate disability and feminist

perspectives and is the starting point for imagining the bridges formed through

accessible care. As mentioned previously, 'accessibility' is not an end result but a

process and an "interpretative relation between bodies" (Titchkosky, 2011, p. 3).

Accessible care, then, positions care as a moving tension that cannot be resolved.

Accessible care builds bridges in four arenas; it works to: account for daily experiences

of disability and support provision in theoretical discussions; challenge feminist

researchers to account for disability critiques while also encouraging disability scholars to consider feminist insights on care, thus positioning care as a tension; address exclusions and strains within disability studies and communities; and finally, position discussions of care within a transnational arena. This formulation of care more adequately accounts for Killian and me, among other applications.

The bridges are established with material from feminist disability theory, or the "feminist voice" in disability studies as Hughes and colleagues (2005) term it, and the feminist political ethic of care. The feminist side of disability studies is often overlooked when scholars write about disability studies and care, as many focus solely on the contributions from Independent Living (e.g., Kröger, 2009). Feminist disability scholars position disability as a pervasive cultural category while, simultaneously, a diverse, embodied experience best articulated through personal narratives. It also promotes a deeply intersectional approach to disability, research and activism and allows for ambivalence around complex issues, including care. These core concepts are the central building blocks for the bridges implied by accessible care.

As we have seen, however, disability studies perspectives do not have all the answers to care dilemmas. Emerging work from the feminist political ethic of care builds on earlier ethics of care scholarship and provides some other vital concepts. This work develops the notions of interdependency and highlights how care can be used in public conversations. I now present each bridge forged by accessible care in more detail.

Bridge one: From daily experiences to theory

Accessible care is grounded in the daily experiences of support provision, highlighting

the intersectional implications of care and uses these experiences to formulate and

evaluate theoretical discussions. This bridge resonates with feminist disability theorists

who hold disability as both an experiential social identity and a cultural category.

Garland-Thomson (2002) transforms the concept of disability from the common

understanding of disability as a readily observable, medical fact, or even the less

common social model understanding that often ignores bodily experiences, to establish

disability as a complex and layered cultural category that can be used to theorize and

understand the social body. Disability is *both* a lens to examine cultural artifacts and

social phenomena and a specific embodiment and minority identity. Quayson (2007)

explains "Disability might also be productively thought of as being on a continuum with

the sublime in terms of its oscillation between a pure abstraction and a set of material

circumstances and conditions" (p. 23; see also Samuels, 2002). Significantly, many

feminist definitions build on social model and Independent Living perspectives rather

than dismantle them or downplay the tremendous material improvements achieved

under those frameworks. As such, disability critiques of care emerging from an

Independent Living perspective are still useful and can serve as a valuable critique of

care industries, medical institutions and charitable approaches.

When exploring the experiential side of disability, feminist disability theorists

highlight the value of embodied, personal accounts that emphasize the agency of

people with disabilities. In the case of personal support, contrary to the presumption

that care recipients are "passive," Marfisi (2010) argues receiving care requires active

adjustment to one's emotional and physical state. While there are some people who

cannot provide firsthand narratives in written or oral formats, as will be further

discussed in bridge three, consumer-control and making room for personal accounts of

care honour the agency of those who can and also reveal the intersectional nature of

support interactions (Asch, 2000; Wendell, 1996). Intersectionality is indeed an essential

component to both feminist disability studies and accessible care; Schriempf (2001)

posits a particularly complex form of intersectionality, termed *interactionism*, drawing

on the work of Donna Haraway (1991).[3] The interactionist approach does not distinguish

the social from the material in the way that the disability/impairment and gender/sex

models do, but rather "is founded on the principle that everything is 'always already'

social and material" (Schriempf, 2001, p. 68). Garland-Thomson (2011) identifies a

recent shift away from the language of social construction toward material-discursive

understanding in feminist disability scholarship, represented by interactionism.

Interactionism is perhaps best exemplified by Clare (1999) who writes: "Gender reaches

into disability; disability wraps around class; class strains against abuse; abuse snarls

into sexuality; sexuality folds on top of race...everything finally piling into a single human

body" (p. 123). This deep intersectionality is essential for understanding the experiences

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[3] In this context, the term *interactionism* builds on ideas set forth by Donna Haraway, who unsettles material 'reality,' that is, observable and experiential 'facts,' by tangling it with the symbolic and socially constructed. This is distinct from the sociological methodology "symbolic interactionism" broadly represented by James Parker, George Herbert Meade, Herbert Blumer and Erving Goffman.

of personal assistance, experiences that are visceral while also wrought with social meanings about gender, the body, race, class, sexuality, ability and so forth. Importantly, interactionism leaves room for more nuanced perspectives including mad/survivor movements, non-disabled allies and d/Deaf culture.

Personal assistants and disabled people form complex relationships that are based on more than just emotions, economics or power, and accounts of these relationships in addition to individual narratives are necessary to bridge the experiential/theoretical divide. Barbara Hillyer (1993a) argues that a person who requires care establishes a "web of caregivers" of seemingly disparate people around him/herself that is a potentially rich location for studying difference. The relationship between Killian and me may not be so remarkable. We both occupy similar social locations in terms of age, economic status, education, sexuality and perceived race. Yet, although our example may not be one of the rich locations for studying difference as identified by Hillyer, the intersections we do embody pervade our interactions. We awkwardly debate about whether helping in the washroom is 'weird,' exposing a common space within personal assistance where privacy, sexuality and gender overlap and require delicate interpersonal negotiation. These moments are awkward because they make us acutely aware of the layered power dynamics inherent to our female/male, disabled/nondisabled and clothed/unclothed embodiment that we more typically prefer to ignore, as it brings the abusive side of care uncomfortably close to the surface. As an individual who appears and identifies as a woman, I invoke the cultural

figure of the 'female caregiver' that I simultaneously embody and resist through my actions. Like disability, the actions of attendant work are not merely performative as certain gestures must be completed in order to adequately meet Killian's needs. While, for example, fork-to-mouth movements might remain constant if our gender roles were reversed, the meanings and perhaps expression of our body language, conversation, and entire relationship would not. As such, our experiences, intersections and relational narratives can bridge into theoretical discussions of care.

Bridge two: Spanning feminist care research and disability perspectives

The second bridge encourages feminist care scholars to account for disability critiques of care and disability scholars to consider feminist perspectives. This requires defining care as a tension between multiple, competing understandings, and includes the critical definitions of care suggested by disability perspectives. This bridge does not aim to include only points of "common ground" (Kröger, 2009) and shared "passionate commitments" (Watson et al., 2004, p. 341), but also irreconcilable insights. For example, work that positions care as oppressive, that is, as a gendered form of work or as a response to disability, is difficult to reconcile with work that argues care is an alternative moral perspective. Yet, these differences are valuable and the insights can still prove useful, as long as they are presented with an awareness of alternative points of views.

In a scattered, riveting plenary speech with a rhetorical style that openly reveals the writing process, Margaret Price (2011) explores the idea of *practicing alliance*, rather than being an ally. This includes "[r]eflecting upon mistakes—sitting with them—listening to them—[which] is painful" but avoiding wallowing in the privilege of guilt (p. 17). It is not easy or comfortable to reflect on the oppressive histories and potentials of care, but it is a necessary component to how nondisabled feminist care researchers can "practice alliance" with the disability community. Creating accessible versions of care is an active and difficult two-way process in which care researchers seek to engage with disability critiques rather than dismiss them as inaccurate or misguided and disability scholars equally resist the tendency to condemn care research and theory as "conceptually contaminated" (Kröger, 2009, p. 399). This active process particularly applies to theoretical approaches to disability and personal assistance, although also applies to work that groups disabled adults with other groups of people in need of support. Accessible care implicates who is included in empirical studies of personal support specifically and other forms of care work more broadly.

The crux of this two-way process is the idea, as introduced earlier, that care is an unstable tension among emotions, actions, values that is simultaneously pulled toward empowerment and coercion. Narrower definitions of care cannot fully capture its varied interpretations and only serve to silence less popular perspectives. Taking terminology as an example, the use of the terms personal support, personal assistance and attendant services force a reflection on the diverse history of care and why calling the

same actions 'care' or 'care work' may not always be appropriate. The abusive side of care shadows these terms; they are employed precisely because they speak back to the oppressive policies and programs that have taken place in the name of care. However, care is indeed a tension that cannot simply be re-worded out of existence. Care is also a form of gendered work, and it is integral to keep this interpretation in analyses of attendant services. If care is kept accessible, or *at hand* in discussions of attendant services it can be used to facilitate the iterative process of critical reflection on its oppressive histories. If we replace the concept of care too quickly, this process may be lost in the shuffle, leaving many care researchers, academics and policy makers undisturbed in their use of such terminology and allowing many disability scholars to overlook the gendered, precarious nature of the work attendants do (Vosko, 2000).

The legacies of institutionalization and the gendered nature of this work are never far from my interactions with Killian as his insistence on taking a relaxed approach to his attendants attests to. The potential for abuse is near the surface, likely contributing to why the most intimate interactions are also the most awkward and the common tendency for Killian to hire by word of mouth and personal referral. Killian also often expresses discomfort about asking for assistance, particularly unpaid assistance claiming he does want to "put people out." This seemingly insignificant, yet common, reaction is often discouraged by Independent Living perspectives that demand personal support as a right, and indeed receiving proper support in daily life should be a right. But presently, most attendant arrangements do not provide all the support a person may

require to participate in the diverse activities of life, leaving large gaps that must be filled through relying on unpaid, unregulated, family and friends. As feminist care research shows us, the systemic presumption that informal care will fill in the gaps of public services is typically shorthand for reliance on women without ensuring the necessary time, space and other supports are in place to do this work. Killian's discomfort and reluctance to ask for informal support acknowledges another oppressive side of care where women and at times paid attendants are "taken advantage" of, required to work in unstable working conditions with few protections and benefits, and at times, although never in our particular example, abused by recipients of care. The complexity offered by a layered definition of care is also useful for sorting through the strains among disability communities.

Bridge three: Across divisions within disability studies and communities

Independent Living redefines independence in terms of decision-making and typically rejects more traditional formulations of care; however, the alternative IL model can be inadequate in discussions of the needs of people with intellectual disabilities who may have difficulty independently making decisions about their lives, or in some cases expressing themselves verbally. This bridge works to explore these tensions, not only to seek resolutions but to present forms of care that are more inclusive, or accessible. Early on in this study, participants and written material revealed the well-documented tension between people with physical disabilities and their organizations and people

with intellectual impairments, their allies, and organizations (Hillyer, 1993b; Ryan & Runswick-Cole, 2008). Too often the tension manifests as a distrust of able-bodied parent advocates and disregard of people with intellectual disabilities. This "hierarchy of impairments" as Deal (2003) terms it, reflects the paradox of valuing self-determination while physically dependent on the support of an attendant. Like the typical societal emphasis on independence (Fineman, 2004), continuing to emphasize even a revised form of independence masks the social, emotional support (sometimes) provided by attendants and the varied degrees of interdependency experienced within support provision interactions.

At this point, it is useful to incorporate feminist disability theorists' call for ambivalence (Clare, 1999; Wendell, 1996). On finding a cure when one lives with chronic pain, Wendell (1996) writes:

> I want to have more energy and less pain, and to have a more predictable body; about that there is no ambivalence. ...Yet I cannot wish that I had never contracted [chronic fatigue immune dysfunction syndrome], because it has made me a different person, a person I am glad to be, would not want to have missed being, and could not imagine relinquishing, even if I were "cured." (p. 83)

Care itself and surrounding research, practice and advocacy are full of tension and conflicting messages; as such, it is necessary to approach some of these dilemmas with ambivalence in order to move beyond some of the prevailing political positions and cultural assumptions. It is worth working on care precisely because it is such a messy and contradictory concept. Ambivalence provides some breathing room by allowing some of the seemingly irresolvable debates simply to remain irresolvable. In this case, it

allows us to respect the Independent Living approach while critiquing it in light of people whom are ineligible. Killian and I embrace the notion of ambivalence by refusing to categorize our relationship as either informal or formal, independent or dependent. The frien-tendant is only sometimes paid, always a friend, and often does not perform any physical support work at all, while maintaining the self-manager should be in charge of his or her support. The frien-tendant potentially represents a new cultural figure attached to the concrete gestures of support and particular embodiment of 'attendant.'

It is important to experience and express self-determination, but it is damaging to position it as the paramount social and personal value. Clement (1996) urges us to see that "relationships, and specifically caring relationships, are a necessary precondition for autonomy" (p. 24) and similarly Kittay (2002) argues the ability to form relationships in the broadest sense should be the basis for personhood, rather than independent, rational decision-making. Autonomy is still important in these revisions, but it is held up by relationships rather than imagined to be a free-floating value that some people naturally have and others do not. Acknowledging and juggling the degrees and concepts of independence, dependence and interdependence with ambivalence maintains the relevance of all three and provides more tools to include people with intellectual disabilities.

The concepts of dependence, autonomy and interdependence whirl around the interactions between Killian and me. Unlike many other care workers, I am not economically dependent on Killian or state-funded home care for my subsistence. But

the state and the economy depend on the interactions between Killian, myself and his other attendants to sustain a hidden and increasingly precarious work economy (Vosko, 2000) and to enable him to participate in the more visible work force. In some ways Killian is also dependent on his attendants, yet, this is successfully obscured under the Ontario Direct Funding program since Killian directs his support and lives independently in the community. Killian is left to negotiate his attendant relationships without regular interference or guidance. Our relationship is two-way, and this interdependency is not merely an idiosyncratic trait of our specific relationship. From past experiences as an attendant in other contexts, I also cannot deny the rhythm and expression of our relationship, including the emphasis on in/ter/dependence, would have a distinctly different tone if Killian had an intellectual disability, particularly if he communicated in non-verbal ways. This does not mean, however, that such an imagined person should be excluded from direct funding arrangements, as they currently are in the Ontario program. Rather, this calls for a more ambivalent positioning around independence to make room for those who cannot attain even revised forms. The final bridge draws more directly on feminist political ethic of care theorists to pull discussions from the local and particular to transnational applications.

Bridge four: From the local to the transnational

Creating accessible forms of care extends beyond accounting for people with intellectual disabilities and challenges us to think about how our formulations and applications of

care account for transnational links. Independent Living, much of disability studies and foundational feminist care research on care largely overlook people with disabilities and support providers in, or who originate from, the global south (Meekosha, 2011).[4] Feminist political ethic of care scholars can help us with this work; they suggest care should be positioned centrally in civic discussions (Sevenhuijsen, 1998) and international arenas (Robinson, 1999, 2006). Accessible care brings oppression into definitions of care, and centralizing this definition can unsettle assumptions, policies and transnational discussions.

The political ethics of care grows out of a notable debate in ethics of care work, that is, how the ethics of care should or can relate to the ethics of justice (Clement, 1996; Kroeger-Mappes, 1994; Manning, 1992; Tronto, 1993). Authors explore whether valuing interdependence, relational ethics and particularity requires a complete rejection of rights, rule-based justice and universal values. According to Robinson (2006), a feminist political ethic of care recognizes care as a crucial aspect of healthy and prosperous societies, and frames care as both a private, particular matter and a public concern, in some ways similar to how feminist disability theorists position 'disability' (see also Sevenhuijsen 1998; Tronto 1993). For example, Fiona Williams' (2001) account of the political ethic of care identifies varied contemporary forms of care and reveals a

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[4] Disability scholarship is beginning to consider movements in the global south and disability issues from transnational perspectives (e.g., see Arenas Conejo, 2011; Charlton, 1998; Erevelles 2006, 2011; Ghai, 2002; Wehbi, 2011). I have not come across research on Independent Living approaches to attendant services that explores the issues of support providers and service recipients who originate from the global south.

complex definition of what counts as care. Williams identifies three developments

related to the concept of care:

> the *universalising* orientation of work around care and citizenship; the
> *particularising* challenges to care from the disability movement; the
> *transnationalising* direction taken in the pursuit of the connections between
> 'race', ethnicity, migration and care. (2001, p. 468)

Williams successfully incorporates disability perspectives, refusing to dismiss them as

inconsequential and serving as an example of how the second bridge between care

scholars and disability perspectives can operate. The "transnationalising" trend Williams

(2001) identifies and takes up in her subsequent work (e.g., Williams 2009; 2011) is the

connection this final bridge seeks to make, as it is essential to consider "geopolitical

inequalities between states affecting individuals in gendered and racialized ways" (p.

470). Care is indeed transnational, particularly represented through the global migration

of care workers (Hondagneu-Sotelo, 2007; Parreñas, 2001; Zimmerman et al., 2006).

This study suggests IL does not provide an adequate framework for analyzing or even

documenting this link, making the feminist political ethic of care even more relevant.

Disability scholars and activists position personal support as a right. As Krogh

(2004) puts it, "home support [is] a necessary service that mediates citizenship" (p. 139),

although arguably this is only a potentiality and not a guarantee of personal assistance.

However, these demands are convoluted in a transnational framework. With a variety of

examples, Charlton (1998) demonstrates some of the common tools of disability

organizing, such as critiques of charity and demands for integrated education, are less

effective when making more basic demands for services and support in countries

restrained by globally induced debt. Indeed, thinking about the global south reveals the

implicit privilege in our conversations about the language and logistics of attendant

services, and perhaps the ways in which these conversations participate in re-

colonization (Meekosha, 2011; Mohanty, 2003).

The proposal of the feminist political ethic of care is particularly intriguing if it is

maintained that accessible care is best understood as an unstable, multifaceted tension.

Transforming care into a civic value thus does not mean pulling universal

charitable/medical definitions to the centre of social and political conversations, but

rather pulling an unstable complexity to the crux of these discussions and perhaps

indirectly changing the meanings of 'civic values.' Instead of an abstract sense of justice,

or an emotional sense of 'caring about,' social policies can be built on care as an

unstable, contradictory category, and can promote a continual awareness of the all

parties involved in care interactions and also a critical reflection on the oppressive

legacies and potentials of care.

How can Killian and I travel across this bridge to the transnational? This bridge

requires some difficult stretching, particularly because disability perspectives often

focus on the local, particular and experiential. Transnational feminists remind us that

such a focus in the global north can mask our contributions to global inequalities,

including those that lie within national borders (Erevelles, 2006, 2011; Meekosha, 2011;

A. Smith, 2005). To reveal the ways in which our mundane negotiations are connected

to these inequalities it is important to return to the shared social locations identified

when speaking about our intersectional experiences. It is not accidental that Killian and I occupy these relatively similar shared social locations as direct funding models do not have straightforward protections against employment discrimination. Users express a desire to hire people they can relate to, which often manifests in hiring those with similar cultural backgrounds. Meanwhile, migrant workers increasingly travelling across borders to provide care work. Under direct funding, personal support jobs, which were previously more accessible to immigrant and/or racialized women, become the purview of post-secondary students. As Pratt (1997) found in her comparison of representations of Filipino and British nannies in British Columbia, the employers' expectations of white, educated care workers differ substantively from racialized immigrant women. Indeed, the existence of what Hochschild (2000) terms the "global care chain" dramatically changes the interpretation of identities, economics and the global impacts of direct funding responses to personal support.

Closing thoughts

Accessible care is not easy; the bridges it creates do not resolve, or aim to resolve, the tensions and contradictions posed by contemporary forms of care that are well documented in academic circles. With these competing and overlapping trends in mind, I argue it is essential to have a layered definition of care that includes the notion that care can be a form of oppression and a critical approach to accessibility that moves beyond "solutions."

Accessible care provides tools for using this unruly definition of care. No single perspective has all the "answers" on care in theory or practice, as I hope the examples provided by Killian and myself demonstrate. Our example represents the first bridge built by accessible care, that is, using personal experiences to explore the theoretical. The bridges built by accessible care clear the way to travel back and forth between differing perspectives without having to declare a "camp" or reject one perspective entirely. This ability helps us to work through some issues within disability studies as, without concepts from feminist care theorists such as Kittay (2002) and Clement (1996), it is very difficult to speak about people with intellectual disabilities. Yet as the fourth bridge reveals, there are risks to focusing too narrowly on the local, as it disguises the ways in which we in the global north contribute to transnational systems of inequality.

It is somewhat of a sleight of hand to present a literature review and theoretical perspective as separate from and prior to the study because my ideas were shaped and continue to be shaped by the interviews and my experiences as a researcher. Thus, with this exploration behind us, we now turn to the mechanisms of this particular study as well as some reflections on conducting research.

Chapter Three

Beyond data collection

The qualitative research process is a turbulent one for the researcher, full of insights revealed by participants alongside awkward silences and truncated responses, moments of clarity about purpose alongside periods of disorientation. This is further compounded since, for many qualitative research projects, the process is brief and contained for participants (even if there are multiple interviews), yet all-encompassing for the researcher. The purpose of this chapter is to document the iterative research process while practicing feminist reflexivity. I briefly explain: how this study employs interdisciplinarity; review the initial impetus for the project and the research design; document the recruitment and data collection phases; explore my role as a researcher; and attempt to capture the practices of qualitative analysis and issues of representation in the writing phase. Through reflecting on the central role of Killian in my dissertation, I question the idea of who constitutes a key informant and present a flexible approach to friendship in the research process. I found the labels of insider/outsider are still meaningful within this study but suggest relational standpoints may form through the interactions between insiders and outsiders and also prove useful in analysis. As I find in Chapter Four, similar epistemologies and ontologies may exist in relationships between attendants and self-managers.

I present these reflections in order to apply my theoretical framework, in which care is understood as an unstable tension positioned at the centre. I consider what forms of care are present in my methods, assumptions and practices and attempt to account for the tensions of care, while also letting them rest as irresolvable. Perhaps research is a form of care, since researchers often care about our participants and about the research questions. But, as disability critiques of care demonstrate, if research is a form of care it requires us to be constantly aware of the potential to slide towards coercion. My research approach and understanding of care is an interdisciplinary one; I now explore how the concept of interdisciplinarity informs this study.

Interdisciplinarity

All of the fields I draw on and am associated with (disability studies, women's and gender studies, and Canadian studies) can be characterized as "interdisciplinary" and this study can also be considered as such. "Interdisciplinarity is not a unified or discrete phenomenon" and there are various debates around the concept (Salter & Hearn, 1996, p. 5). Contrary to some accounts, interdisciplinarity is not only about problem-solving and the integration of disciplines (e.g., Brewer, 1999), but encompasses a critical approach to scholarship that can be applied to a variety of topics and expressed through a number of methods.

In contemporary social sciences and humanities, there are very few topics, courses, and fields that would not be considered interdisciplinary. In fact, some scholars

challenge the very notion of disciplines. Salter and Hearn (1996) find "[l]ittle historical or sociological evidence exists to support the notion of 'core disciplines'" (p. 6). Instead, they apply the idea of "registers," which is "the manner in which information is understood, arguments are marshalled, and issues are discussed in different communities" (Salter & Hearn, 1996, p. 23). In this study, an example of a register is the ethic of care literature or the disability critiques of care, discussed in Chapter Two. Significantly, those who contribute to these registers do not necessarily originate from a shared discipline. For example, the ethic of care literature was developed by scholars working in psychology, philosophy, political science, social work, women's studies, and so on. Yet, the literature can be clearly identified as a coherent register, utilizing common terminology, cross-referencing, critiquing and building on previous work, and discussing similar topics.

In this study, my interdisciplinary approach encompasses a critical interrogation and synthesis of knowledge across two key registers, that is, broadly speaking, disability studies and feminist care scholarship (which could both be characterized as interdisciplinary themselves). My approach both appreciates the similarities of these registers and challenges their prevailing assumptions. My intent, most clearly demonstrated through the concept of accessible care, is "aimed at enhanced understanding rather than victory for one point of view" (Szostak, 2007, p. 2). Thus, in this study, interdisciplinarity forms the foundation of my scholarly approach, informs

the primary research questions and review of the existing literatures, and pervades the choice of methods and participants, as will be further seen in the research design.

Research design

My interest in disability and attendant services stems from a variety of sources, including: reflecting on former employment as an attendant in differing settings, observing friends who employ attendants, and prior research on models of support provision during my master's degree. My dissertation questions crystallized through thinking about Killian, a close friend who uses the Ontario Direct Funding program. Killian knows he is often my reference point in terms of working through complex ideas and he figures in other parts of this dissertation. Thus, I cannot claim my questions arose solely from reading academic articles and books, but rather grew from personal experiences. Choosing to include elements of autoethnography came about organically, as it is the way I make sense of theoretical questions. Autoethnography reflects the values of feminist standpoint epistemology, encourages self-reflexivity, and gestures towards the techniques of influential scholars and allied scholars in disability studies, making it well-suited to this study.

While adding to a rich and transparent description of the research process, autoethnography also carries a unique set of challenges. Before my dissertation work began, I was confronted with my first ethical dilemma – were my observations and interactions with Killian mine? His? Ours? I asked permission from Killian, but continue

to struggle with how to represent him fairly. He informs so much of this work that it would be unfair to leave him out, yet in some ways, unfair to include him when it is my voice and not his that appears in these pages. Ellis (2007) grapples with the many ethical dilemmas of research that arise outside of "procedural ethics." She argues: "To write an effective autoethnography demands showing perceived warts and bruises as well as the accolades and successes" (Ellis, 2007, pp. 16-17), but such an approach violates the basic agreements of friendships when autoethnographic accounts include interactions with other people.

In our frequent conversations we joke about our ethically questionable relationship. Killian seems at ease, trusting and light in these conversations, but under the laughter I am tense and anxious about violating an imaginary set of research rules. I was reluctant and nervous to show him my writing at first, despite his ongoing support and interest in the project. What would he think? Was I slipping into what Haraway (1988) terms the "godtrick" or a complex, subtle form of ventriloquy as Michelle Fine (1992) describes? I continually fret over these ethical, relational and representational conundrums while working on this project, tentatively making decisions and waiting anxiously for the inevitable slips I will make.

Although writing about Killian is both the easiest and the most difficult part of this dissertation, I do not claim my interpretation as his experience. What is it about Killian that informs this study in such a foundational way? Killian appears to live an independent life, supported by a vibrant network of attendants that he has carefully

cultivated over the past decade. My thoughts about Killian, and feminist ethicists writing about interdependency (e.g., Clement, 1996; Fine & Glendinning, 2005; Gilligan, 1982) begin to reveal the inadequacy of common approaches to care, particularly in light of my own experiences living and then researching L'Arche, an intentional community for people with intellectual disabilities that requires meaningful relationships to operate (Cushing & Lewis, 2002; Kelly, 2010a). As such, for this project, through and beyond the autoethnographic reflections, I explore the places where notions of independence overlap and collide with care and relationships. I do this through examining how people with disabilities, their attendants and informal supports conceptualize care while using the Ontario Direct Funding program, an Independent Living model of support. I also examine advocacy and related government responses to the tensions between Independent Living and care in order to understand the policy implications of how care is handled and understood.

I initially proposed to collect data through co-constructing a limited number of in-depth care narratives with people using, working under and beside Direct Funding, conducting semi-structured key informant interviews, and undertaking a discourse analysis of written material. Due to the difficulty of recruiting participants for the initial interview, and a personal discomfort around asking too much from the busy participants, I moved away from the care narrative idea early in the process and increased the number of participants. I had assumed that all participants would be as invested in the research as Killian, while also underestimating the creative processes

inherent in qualitative interviews. That is, a creative aspect of the study could be found within the interviews without having to ask for more time from the participants.

Recruitment and data collection among friends and new acquaintances

I interviewed key informants to reflect the various sectors involved in the formation and ongoing administration of the Ontario Direct Funding program, that is, public servants, politicians, community advocates, and people working in the daily administration of the program at IL centres. I also analyzed written material from government and community sources in order to document the public, formal narratives surrounding the Direct Funding program and individualized funding more broadly. These more formal narratives both support and contradict the narratives of other sectors and participants thus providing important context for understanding the situated experiences of Direct Funding and useful for understanding the policy implications of these experiences.

Recruiting the key informants went fairly smoothly, and the majority of interviews were completed between February and early April 2010. I contacted the Centre for Independent Living in Toronto for recommendations of potential key informants. They provided me with a thoughtful list of contacts from various sectors and I followed up with each recommendation. I used a snow-ball recruitment technique and made note of references to other people within the interviews. I ended up with a total of 19 key informants and the breakdown of the participants is summarized in Table 3-1. In general, the identities of the key informants are not anonymous in order to

Table 3-1: Breakdown of key informants

	Government Employees & Politicians	IL Employees	Also Direct Funding Recipient	Community Advocates	Researchers	Individualized funding – Parent Advocates
1.		■		■	■	
2.		■	■	■	■	
3.		■	■	■		
4.			■	■		
5.			■	■		
6.			■	■		
7.				■		
8.			■	■		
9.						■
10						■
11						■
12					■	
13					■	
14		■				
15		■				
16		■	■			
17	■					
18	■					
19	■					
20	3	3	6	8	2	3

encourage them to speak from their official roles. I do mask the identity of key

informants at some points in later chapters mostly to avoid blaming specific individuals

for systemic issues, as I explore shortly.

The categories for recruitment often overlapped, demonstrating some drawbacks of approaching policy issues with a sector framework. Public servants and program administrators acted as advocates in some cases and people shifted across the public/non-profit divide and back again throughout their careers. Some key informants were also self-managers and would talk about their own experiences with Direct Funding, which complicated their perspectives as public figures. The overlapping identities of the key informants adds layers of meaning to the interviews, which helped go beyond straightforward "official" messages, as will be seen in Chapter Five.

Early on in the recruitment and interview process the topic of individualized funding, a separate advocacy movement coming from people with intellectual disabilities and their allies, arose and I began asking for materials and referrals to people working in this area. I was curious about how the push for individualized funding evolved (and remains) distinct from efforts surrounding the Direct Funding program despite obvious similarities. I conducted the majority of key informant interviews in person, making several trips to Toronto and other parts of southern Ontario. The semi-structured interviews (see Appendix 1 for interview guide) took place at the participants' place of work, occasionally over the phone, or in public locations such as coffee shops and generally took between 45-90 minutes. I bought or baked a small gift for each participant, which although time-consuming, appeared to be sincerely appreciated.

At each interview, I requested documents or written material that might help contextualize the issues we spoke about. Participants were willing to share published or publically released documents including newsletters, reports and press releases, but reluctant to share meeting minutes or less formal documents. There is one notable exception to this, that is, I have access to extensive documentation from the Individualized Funding Coalition for Ontario. There were plausible explanations for this reluctance, including that participants did not have hard or electronic copies of the information any longer. I found other documents through my role as a volunteer board member for Citizens with Disabilities-Ontario, a provincial non-profit group (CWDO, 2011). Different articles and resources were drawn to my attention through email discussions and listservs or through references in the documents that I was given by participants. I ended up with an assortment of sources that provide interesting counter and supplementary narratives to the qualitative interviews (see Table 3-2 for a list of the documents).

As much is learned in the research process as in the actual interviews and one particular telephone conversation while recruiting key informants stands out as a pivotal point in the research. One community advocate/past program administrator was difficult to contact, and we finally connected over the phone. I was in the basement of my parents' house, where I stayed while conducting interviews in Toronto, and indeed, the irony of being scolded by this potential interview participant while in the home of my teenage years was not lost on me. He angrily admonished me for talking about 'care'

Table 3-2: Nature, source and rationale for documents analyzed

Documents Related to Direct Funding			
Name	**Nature**	**Source**	**Rationale**
Direct Funding Application Guide (5th Edition, Aug 2001)	Guide instructing people how to apply for Direct Funding	Centre for Independent Living in Toronto	Core document given to all potential self-managers
Financial Administration Start-Up Package for Self-Managers and Bookkeepers (Revised Jul 2008)	Information on how to manage Direct Funding and reporting required	Centre for Independent Living in Toronto	Core document given to all self-managers
Power Shift (Mar 2000)	Support for the Ontario Direct Funding program	Ian Parker, Hazel Self, Vic Willi, with Judith O'Leary	Document demonstrating the success of Direct Funding
Final Evaluation Report (Mar 1997)	Evaluation for the Pilot Project of Self-Managed Attendant Services in Ontario	Centre for Independent Living in Toronto	Important document in securing Direct Funding as a more permanent program
Direct Funding General Information (4th Ed, May, 2000)	General information on the Direct Funding program	Centre for Independent Living in Toronto	Core document given to all potential self-managers
A Case Study of the Ontario Self-Managed Attendant Services Direct Funding Attendant Service Pilot: Independent Living in Action	Academic evaluation for the Pilot Project of Self-Managed Attendant Services in Ontario	Partnership between CILT & Department of Physical Therapy at U of T (Karen Yoshida)	

Documents related to individualized funding advocacy			
Name	**Nature**	**Source**	**Rationale**
Sample of First Choice News (May 2003; Feb/Mar 2009; June 2009)	Newsletter geared at families and community advocates	Special Services at Home Provincial Coalition	Documentation of advocacy surrounding Special Services at Home, an early form of individualized funding
Past Initiatives and History of SSAHPC from 1982-2007	Timeline posted on website	Special Services at Home Provincial Coalition	Example of early advocacy work seeking individualized funding
Meeting minutes and documents (2004-Mar, 2007)		Individualized Funding Coalition for Ontario	Documentation of successful individualized funding advocacy

Mission Statement; Values and Principles document	Material from website explaining the nature of this group, a group mentioned by some participants	Family Alliance Ontario	Another example of advocacy related to individualized funding

Context: Current Issues related to Disability

Name	Nature	Source	Rationale
Handouts from council meeting (Jan 2010)	Information on the UN Convention on the Rights of Persons with Disabilities from Canada's national umbrella group addressing disability	Council of Canadians with Disabilities	Context on current priorities of national disability movements in Canada
The Right to Legal Capacity under the UN Convention on the Rights of Persons with Disabilities (Oct 2009)	Discussion paper prepared for Inclusion International for the Day of General Discussion (Oct 21, 2009)	Michael Bach, Executive Vice-President of Canadian Association for Community Living	More detail issues related to UN Convention, which is of central importance to Canadian disability groups right now
Press Release (Dec 3, 2009)	Information on the tabling of the UN Convention on the Rights of Persons with Disabilities	Council of Canadians with Disabilities	Background on the UNCRPD
Spotlight on *Transformation* (Feb 2007-Dec 2010)	A developmental services bulletin highlighting developments in the *Transformation* of developmental services in Ontario	Ministry of Community and Social Services	Current context and comparison of individualized funding and Direct Funding approaches
Multiple drafts of the Attendant Support Services Protection Act (dates unclear, 2008?-2011)	Draft legislation working to protect consumers of attendant support services	Scott Allardyce	Current advocacy work related to attendant services in Ontario
Multiple drafts of the Canadians with Disabilities Act, (dates unclear, 2010?)	Draft legislation modeled after AODA and ADA	Scott Allardyce	Current advocacy work related to disability in Ontario
Blog Posts (2010 & 2011)	Website and blog post on the issue of the right to protest outside group homes from respectourhomes.ca and http://www.yufreepress.org/?p=1724	Samantha Walsh	Current advocacy issues related to attendant services in Ontario
Emails from listserv	Information regarding the Huronia Regional Centre Class Action Suit	David Rosenfeld law Office	Context regarding evolution of Ontario deinstitutionalization
Final Report	Independent Review of the AODA	Charles Beer	Context related to current disability issues in Ontario

and even 'advocacy' in my research materials. "We don't need care!" and "We're not allowed to do advocacy!" he proclaimed. After some back and forth, I eventually outlined my personal connections and history of involvement with disability organizations and issues, a practice that would be required to varying degrees in my interactions with disability advocates. I convinced him that I was examining if 'care' was still as controversial as it once was. This conversation had a few lasting effects on the research; primarily, I downplayed the word 'care' in the research materials, mentioning it only once in the letter of information so as not to offend potential participants before we started. When meeting with the participants, I continued to ask directly about care, but much later in the interview and framed it as a matter of language and semantics. Secondly, this conversation encouraged me to use my own experiences and connections strategically to increase the level of trust, although I continue to feel uneasy about taking advantage of my husband's identity as a disabled person and my volunteer work for personal gain as I cannot guarantee it will benefit the participants in the long term. The recruitment and data collection for the rest of the participants, that is, the self-managers, attendants and informal supports, was a different process and experience.

Interviews with self-managers, attendants and informal supports

Perhaps the most important data I collected came from the interviews with self-managers, attendants and informal supports, particularly because doing so addresses the lack of studies related to direct funding and care that include multiple perspectives.

Further, the feminist ethic of care is grounded in daily experiences of giving and

receiving support, while feminist disability scholars value personal narratives, making

these interviews an important reflection of the theoretical framework of this study. The

interviews with self-managers, attendants and informal supports had a different tone

and pace than the key informant interviews. I started with Killian, who made

researching easy. Killian was proactive, eager and willing and the formal research was

completed quite quickly. Even though I was fumbling and a little rigid with my questions

during our first interview, Killian's responses were graceful and deep, and I knew our

previously established rapport contributed to the success of the interview (see Appendix

2 for interview guide). I learned to be less "professional" during these interviews, which

often took place in the homes of the participants or coffee shops and took between 60-

90 minutes. I conducted follow-up interviews with a few attendants, and with almost all

of the self-managers. Generally, the follow-up interviews took between 30-40 minutes.

Outside of our interview, Killian quickly passed on contact information for his attendants

and informal supports and spoke to them directly about my research, a process that

when repeated by other self-managers greatly increased the chances of participation.

We frequently joked about the difficulty in maintaining confidentiality as he was curious

to know what his attendants and informal supports were saying to me and how the

research was going.

Killian and I are still friends and in our regular interactions, he continues to

inquire about the research. I cannot overemphasize the support and encouragement he

provided (and continues to provide) throughout the entire process. He checks in, offers

advice and assistance in whichever way he can. His confidence in my abilities and the

value of this project never falter, which was particularly useful when I was discouraged.

While the importance of developing rapport and forming a variety of

relationships in an ethnographic field is well-documented and discussed in even the

most introductory methods textbooks, there is little methodological literature on

including previously established friends as participants, with some notable exceptions

(Taylor, 2011; Tillmann-Healy, 2003). Taylor (2011) discusses the benefits of already

established rapport and the access to the "significant yet often random and

unexpected—moments that one is only privy to as a result of intimate contact" (p. 11).

But Taylor also recommends a "mix of intimately familiar and unfamiliar informants" in

order to avoid the pitfalls of an insular study (p. 15). In this particular study, including

intimate informants in some ways replicates the ambiguous relationships that form

between attendants and people with disabilities, relationships that tread across

formal/informal, professional/friend boundaries. Perhaps including friend participants

provides access to some of the ethical dilemmas attendants and self-managers may

face, particularly when hiring friends as attendants (Kietzman, Benjamin, & Matthias,

2008; Matthias & Benjamin, 2008; Whitlach & Feinberg, 2006).

After Killian, I had some difficulties with recruitment for this phase. At the

outset, I presumed more self-managers would know each other, but as I found, the

participants in this study were very busy and somewhat disconnected from one another.

After only finding two Ottawa participants with the snowball technique, I switched tactics and opened the study to anyone in Ontario. I included three other friends as participants, which in one case worked as smoothly as Killian, while the other case presented some difficulties in obtaining a signature for consent and contact information for attendants. The Centre for Independent Living in Toronto was not willing to send out an email on my behalf due to privacy concerns, which was discouraging but also understandable in light of the history of outsider research *on* people with disabilities. I ended up contacting people through other disability organizations, although I had little response from mass emails (only one participant, who never passed on her attendants' contact information). I also contacted the local Independent Living Centres in Ottawa and Kingston and received two participants that way. My husband comes across people with disabilities through his work and participation in adapted sport and referred two participants to this study. Eventually, Killian sent out personalized emails to individuals on a private contact list from the Centre for Independent Living in Toronto. This was Killian's idea, and he was more than willing to send approximately 20 emails for me, stirring up three more participants, one directly and two through snowballing.

In short, recruitment was slow and difficult, and much more complex than I initially anticipated. Four times, I conducted an interview with a self-manager, but he/she would not pass on attendant contact information, or the attendant was unwilling to participate. On three occasions attendants did not want to participate due to language concerns (i.e., English was not their first language), revealing a substantial

limitation of this study. The attendants seem to be a very elusive group of people, unaffiliated with each other or formal organizations and most often working for only one self-manager. As for the informal supports, although the number of participants is low, many self-managers insisted they were not reliant on informal supports at this point in their lives. There was some tension around this insistence, as participants also reported not having enough hours and detailed strategies for finding extra help, as discussed in Chapter Six. See Tables 3-3 and 3-4 for a breakdown and explanation of this group of participants.

All the participants are given pseudonyms, and Killian actually has two so that he does not stand out in the findings. I was concerned that people who know me personally might be able to identify who Killian is, making it important to protect his identity, particularly in comments revealed during interviews. After the slow and difficult recruitment process, it is understandable why I was reluctant to ask more of the participants than an interview and why the care narrative idea did not fit any longer. The interviews were recorded with an MP3 recorder and transcribed by myself, or one of three people who I paid to help - a former roommate, an undergraduate student and a professional transcriber, all of whom signed confidentiality agreements.

Generally speaking, I was the most confident and the process was the quickest with participants with whom I had an established relationship, perhaps reflecting the natural rhythm Tillman-Healy (2003) suggests in her "friendship as method" approach. Yet, our interactions were not completely natural. A somewhat formal interview

Table 3-3: Relationships between self-managers, attendants, and informal support

	Self-managers	Attendants	Informal Supports	Complete*
1.	A (2)	Aa (1) - *also worked for B* Ab (2) Ac (1) Ad (1) Ae (1)	Af (2)	Yes
2.	B (1) & C (1) + (1) shared	BCa (2) *Aa (see #1 above)*	N/A	Yes
3.	D (2)			No
4.	E & F (2 - shared)	EFa (1) EFb (1)	Ec (1) Fd & Fe (1) shared	Yes
5.	G (2)			No
6.	H (2)	Ha (1)	N/A	Yes
7.	I (2)	Ia (1) Ib (1)	Ic (1)	Yes
8.	J (2)	Ja (1) -*also worked for A & M*	N/A	Yes
9.	K (2)	Ka (1) Kb (1)	N/A	Yes
10.	L (2)			No
11.	M (2)	*Ja (see # 8 above)*	Ma (1)	Yes
12.	N(1)	Na (1)	N/A	Yes
Sub-total	14	15	6	
	+ 6 key informants			
Total	20	15	6	9

Legend
(#) = Number of interviews completed
* **complete** = Self-manager plus at least one attendant; informal supports only if self-managers felt it was appropriate

Table 3-4: Gender of self-managers, attendants and informal supports

	Male	Female	Total
Self-managers*	9	11	20
Attendants	3	12	15
Informal Supports	2	4	6
Total	14	27	41

* The breakdown includes the six key informants who were also self-managers.

structure was signified by use of the MP3 recorder, scripted questions for the first few

participants (until I felt confident to interview without the guide) and a notebook.

Regardless of prior relationships, many participants seemed to prefer a formal interview

structure. That is, one in which I would ask a question and the participant would

respond directly, as contrasted with a more conversational tone. This was surprising in

light of the focus in feminist research approaches on leveling power imbalances. Fine

and colleagues (2000) offer a possible explanation:

> many of the women and men we interviewed both recognized and delightfully
> exploited the power inequalities in the interview process. They recognized that
> we could take their stories, their concerns, and their worries to audiences, policy
> makers, and the public in ways that they themselves could not, because they
> would not be listened to. (p. 115)

Many, perhaps most, of the participants in this phase of the research saw the interview

as an opportunity to voice concerns and potentially improve the Direct Funding program

and thereby improve the daily lives of both the self-managers and attendants. The

participants were invested in creating/maintaining a position for me as a professional

researcher with some authority in the world.

I was not friends with the majority of participants, and still would not categorize

our relationships in these terms. I do not maintain continual contact with the

participants who were difficult to make initial contact with. Outside of my scholarly

commitments, I actively volunteer in the disability community, sitting on boards of

disability organizations and volunteering with a national disability sports team, among

other activities. I hope this involvement can be interpreted as a form of giving back.

While it is important to respect and engage deeply with people who participate in research projects, and the points of established friendship proved particularly fruitful, I am not convinced progressive research should demand forming close relationships with all participants. This sometimes seems like the logical extension of discussions about the importance of rapport within anti-oppressive research. As Ellis (2007) points out "Who wants to spend time with someone who is out to use you for their own purposes? And how pleasant can it be to spend time with people who feel you are intruding into their lives?" (p. 7). At many points throughout the process it did feel as though I was intruding and in future projects, I would like to offer an honorarium to help mediate this and more formally acknowledge the contributions of the participants.

One complication with friendship in the research process is the tension between "trustworthiness and reciprocity" (Harrison, MacGibbon, & Morton, 2001). That is, meeting standards of credibility in the research community while honoring the participants, the latter arguably also requiring an element of trust. While these aims are not always mutually exclusive, there are moments that require discretion and ethical consideration. It is difficult to deal with contradictions and negative statements from friend-participants when the natural inclination is to protect the relationship by focusing on unproblematic elements. Further, there is a problem of never-ending consent that I particularly experience with Killian, as his trust in me in so great that he never declines if I ask to include something in the research (see also Bhattacharya, 2007).

Despite these problems, I know including Killian and other friends added greatly to this project. Garton and Copland (2010) suggest prior relationships require a complex negotiation of roles in an interview setting, and this process poses more difficulties for the interviewer than the participant, which feels accurate in this case. Yet, it provided an opportunity for some participants to take central roles and others to be less involved. While reflecting on my data collection experience, I am now unsure about who constitutes key informants. In this project, instead of official public figures with authoritative viewpoints, perhaps key informants are central participants who are deeply involved in the entire research process echoing a participatory action approach (Dick, 2009; Herr & Anderson, 2005). It is essential for these people to directly or indirectly indicate a high level of interest and availability in order to avoid unnecessary burden and ensure participation of other people who may not want such a level of involvement. An opportunity can be presented to these self-identified participants to become more involved that is not mandatory for the project to proceed. This relaxed approach allows for friendships to (sometimes) develop or be drawn on, degrees of participation and a reciprocal accountability that is not overly taxing on participants.

Role of the researcher: Where 'in' ends and 'out' begins

What about me? How do my identities interact with the research process? I am a former paid attendant, L'Arche assistant, team leader at a camp for people with disabilities, and current 'frien-tendant.' My husband has a physical disability, although we do not

currently use attendant services. I have a Master's degree in disability studies and read, write and teach about disability, gender and care. As previously mentioned, I am involved as a volunteer in the disability community. So am I in or am I out? An eloquent, in-depth film review boils down "worth seeing or not worth seeing" and, similarly, while academics write about degrees of insider/outsider status (Hesse-Biber, 2007), everyday experiences of research presents a simple yes or no question. I was regarded with ambivalence and even hostility from some research participants, even when I was open about my involvement with disability communities. As previously mentioned, at one frustrating point, Killian canvassed on my behalf in order to recruit participants using his insider status. Throughout the research process, I have been painfully aware of my outsider-label.

I can claim to live with disability, but I am not disabled. I say this not to avoid a stigmatized label or imply that disability is something different from me, but rather out of concern for co-opting a marginalized status and identity to which I do not feel entitled. Besides, this is too easy. Adopting a disabled identity would do nothing to challenge simple notions of insider/outsider (see also Davis, 1995).

I am openly 'out' about my varied roles and clearly 'in' this dissertation. I knew I had to engage with autoethnography to reflect my blurred position between in/out and the benefits and limits of identifying as an ally. In feminist disability studies, there is a preference towards writing from personal experiences of disability, or what Garland-Thomson (2002) terms "sitpoint epistemology" (see also Kimpson, 2005; Lindgren, 2004;

Linton, 1998; Mairs, 1996; Titchkosky, 2003). This draws on the tradition of feminist

standpoint epistemology (Collins, 2009; Naples, 2003a) or "situated knowledge" that

presumes "only partial perspective promises objective vision" (Haraway, 1988, p. 583).

This is distinctly different from writing from the role of an ally. In disability studies, it is

less common to endorse allied positions in research and theorizing, likely because of the

tendency to "speak for" disabled people who have been so often spoken for throughout

history. Price and Shildrick (2002) comment:

> It is as though there is a reluctance [in disability studies] to acknowledge that
> someone without evident disabilities could have anything useful to say, or at the
> most her role would be strictly subsidiary. (p. 64)

There is a profound "danger of romanticizing and/or appropriating the vision of the less

powerful while claiming to see from their positions" (Haraway, 1988, p. 584). Yet,

particularly for someone who sits on the precarious edge of insider/outsider and deeply

identifies as an ally, where and how I can speak? Is the act of

researching/observing/interpreting from an outsider position an inevitable form of

epistemic violence (Spivak, 1988)?

Some disability scholars who are also parents of people with disabilities present

compelling analyses from their positions as allies (Bérubé, 1998, 2010; Douglas, 2010b;

Hillyer, 1993b; Kittay, 1999, 2010; Ryan & Runswick-Cole, 2008). Feminist disability

studies makes room for ambivalence (Clare, 1999; Wendell, 1997) and third wave

feminism highlights the usefulness of contradiction (Renegar & Sowards, 2009). While it

is important to be cautious and sensitive to our essentialist tendencies and weary of

"speaking for another," we cannot shut down the conversation that emerges from the complex engagements with our shifting identities and relationships. Hillyer (1993b) concludes her chapter on mother-blaming: "The politics of disability are incomplete without our hearing also the stories of nondisabled people who nevertheless live with disability" (p. 107). That is to say, allies to people with disabilities, particularly close allies (e.g., family members, life partners, even long-term attendants) also have understandings of disability. These viewpoints are not the same as experiencing and identifying as disabled, but they still count. Further, as feminist ethics of care scholars have shown us, we are interdependent and live through relationships. Knowledge is created through these relationships (Lugones & Spelman, 1983) and perhaps there are relational-standpoints that exist and are created through qualitative research. Knowledge about disability, care and programs such as Direct Funding is created in interactions between attendants and self-managers. In this dissertation, the knowledge I present was (is) created through past and ongoing interactions with disabled people. The challenge, however, is how to capture this space while writing independently, a challenge I do not have a simple solution for.

Analysis and representation

What happens between qualitative data collection and the final written product is often veiled by what Doucet (2006) terms a mysterious "gossamer wall" between the researcher and readers. It is particularly difficult to explain qualitative data analysis

since much of it is intuitive and builds on the prior knowledge and insights of the researcher, despite claims in methods textbooks regarding "reliability" and "validity." My analysis of the interview material and documents can be considered a discourse analysis. According to Starks and Brown Trinidad (2007), discourse analysis "is concerned with language-in-use, that is, how individual accomplish personal, social, and political projects through language" (p. 1374). I attempt to interpret the messages about care and practical relevance of these messages through my interpretation of what was created between the participants and me during our interactions, and what is conveyed through the documents. This is why it is more challenging to analyze my interactions with Killian since they are not time-bound. In writing, I attempt to explain my thoughts and gesture towards other studies that may confirm or refute these interpretations.

For this project, I began by using NVivo, software designed for qualitative data analysis. These types of programs aid the researcher to break down and classify large amounts of information, almost beyond recognition. When using this program, I can lose sight of the context central to qualitative analysis. The program attempts to quantify the unquantifiable, and can easily cause the researcher to miss passing details, or complex examples that do not easily fit into categories. These passing details might not have general significance, but sweeping conclusions are not the point of qualitative research. Sometimes small, seemingly unrelated moments are the most revealing and interesting. On the other hand, the software does provide a starting point for the daunting process of sorting through large amounts of information. When I use NVivo to

review transcripts, I classify, break-up and compare information among participants. As I read through, I attempt to identify what we are discussing in a particular example in a transcript. Using the program, I then file the example into categories that I create such as 'family' or 'attendant relationships' where it will be joined by examples from other interviews later on, or not if it is unusual. I also use the search feature to find all occasions where certain phrases were used. This technique is useful when trying to gather information on a particular theme; for instance, I did so when preparing a paper for a conference on mothering by searching 'mother; mom; father; dad; parent; child; kid; family'.

As often as I use NVivo, I also turn it off and turn away from it. My analysis includes hand-written notes and diagrams, thinking of the big picture and trying to remember the small details. I read related and unrelated journal articles, news stories and books. I print out certain transcripts and documents for closer readings, making notes in the margins. Through these varied exercises I begin to make connections, for example, between an article, something Killian said just the other day, and something the most recent participant said. I jot them down to later evaluate for the usefulness and completeness. These connections spring up unexpectedly, while on the bus or doing the laundry. For example, the seed for the theoretical framework of accessible care not only grew out of reading for many years about care, but also through reflecting on the phone conversation with the participant who was upset with me for using the word 'care.' That conversation reminded me, despite recent academic literature suggesting

that "[t]he fundamental conceptual antagonism between care research and disability studies seems to have become diluted recently" (Kröger, 2009, p. 406) in Ontario it is still a highly loaded, and even offensive, word for some. I could not forge ahead with my use of the term, but had to reflect on it and change it to make it inclusive, or accessible, for people with disabilities, or else avoid using it all together. Once the connections are evaluated and some important themes and examples identified, I turn towards writing.

Representation

Putting the pen to paper, so to speak, is a daunting process. I had (have) deep fears about using the highly critical tools of academic accountability on (against?) the disability community, Killian and the other participants. It can be difficult to achieve a balance between these two aims, particularly when less-than-flattering insights emerge. I often think of Ellis' (2007) infamous return to the fishing communities she studied for many years, where the participants felt betrayed and offended by her work; she recounts: "When I returned to Fishneck, my friends there confronted me with the words I had written" (p. 11). On top of describing the participants, I must consider how to represent the people whom they represent in their narratives. This dilemma is what Michelle Fine and colleagues (2000) refer to as the "triple representational problem," that is, how to represent ourselves, the participants, and the "others"- the people left out of the study who are never-the-less evoked and represented by the participants, often in hurtful ways. In my case, this meant I could choose to present surface-level, but

constructive, critiques of the Direct Funding program (Spandler, 2004) or choose to engage with some of the more troubling elements such as the exclusion of people with intellectual disabilities and often hurtful comments about these people and their allies.

Fine and colleagues (2000), who identify the triple representational problem, also suggest possible techniques for addressing it. For one, they urge researchers to "refrain from the naïve belief that these voices should stand on their own or that voices should (or do) survive without theorizing" (pp. 119-20). It is important to include the potentially hurtful elements of analysis, but pull them away from individuals. These comments must be situated in a broader context that does not blame specific participants. This extends to contradictions and errors in information, as it is not my role or the purpose of qualitative interviews to "catch" participants making mistakes (Portelli, 1991). Secondly, researchers must also avoid imagining meanings that were not intended, for example "repoliticizing perspectives narrated by people who have tried hard to represent themselves as nonpolitical" (Fine et al., 2000, p. 218). This was applicable when I asked participants about their relationship to the Independent Living movement. Quite a few participants saw Direct Funding as just another means to the end of attendant services, albeit a much better means than other options, and had no opinion on Independent Living as a movement.

Some scholars suggest the strategy of "respondent validation" or "member checking" at this phase, or earlier phases, to help address some of the issues of representation (Hesse-Biber, 2007; Maxwell, 2005). I did so in during my master's

research and found the process to be time-consuming and the vast majority of

participants uninterested in making further contributions of time. In my master's

research, the few who did review the transcripts were key informants, and seemed to

want to protect the "official line." In the present study I decided not to member-check. I

did, however, make sure to include space for the "official line" of the key informants

and disability organizations and will be offering a finalized version of the dissertation to

all participants. Further, discourse analysis is concerned with "language-in-use," and

qualitative interviews provide a conversational snapshot (Starks & Brown Trinidad,

2007).

It is important to be cognizant and careful when writing and analyzing words that

come from another's standpoint, particularly when those words emerge at the urging of

and in relationship with the researcher. The participants, however, cannot do this

delicate work for the researcher. Nor is the answer to promote "insider" research; a

sense of a shared identity may initially open doors, but it is highly fluid and "can change

even in the course of a single interview" (Hesse-Biber, 2007, p. 143).

Closing thoughts

Qualitative research can be a nerve-wracking, all-encompassing process requiring

vigilant awareness of power on the part of the researcher and constant evaluation of

methods and assumptions. Self-reflexivity and autoethnography help to make this

process transparent and accountable while still maintaining a sense of interdependency.

I hope what I present in the next three chapters is a balanced, honest representation and analysis of what the participants said and the documents convey, and the implications of these messages.

Chapter Four

"In my mind that's not what care is": Care is not what happens here

Despite, or perhaps because of, frequent use in colloquial discourse, the meaning of 'care' is ambiguous, contested and shifting. Many academics attempt to pin down the fluidity of care in order to explore it with more accuracy, as discussed in Chapter Two. The slipperiness of care is also reflected in this study in comments from the interviews and related documents. When asked if he sees himself as providing care while working as an attendant under Direct Funding, Adam states: "With [the self-manager] it's more like I'm just helping him out. In my mind that's not what care is. Of course it is, but it's probably my own personal ideas about what that word means." The distancing from care does not seem to be only Adam's "personal ideas" as for additional participants in this study, it is easier to describe what care is *not* than what it is.

In the following two chapters, I address the initial aim of this study, that is, to sketch contemporary forms of care through exploring the Ontario Direct Funding program. Generally, care is not what happens 'here' within the Direct Funding program or attendant services more broadly, a sentiment summarized by Adam's statement. There is also a conflicted and convoluted sense of what care *is*. According to the participants, care has multiple elements, some of which are consistently condemned while others must happen and may even be appropriate in attendant services. The

inclusions of care surrounding the Direct Funding program will be explored in the subsequent chapter.

This chapter 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.' Garland-Thomson (1997) and other disability theorists demonstrate that disability becomes a reference point for defining 'normal,' and similarly, establishing what is 'not care' will allude to what remains of it.

Through accounts of daily interactions, it is clear that attendants play multiple roles; however, there are two dominant descriptions that emerge: attendants as 'arms and legs' and attendants as relationship workers. The 'arms and legs' role refers to the tangible tasks of attendant work, done under the direction of the self-manager. I explore the implications of being directed, varying levels of responsibility and the idea of automation. The second role, relational work between self-managers and attendants, remains 'not care,' in spite of the emotional and interpersonal elements of the descriptions. Relational work is freely spoken about, difficult to describe and negotiate, mandatory, and can also become inappropriate. I argue the relational work is skilled yet distinct in some ways from the concept of emotional labour. I then explore a specific technique of this work; the more experienced attendants develop a chameleon

personality while self-managers also report leaving room for attendants to exercise agency. These strategies are quite similar, resulting in a blurring of actions and identities that create relational epistemologies and ontologies between attendants and self-managers. While in some ways these two dominant descriptions reflects the feminist distinction between caring for/about (Finch & Groves, 1983; Grant et al., 2004), it is significant that many participants and documentation insist this is not care.

Before presenting themes from the interviews, I return to the first and second bridges of accessible care. The latter is the bridge between feminist perspectives on care and disability perspectives. This bridge compels us to see multiple points of views, and to understand how one individual may embody these sometimes conflicting perspectives. In this study, this bridge is reflected in the scholarly inclusions of feminist and disability literatures and more tangibly in the inclusion of recipients, providers and a few informal supports as participants. Further, there are limited attendant themes or self-manager themes in this study, as I try to interpret comments together, alongside and occasionally against each other. Including varied scholarly and participant voices helps present a fuller picture of Direct Funding. Inclusions of multiple perspectives grasp onto the disability studies' notion that we are all "temporarily-able-bodied" (e.g., Davis, 2002a) and onto the idea that disability is a pervasive cultural category (Garland-Thomson, 2002), implying anyone can potentially contribute to discussions related to disability. Yet, including diverse voices also respects the feminist notion of standpoint epistemologies that suggest that individuals occupy unique social locations with a

distinct outlook on the world (e.g., Collins, 2009; Naples, 2003a, 2003b; or "sitpoint

epistemology" as reclaimed by Garland-Thomson, 2002). The focus on narratives and

interactions stems from the first bridge of accessible care, that is, the use of daily

experiences to explore theoretical questions. I now turn to the material that

demonstrates that care is not what happens under Direct Funding.

Care: A "bad four-letter word"

For many, care remains somewhat of a "bad word, bad four-letter word" as Frank, a

self-manager notes. As expected from surrounding academic literature discussed in

Chapter Two, some of the self-managers, attendants and many of the key informants

made clear attempts to distance attendant services from care. To be precise, 21 of the

54 participants cared about using the word 'care,' particularly the key informants

(13/19); another 21 participants claimed 'not to care' but expressed elements of the IL

critiques in their interviews (i.e., they may not care about the word itself, but they are

concerned about the ideas behind it). As such, 42 of the 54 participants had some

concerns with the concept of care, with varying degrees of urgency. Of the 12

participants who seemed unaware and unconcerned about the tensions around care, it

is notable that 5 were informal supports, and thus a 'step away' from the Direct Funding

program.

Tracy Odell, community advocate and self-manager, describes how Independent Living and care are "diametrically opposed" and infers the concept of care is irredeemable:

> TO: I see them as diametrically opposed. So I think that [academic care researchers] don't really understand what Independent Living is all about if they need to bring the word 'care' into it.

> CK: But some talk about changing the meaning, though, they don't talk about bringing what we think of as 'care,' but sort of reclaiming care is the idea.

> TO: Yeah... no. That doesn't work for me. There's just too much toothpaste out of the tube on that one.

> CK: Too much baggage?

> TO: Yeah exactly, too much baggage. Too many associations with the word 'care' to be able to redefine it. It's like "let's redefine what red means." Like, everyone knows what red is, as a colour. Red is red. But you're not going to say that "red is the new purple." You're going to spend so much time explaining what you mean and don't mean by 'care.'

Odell's position implies that it is easy to define care, red is red and care is care, and that it is simply not what is happening in Independent Living models of support. Care, for Odell, and in the previous quotation from Adam, encompasses too much to describe attendant services, which only includes help with daily needs, and nothing more.

It was easier for interviewees to describe care as happening *somewhere else* than to describe what is actually different about personal assistance. Mathieu, an attendant with many years of experience, describes the other settings he works in:

> Mathieu: Uh well, well, I have a few evening shifts and day shifts at [a shared-attendant arrangement], and then I have a, a private client who I take care of. Well in, well, I say 'take care' because it feels more like I'm doing at-home nursing for him.

CK: It, it doesn't feel like attendant care, is that what you mean? Or?

Mathieu: Well, yeah. Well, it's because he's sort of a, um. He uh, he has a
            spinal cord injury and is very much into sort of staying in bed
            and...cause it feels more like you're kind of nursing him.

As we see further in the next chapter, for Mathieu care is done by professionals, often

for sick people, and is not what attendants do under Direct Funding.

Harry Pott, a parent-advocate, confirms the connection to illness in his

description of care:

> If you need care all the time, people that are sick and dying may need care. And
> if you get really sick and have to go to the hospital you need care. But you don't
> need care day to day. [...] It's the things we do to give [my son] a [pause]
> meaningful day! To give him a normal, I hate to use the word 'normal,' but you
> know, to give him a day like the days that all of us have, and whatever it takes to
> do that I think we owe that to him. And that's different than 'care' because care
> assumes a [pause] debilitating thing. If I break both my legs I need care because
> there are certain things I probably won't be able to do without assistance
> because I've injured myself.

Pott's adult son has an intellectual disability and is therefore ineligible for the Ontario

Direct Funding program, distancing these comments from the Independent Living

framework, and suggesting other disability advocates do not want to claim care either.

Pott's definition implies care is not enough to provide an adequate life for his son. For

Pott, 'care' is physical, hands-on support, although perhaps acute support rather than

ongoing. Ironically, physical, hands-on support is an eligibility requirement for the

Ontario Direct Funding program and positioned as 'not care' in the definition of

attendant services posted on the Centre for Independent Living in Toronto's (CILT)

website:

Attendant Services are consumer-directed physical assistance with routine activities of daily living which the person with a disability would do him/herself were it not for physical limitations. This assistance is provided by another person, an attendant. The consumer takes responsibility for the decisions and training involved in his/her own assistance.

Attendant Services do **NOT** include: professional services such as nursing care, physiotherapy, occupational therapy or physician services; respite care; supervision; "care" or taking responsibility for the person with a disability. (CILT, 2000, emphasis in original).

Notably, this definition does not include any indication of the interpersonal relational work involved in attendant services, which I found to be a mandatory job requirement. Pott's idea that care is physical assistance (albeit after an injury) starkly contrasts the IL definition that uses similar parameters to describe what care is *not*. Even though the sense of what care *is* varies in these examples, it is consistently expressed that care is not what happens here. Care is too much, and not enough, to describe the supports needed for people with disabilities. Care is for 'them', over there, and this is even expressed by people who are implicitly and at times explicitly excluded by program eligibility requirements.

'Arms and legs': Attendants as assistive devices

No one seems to want to be cared for, or to claim care, particularly those associated with Direct Funding. If it is not care, then what is happening in Direct Funding arrangements? There is a lack of language as demonstrated both in stammering descriptions and explicit statements; Sandra Carpenter, self-manager and current Executive Director at CILT demonstrates the latter:

[Attendant services are] totally, completely misunderstood. The only groups that really understand it, there's exceptions of course, are people with disabilities who use attendant services, or people who are working as an attendant. Those are the two, but I can't tell you the number of times that my attendants have said to me that they've tried to explain to their friends what they do for a living and their friends invariably don't understand.

The ambiguity of what attendant services are, aside from 'not care', is also reflected in the tension between two of the most dominant descriptions of attendant work emerging from the data: one, in which attendants are characterized as the 'arms and legs' of the self-managers, and two, in which attendant work is described as a complex, interpersonal relationship. The descriptions are fluid and often come up in the same interview, and I am not suggesting that certain self-managers have an 'arms and legs' approach to their attendants while others have an interpersonal approach.

In the first case, the idea of 'arms and legs' draws on descriptions of attendant services that can be found directly in material produced by Independent Living organizations (e.g., CILT, 2000; 2008; Parker et al., 2000). For example, in CILT's publication *Power Shift* the authors note, "To understand the importance of attendants to us, think of them as our 'arms and legs'" (Parker et al., 2000, p. 1). As 'arms and legs,' attendants become extensions of the self-managers' bodies, present to pick up where the body leaves off under the direction of the self-manager, as explained in the earlier definition from CILT's webpage. The focus is on the tasks of attendant services, but in contrast to feminist notions of 'caring for,' this focus includes clear and firm parameters about who is responsible for determining how and when these tasks are completed (i.e.,

the self-manager). Self-managers are presumed to be consenting adults with physical

needs, capable of self-directing their 'arms and legs.'

The sense that attendants are 'arms and legs' is reflected by a number of the

participants, perhaps suggesting a thorough endorsement of the approach. Rob, an

attendant, describes,

> So, you know, you can almost reduce it down, you know I don't want to reduce it
> too much, but you can reduce it down to like if I'm a little taller than you are and
> we're both in the kitchen and you want the rice off the top shelf, I'll just hand it
> to you.

Similarly, Mike Murphy, Executive Director of Independent Living Centre Kingston

explains:

> I think the relationship, regardless of whether it's Direct Funding or Attendant
> Outreach, if you've got someone coming into your home to provide attendant
> services, they should just be an extension of your arms and legs, it should be
> your home and your environment and you should be able to maintain control
> and dignity.

The attendants are not represented as 'hearts' or even 'heads,' which might convey a

sense of charity, or in the latter case, professional expertise, and in both cases, arguably

more of a sense of care. Attendants are specifically 'arms and legs', disembodied,

genderless, non-selves present to provide tangible assistance with specific tasks and not

to offer advice, empathy, or exercise control over the self-manager's life. In many ways,

attendants are assistive devices, like a prosthetic limb, wheelchair, or Hoyer lift,

operated by directions of the self-manager. The 'arms and legs' representation contrasts

the layered interpersonal descriptions to be explored shortly, descriptions that

demonstrate that not only are the whole, embodied selves of attendants required for

attendant work, but in fact uniquely combined selves are developed through relational

ontologies.

Direction, responsibility and automation

As 'arms and legs,' a substantial aspect of attendant work is following the directions of

the self-managers. The attendants do not resent following directions, contrary to what I

expected. The attendants do not want to make personal, minute decisions or assume

liability for someone else, and, of course, the self-managers largely agree. For example,

Carolyn explains her work history as an attendant:

> Yes I worked in two different nursing homes. Yeah, and it was always different people and I did not like that. [...] You know without looking at a chart, you don't know if they can eat by themselves or if they can chew or swallow or. I don't know, just weird. [...]. Again I didn't like, I didn't like um not knowing what they wanted or needed like 'cause they weren't able to tell me.

Carolyn likes that the self-managers can tell her what they want and need because she

will not have to make assumptions, or claim responsibility for erroneous assumptions.

Similarly Melissa, another attendant, explains,

> Well, the whole thing with like a mental disability is like a lot of them can't tell you what they need, right? Whereas, with just like a physical disability, they can tell you what they need, so it's more, it's more of a direction, right, for Direct Funding. Like they tell you what you need to do.

There is no guessing involved when the self-manager can articulate his or her needs to

the attendant. A third example from attendant Margot:

> The boy I worked with, he was about 12 and it was more challenging because I was more in control, right? I was supposed to be kinda telling him what to do as opposed to being told what to do, right?

Margot does not have to 'tell' a self-manager what to do, or figure out what he or she

needs. In some ways, attendants appreciate being 'arms and legs' when it comes to

tasks and not feeling responsible for decisions that are made while working.

The 'arms and legs' characterization of attendant work in combination with the

home setting creates a low-stress work environment and the recurring sense that it is

'not like work,' perhaps explaining why there are limited demands from attendants to

improve the material working conditions. Themes about work and working conditions

are expanded in Chapter Six. Responsibility is layered for attendants as outside the

home/work environment there is a heightened sense of obligation that goes beyond

other types of work. Attendants are aware of how important their work is, and self-

managers stress this urgency. For example, not showing up for a shift is a common

reason for a self-manager to fire an attendant:

> CK: Have you ever had to fire someone?
>
> Greg: Uh...in 12 years I think we've fired two people. And that was for not, not showing up.
>
> CK: They just didn't show up at all? Did you fire them right away or did they have a warning, or how do you normally do that?
>
> Greg: I think they had one warning. We put, we put up with a lot. But if you, if you don't show up, then that, we take that seriously.

The attendants reflect this urgency. An attendant, Margot, explains:

> ... Actually that would probably be the one complaint about the job that I do have. Is that it's very difficult if I get sick. Like I have had to work through a lot of shifts when I was really sick because you can't get people to come just at the last minute. Like no matter what, [self-managers] need someone there right?

Because otherwise they can't get up, they can't eat, they can't go to the washroom, you know? They need someone there. So I all of a sudden get sick an hour before my shift then chances are I'm not gonna get anyone to cover it, right? So I have to go in anyways.

Feeling obligated to go to work in spite of other factors was common. Hailey, an attendant, concurs:

Hailey: Like if you're scheduled, you have to go and there's no one else. So, I think like one time there was like a ridiculous snow storm and it was my shift. And there [slight laugh] there was like, there was, I had to walk for like two hours in like snow up to my waist to get to [the self-manager].

CK: [slight laugh] Wow.

Hailey: And like I had to do it, right? I mean you can't, I couldn't, you can't leave him.

This sense of urgency and responsibility stressed by the self-managers and reflected by the attendants is compounded by the sometimes-rewarding, complex relationships that they form together that reinforce feelings of obligation, which will be discussed further in Chapter Six. However, within the home, the attendants' sense of urgency and responsibility relaxes. An attendant, Sheila, describes:

I do their care quite often and I think that we just like work together and it's like...I don't know I just find it so, it goes so smoothly and so effortlessly. And we just know, or like I guess we both know exactly what we need to do. And I don't know, I guess once you work with someone for quite a long time, you get to that point where it's like you just know what that person needs or know what that person wants and I kind of like that a lot.

That is, attendants do not need to be directed step-by-step in every action they complete but rather it becomes *automatic*. The self-manager's direction is 'working'

when attendants do tasks without request in a manner that is suitable, and likely slightly

(or substantially) variable by attendant. Another self-manager describes:

> ...she's been assisting me for so long now that in the mornings it's a very, it's sort of like, it's like a machine almost. It's like you know, bang, bang, bang, you know. Or doing this, and I'm doing that, and I'm doing this, and she's maybe doing some meal prep, or something like that. Or, or, or...you know it's very, it functions very smoothly and stuff like that.

Automation in this circumstance does not mean thought-less and care-less actions, but

it means a comfortable, and paradoxically, mutually-respectful subservience to the self-

manager, perhaps as one might have with a supervisor in a more traditional work

environment.

While their actions may become automatic, attendants are not only assistive

devices. Curiously, even while describing attendant work with automated 'arms and

legs' terms, attendants, such as Carolyn, can be offended at reducing their work to mere

technical actions:

> [My friend] introduced me to her friend and he's like "Oh, you know, what do you do for a living?" and my friend was kind of like "Oh, she showers people and wipes bums and things". [...] It's just funny because the misconception. [...]. You know they don't realize like you know what, this person, this person is independent. This person goes to work. This person...they don't see all of that and the relationship that you have.

Attendants do in fact "shower people" and "wipe bums" but they see this work as

having broader significance, partially stemming from the relationships and also from the

Independent Living emphasis on following self-managers' instructions. Robots are, in

fact, used in some places for home care purposes and found lacking because of the

missing relational components (Folbre, 2006; Parks, 2010). Attendants are not actually

assistive devices, and there are many features of attendant work that cannot be

automated, namely the mandatory relational work.

Mandatory relational labour, optional friendships

The automated 'arms and legs' descriptions do not last long in discussions of attendant

services, but many use it as a reference point to distinguish personal assistance from

other forms of care. In practice, the 'arms and legs' sense of Direct Funding has more to

do with responsibility around decision-making in daily interactions than around the

actions performed or the value placed on the attendant. Attendants, self-managers and

key informants did not want to talk much about 'arms and legs' tasks. It is difficult to

discern whether it was my questions, privacy, or the interests of the participants, but

generally a substantial portion of the interviews focused on relationships. Frank

Wagner, often cited as an ally working within the Ontario government during the

establishment of the Direct Funding program, summarizes the transition from 'arms and

legs' to more relational descriptions:

> It's based on the original concept, which has been reworked now, that it's an
> extension of 'arms and legs' for a person. Then you, by virtue of the fact that
> you're that person, they become your 'arms and legs'. That's been modified of
> course. It's been modified in part in relation to relational care because you can
> only do that so much. If there's an individual, a human being and you've got to
> treat them that way, or all you're going to get is 'arms and legs'.

However, it is the combination of accepting the 'arms and legs' role and the relational

work that is important. Julie, a self-manager, stresses that attendant-work is not *only*

about relationships and does require some technical skill:

Julie:	And I remember my first ever attendant, they, they somehow got this crazy idea in their head, the attendants, and the people who sent the attendants that I needed a friend. So they sent someone with no attendant skills at all. And the first time she tried to use my ceiling lift I fell out the side of the sling.
CK:	Nice friend, geez!
Julie:	So I said, after a couple months of that, I sat down with everyone, and I said, "I can make my own friends thank you. I need someone to do attendant care."

Julie does not need to hire friends; she needs attendants to be her 'arms and legs' first and foremost, and a friendship may or may not develop during the course of their interactions.

Marilyn Dolmage, a parent-advocate of a son with physical and intellectual disabilities (unfortunately, he had recently passed away at the time of the interview), eloquently describes the aspects of support that go beyond 'arms and legs':

> The week that Matthew died was his sister's birthday [...] on her actual birthday we met her downtown for lunch. [...the whole family and the attendant] all met in a restaurant. [...The attendant] has a picture from that lunch and I believe it's the one where she's pulling the dirty dishes out of the photograph, so it's to make it a nice picture of Matthew and his sister at her birthday without it looking like he needed care, which is the ultimate, I think, in supporting somebody. To make that look seamless. To make that look like this is Matthew, this is his life. My job is to clean up the dirty dishes if that makes the picture better. Whatever it takes. So calling it 'care' is too narrow. It's whatever support it takes. And introducing him to the world as a person who's more than about needing care. About the contributions he could make.

Care is not enough, it is "too narrow." There is a sense that support encompasses, but is more than automatically "clean[ing] up the dirty dishes." It is not easy to describe precisely and succinctly what the 'more' is that "makes the picture better," but Dolmage

alludes to relational work that is not considered care. It is noteworthy that Dolmage

articulated this point of view as her son would not have been eligible for Direct Funding,

further indicating it is not solely an Independent Living rejection of care.

The intricate, relational side of personal support is a necessary component of

attendant work, and is the space where the figure of the frien-tendant, to whom I can

relate, *sometimes* emerges. Not fully employee, nor friend, nor family member, nor

stranger, the frien-tendant is certainly ambiguous. Extremely intimate, yet also

professional, it is difficult to describe these relationships as articulated by one self-

manager:

> CK: ....would you say you become friends with your other attendants?
>
> Jason: Oh yeah definitely. Definitely, more than friends. Uh, and friends isn't the right word. I, you know, the correlation I have to make, and this is probably a terrible, terrible correlation and you know if I made it in front of the people who run Self-Directed Funding, they'd probably freak out and might revoke all my funding but I really, I really relate it, it's a lot like dating. It really is. It's, it's, deeper than friendship. It's not quite dating, you know I'm not gonna take them out on the anniversary or our first, our first shift or anything like that. But, um, you know there is a very, very deep connection that forms, on both sides.

Comparing attendant relationships to "not-quite" dating implies a deep and ineffable

intimacy. In a poem to her personal assistants, author Connie Panzarino (1996) reflects

Jason's characterization by asking "Not-a-lover-not-a-friend, but who?" Jason, among

others, recounted some difficulties that can arise when hiring pre-established friends or

when attendants get 'too close.' That is, while highly intimate relationships form, there

is a limit to their value.

The relational side of attendant services is not optional as all attendants and self-managers described this aspect of work. One attendant, Rob, describes a "professional sort of closeness" likening the relationship to being "cousins," while another attendant, Adam, explains "It's such intimate care that it's really impossible to keep that [employee/employer] line." This work is complicated when children, partners or spouses of self-managers, and other family members are present or involved in attendant interactions, and even more so when such people also require support from the attendant as appeared in a few interviews. This is also the space where gender, age, racialization, and other demarcations of social location resume relevance. For example, all of the female self-managers in this study expressed some degree of discomfort with the idea of male attendants assisting them, particularly with intimate needs. The ineffable attendant relationship becomes too difficult to negotiate when the power dynamics shift in one direction, often embodied in personal identities. Compounding power differentials between disabled/non-disabled with gender, sexuality, etc. in ways that make the self-manager more vulnerable in combination with intimate 'arms and legs' tasks further complicates already-complicated relational work to a point where many choose to avoid hiring certain people. With the heightened vulnerability implied by estimated power imbalances ('estimated' as such factors can never be measured) comes an increased risk, or perception of risk, of abuse, as will be explored in the next chapter.

The mandatory relational component of attendant services does not necessarily

mean friendship, and resides in the hyphen between friend and attendant. That is, while there is always relational negotiation required (on the part of *both* attendants and self-managers), this does not always translate into close friendships. Two extreme examples from self-managers demonstrate this variance. When reminiscing about some enjoyable times with attendants, Ryan, a self-manager, states: "So, so, Direct Funding can be a great place to develop friendships. Like a fantastic place to make, to make friends."

While another long-term self-manager, Marc, facetiously takes an opposing view:

> I've got a rule that we don't necessarily get on friendly basis. Um, it's fine if one day we go for a beer, but you're not going to become my best buddy and you're not gonna....we're not gonna have sleepovers [slight laugh], we're not gonna watch TV until the wee hours of the morning [slight laugh].

Both of these self-managers talk about how their attendants share a lot of personal information through conversations and many self-managers report being 'sensitive' to the attendants' moods, and vice versa, during the course of Direct Funding interactions. Again, this relational work is seen as 'not care.' It is also not empathy as when asked if attendants ever required personal support or thought about what it would be like, most did not have much to say or seemed to avoid thinking about such possibilities.

As Julie explained, while relationships are an important part of attendant work, they are not the only aspect and, in fact, there is a limit to their value. Participants talked about when boundaries become too blurred and when friendships go 'too far.' The limit to the relational side of attendant services emphasizes the sense of *work* that requires monitoring and thoughtfulness particularly on behalf of the self-manager. For example, one self-manager explains why she had to let a long-term attendant go:

Hélène:	Because when you have one for more than five years, they...they become more...your friend and you don't want a friend to be doing it all the time, you want someone who understands you but not someone who tells you what to do.
CK:	And that can become blurry when you're too close?
Hélène:	Exactly. Exactly. So it's, that's how I see it. After five years, might as well, I just try to look for somebody. Not because that person's not good...

In a way, this self-manager is describing a time when the attendant is no longer adhering to the 'arms and legs' role, but too strongly asserts control and provides an unwelcome form of care. Mathieu, an attendant, echoes this sentiment, explaining the concrete implications of being 'too close',

> Because you pal around and joke around with that person [....] There'll be effort involved, but the work kind of starts to take a hit. And you don't think that you should have to do all that much for that person because you know who, come-on they're your buddy! Why are you asking to get up and go do this, get up and go do that?

Elsa, another attendant, describes the emotional toll of being too close: "I wouldn't say we're, we're 'friends *friends*', um because I think at the beginning I got a little bit too involved and I found that that was draining me." The relationships cannot be described in terms of light, easy friendship but require ongoing negotiation that can sometimes veer into uncomfortable territories.

Relational work and emotional labour

While rewarding at times, relational negotiations are still a form of *work* requiring effort and commitment on behalf of both parties. Sara expresses the sense of being 'on' all the

time when the attendants are in her home:

> But then on their days off sometimes, I come home and I'm like, phew! [laugh] I don't have to be cheerful! [...] Someone said to me, actually [another self-manager] said to me, you know that he was 'on' all the time. And, and I didn't really think about it 'till he said that. But especially for someone in his position where from the moment he wakes up to the moment he goes to bed, there's someone around. You know I could really see that. And there is, there is a lesser um, there is that same feeling for me from a lesser degree.

In this quotation, Sara reflects the sense of managing one's emotions as described through the concept of emotional labour originally articulated in Hochschild's (1983) study on flight attendants and in more recent developments of the concept (Steinberg & Figart, 1999; Wharton, 2009). In brief, emotional labour refers to the process whereby workers "induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind in others" (Hochschild, 1983, p. 7). Yet there is something distinctive going on; note that it is the *self-manager* who is doing the emotional management and is not being paid to do it. In attendant services, the product is not a 'state of mind' as it is for many people working in service industries. Further, Twigg (2000) found in her study on community care and bathing, unlike the flight attendants in Hochschild's study, the attendants and some self-managers often describe relational aspects as *rewarding* and not as a taxing part of their work (see also Korczynksi, 2009). In Wharton's (2009) review of the concept of emotional labour within sociology, she notes: "Research on caring occupations, such as nursing or midwifery, shows how change in the structure, practice and professional norms guiding these fields have the potential to increase or diminish workers' positive experience of caregiving" (p.

154). This is certainly the case with the Ontario Direct Funding program, and one might argue that the potential "burden" of emotional management is diminished in the unregulated home environment of Direct Funding, where the expectations around affect are fluid or negotiated between the recipient and care worker more so than in other, more formalized care arrangements (Lopez, 2006).

While not denying the importance of the concept of emotional labour, Payne (2009) expresses concern over the tendency to frame it as a complex skill, pointing towards individuals working in fast food and retail industries. He argues that emotional labour is not necessarily 'complex' particularly when it draws on common socialization and a "basic requirement for politeness" in service work (p. 357). Payne does make distinctions between "the ability to empathize" as a care worker and common manners required by other service workers, but suggests this ability is better framed as an aspect of a person's moral and ethical self (p. 357). I agree with aspects of Payne's critique, particularly around the level of 'skill' in emotional labour used in certain service jobs and the need to differentiate levels of skill in varied forms of emotional work; however, I argue the relational work required in attendant services and other long-term care (by both recipients and providers) is, in fact, *skilled*, and should not be framed as a moral imperative. For one, it is complex in that it does not draw on common socialization; it is uncommon to have/be a semi-stranger involved in the intimate details of another person's life or to help someone/be assisted as an adult during highly personal tasks

such as bathing or toileting. No common socialization processes prepare us to carry on a 'polite' conversation during these times.

In this study, self-managers talk about helping attendants become accustomed to these interactions while attendants often report (and laugh about) awkward stories of their first time helping someone in the shower, or toileting. For example, attendant Carolyn describes:

> I mean at first, at first like, you're like showering a man and you think it's super-strange 'cause I'm just some girl off the street and I never even did nursing and I'm showering a man. But then [laugh], but then you develop a relationship and it's like, well, I don't really care who I'm showering. It's the same people that I'm always with and it doesn't bother me at all.

The awkwardness dissipates over time as attendants learn the skills of relational work, under the guidance of the self-managers, including attempting to address the power imbalances in their interactions. Furthermore, framing care work as a moral imperative undermines the hard won rights of disability movements, placing attendant services back into the realm of charity. Attendant Carolyn further infers an aspect of the skilled relational work involved in attendant services:

> Like a lot of times, staff don't really know how to deal with that and if they're in a bad mood 'cause of something happened at home. They come in and they're grouchy and they're, you know, trying to hurry up and trying to, and the client feels awkward. Um, I'm a straight up person. I walk in, I say, "Me and my boyfriend are having a fight. I'm in a terrible mood and it's nothing you did and I'm gonna try my best to be happy, we're gonna do this call anyway and it's nothing you did." You know? And so yeah, I'm, I always think it's best to name the problem, so that they know it's not them. 'Cause a lot of people take things as it's their fault.

Carolyn must anticipate the self-managers' reactions while also evaluating and trying to

control her emotions. The self-manager on the other end of this interaction may be

sensitive to the attendants' moods, and must also determine how to respond to this

'straight up' announcement while being assisted with daily tasks. This is 'skilled work'

because the relational negotiation must take place during highly intimate interactions.

While the relational work is skilled, it may not necessarily be emotional labour,

since it is not only about managing one's individual emotions, but also about managing

an ongoing relationship. Furthermore, the emotional management aspects of the job do

not seem to include the 'surface' and 'deep' acting aspects of emotional labour

(Grandey, 2003; Hochschild, 1983). There is a sense of genuineness under Direct

Funding that is lacking in other work environments requiring emotional labour. For

example, for a young attendant named Katharine, the difference between working as an

attendant and working in retail is that "[In retail jobs] you smile and nod," while self-

manager Marc notes "Like people that I have a better rapport whatever, then they end

up respecting me and they kind of end up seeing, you know, that this is for real and

we're not just flipping burgers here." Attendants feel more 'themselves' in some ways

when interacting with a self-manager than they do/would working in other jobs,

reflecting the sense that doing care work is often regarded as part of one's identity

(Christensen, 2010; Cushing & Lewis, 2002; Macdonald & Merrill, 2009). Feeling genuine

takes out the acting implied by emotional labour, but not the skill, particularly during

the most intimate interactions where attendants and self-managers must learn and hone the skill of relational work.

Attendant work is too informal, relational and personal to be framed by emotional labour. Hailey, another attendant, describes a conflict between the self-manager and herself:

Hailey:	I don't remember, but I remember telling him to go fuck himself.
CK:	You telling him?
Hailey:	Yes. And him spitting water at me.
CK:	Like would that... not, not, being funny, like really mad at each other?
Hailey:	Yes. [slight laugh] And we still go on trips together. I don't remember what it was about and I was so mad at him for something. And then like with him, [another self-manager] will drink from the straw no matter what, but [this self-manager] will try to drink from a glass at times 'cause it's easier. And I couldn't get it and I kept spilling water on him. And it's totally by accident. So he got mad at me and he took the water that was in his mouth and he spit it at me. And he's like, "How does it feel?" But it was like, but the difference is I'm not *trying* to get you wet.
[...]	
CK:	What's a deal-breaker for you? ...Would you ever quit? [The self-manager] spitting water at you is...I mean that's abusive in a way. I know we were laughing about it.
Hailey:	But it was like, I don't know. It was more entertaining than anything because I was seriously, you just did that? [slight laugh]
CK:	You have a good attitude. I would have been like "I can't believe you!" I would have freaked out [slight laugh].

| Hailey: | Yeah. But I remember after I swore, because I was so mad at him. It was like "fuck this" [slight laugh]. He was like "let's talk about this." And he totally diffused the situation...I don't remember what it was now, but I remember being so mad at him, I swore. And I swear, but I won't often swear at people [slight laugh]. |

This unusual type of conflict sounds like a personal argument with a family-member,

life-partner, or perhaps close friend more than a work-related dispute, and particularly

the fashion in which it was diffused. Being permitted to lash out (on both parts, the self-

manager's initial over-reaction to the spilled water and the attendant's response)

without it marking a termination further indicates that the relational work required in

attendant services cannot be considered emotional labour. Attendants are not required

to simply 'smile and nod' in spite of inappropriate actions of the self-managers, or vice

versa, as the flight attendants are in Hochschild's original study. There is more room for

people to 'be themselves' and employ what attendants and self-managers regard as

genuine styles of interpersonal relating within Direct Funding arrangements as opposed

to other service-oriented jobs where workers must pretend to care and sometimes

follow pre-set social scripts. This allowance may be directly linked to the home

environment where most attendant work takes place. In emotional labour terms,

attendants *and* self-mangers (who are also 'working' during attendant interactions) do

not have to engage in "surface acting" and perhaps not even "deep acting" as their

countenance may reflect how they truly feel at any given minute. At the same time,

they must constantly interact in private spaces and moments, developing an uncommon

skill set. It is about managing not only emotional reactions, but a joint relationship as well.

Direct Funding interactions are a combination of mandatory, skilled, relational negotiation and accepting the role of 'arms and legs' or an assistive device. Care does not encompass enough to describe the complexity of the two-way relational work, and yet it encompasses too much to describe the tasks. Philosophically these two descriptions simultaneously reinforce and break down distinctions between the autonomous self and interdependently intertwined selves. Disembodied arms fill-in the gaps of bodies with disabilities, correcting what Garland-Thomson (2011) terms 'misfits' and maintaining a semblance of the myth of autonomy. But attendants are not body parts; the physicality, intimacy and isolation of attendant work under Direct Funding demands and creates new ways of relating and interpreting the boundaries of the self, as we will further see.

Chameleon attendants and responsive self-managers

The tension between the 'arms and legs' descriptions of attendant services that abound in Independent Living perspectives and the mandatory, complex relational work in which no assistive device could be directed is not entirely unexpected as suggested by a few other studies and my own observations prior to this study (e.g., Earle, 1999; Gibson et al., 2009; Hughes et al., 2005). Attendants and self-managers manage this ambiguity through the development of relational strategies. For attendants, particularly those who

do attendant work with more than one person, this means adopting a chameleon-like

personality. Mathieu describes the work required to relate with a variety of people:

Mathieu: ... I'm not like, not a chameleon but I can sort of still be myself. Yet I've always sort of been able to kind of, my personality has rarely really clashed with a lot of people for the most part because when I, when I, when I'm thinking of it, I can always sort of try to adapt. And not really um you know be...I guess it's kind of personality that I can kind of switch over and kind of adapt and tune into somebody else's personality and meet them at that place. And that's sort of why I guess I've enjoyed doing it because it seems to be something that people kind of receive well. And that's what I've kind of enjoyed about working.

CK: So would they sort of take the lead a bit?

Mathieu: They take the lead a little bit, and I'll sort of work from there and find out a little more about them and try to sort of connect with them after they've taken the lead...

CK: Find something you connect on.

Mathieu: ... And yeah and then we have a bit of a common thing going on and I, I don't sort of walk into a room and say, "Here's me!"

CK: I'm here! [slight laugh].

Mathieu: "Here's my personality, this is what I'm all about! And... Like, what are you not like me? I just kind of try to sort of sit, sit in the shadows for a bit and see what's happening and what people are all about.

The attendants who do this work for the longest seem to embody flexibility, perhaps

suggesting Waerness' rationality of caring (1996). Experienced attendants can work just

as easily for a formal employer-style of one self-manager and for a very informal,

relaxed style of another. Attendants are there beyond just following directions and

doing tasks but also to respond relationally to the personalities of the self-managers.

Feminist studies on care often focus on the efforts of care workers, yet this relational work is two-way (Marfisi, 2010). Indeed many of the self-managers expressed being responsive to their attendants by taking into account their gender, age, and the social position during interactions. That is, self-managers acknowledge that not all 'arms and legs' are the same. Self-managers develop incredible empathetic interpersonal skills, and part of this work shields against abuse and the legacies of institutionalization as both recipients and attendants are humanized. Self-managers talk about being 'easy going' with attendants, and despite the emphasis on consumer-direction, self-managers leave room for attendants to express their own interests, ideas and even ways of performing attendant tasks. The centrality of 'directing' wavers considering the influence attendants have on daily decisions and how specific tasks are completed, in addition to the 'automation' feature when direction is no longer required, as discussed earlier. Long-term attendant Hailey recounts a clear example of a responsive self-manager, which she was surprised to discover:

Hailey:	...with [one self-manager] I found out, I think it's like he would rather finish one whole thing. Like on his meal, like on a plate, like say your potatoes, meat and carrots. He'd rather finish all of his carrots and then all of his meat, then all of his potatoes, than picking and choosing bits and pieces of it. Whereas some people, and I, it wasn't even [the self-manager] that told me this. It was somebody, I think it was [his friend] that was upstairs at dinner one night. And she looks at me and looks at [the self-manager] and she goes "I thought you liked your meal this way?" And he's like, "Well, I do." I'm like, "Shit! I've been working for you like two years, why haven't you said anything?"
CK:	You didn't tell me, yeah.

Hailey: He's like "Well it's not really that big of a deal."

Hailey is surprised that the self-manager does not mind how he is assisted during meals;

Hailey had assumed she was following his directions, letting him take the lead.

Beyond just making room for attendants to develop their own ways of doing

certain tasks, all of the self-managers described being a sympathetic ear for their

attendants often as a strategy for helping new attendants feel at ease, particularly

during very intimate tasks. For example, self-manager Marc notes: "Yeah I become the, I

don't know, the psychologist of the place. My boyfriend this! It's like ah-ha! Here we go

again!" Margot, a young attendant, recounts how the self-manager she works for is

sensitive to her social anxiety:

> But generally, I don't know, we're so open especially [the self-manager I work
> for] knows me really now. For example, I have a lot of social anxiety as well so
> big crowds, going to the mall sometimes creates anxiety. And [the self-manager]
> will actually ask me now because she knows me. Uh, you know, are you okay
> with this? Does this make you anxious? Let me know if you get feeling anxious
> you know?

Self-managers are active recipients of support in multiple ways from subtle physical

accommodations to relational management, just as Marfisi (2010) argues in her

discussion of attendant services. 'Give and take' with attendants is seen as an important

part of being a self-manager and creating a positive working environment. Audrey King,

an advocate and self-manager describes the importance of 'give and take':

> And the one thing that happens, and maybe not everybody is comfortable, but
> one of the advantages with Direct Funding is the direct accountability between
> you and your worker which leads to much more respect and support for each
> other. For example, if a worker said to you, "My kid, the school pageant is
> tonight and it's going to make me really late getting to you." Then I would say,

> "Oh heck, I don't mind! Even if you come at midnight that's ok." In turn maybe I
> want to go out one night and won't be home 'till midnight and talk to the worker
> about it, and say, "You know I'd really like to go to this." And the worker would
> say, "Oh ya sure." It's a give and take.

The 'give and take' and having an empathetic ear are important as self-managers want

to make sure attendants feel appreciated and will want to stay extended periods of

time. Self-manager Cheryl describes:

> ... And that's why I try to get to know them [on a] personal basis. You know and
> try to be interested in each one. And then try to remember what they said [slight
> laugh]. Try not to make it all about me, you know? Because that's what it is, it's
> all about me.

The ambiguity between 'arms and legs' that follow directions and the advanced

interpersonal skills required is generally managed through adopting chameleon and

responsive approaches. These approaches are actually so similar that the distinction

between roles and outcomes blend together. Ironically, the attendants talk about being

chameleons by "sitting in the shadows" as Mathieu says, in order to let the self-

managers "take the lead," while the self-managers use empathy and relax their

expectations around how certain tasks should be completed to make room for the

varied social locations and personalities of their attendants. Neither is truly happening

then; the attendants are not 'overshadowing' nor are the self-managers 'shining' and

completely directing the interactions. Attendants and self-managers interact in a space

where new forms of relating are created by attempting to bend to one another. Kelly

Fritsch (2010) draws on Deleuze and Guattari to theorize these moments as "relational

assemblages" arguing "The emphasis, then, is placed not on what you can do for me but

rather what we can create together" (p. 11). Barbara Gibson (2006) draws on the same

theorists and describes an attendant facilitating sexual interactions for people with

disabilities:

> The attendant is expected to be a detached "tool" for facilitating their coupling—
> a means to an end. Despite knowing her role, she experiences a leaking of her
> identity, a mingling of her own sexuality with theirs; their coupling is also hers (a
> ménage). (p. 192)

Assistance with sexual interactions stretches and challenges the common definitions of

'intimate,' but a blurring of identities in attendant relationships occurs beyond those

types of activities. Erickson (2007), a self-proclaimed queer, femmegimp describes her

personal support:

> The care that I need requires a lot of physical and intimate touch and contact,
> not to mention coordination. References to dancing occur on many occasions as
> my personal assistants help me because of the constant conscious and
> unconscious negotiation that has to transpire between us. This
> negotiation occurs because my personal assistant and I, and our bodies, are
> functioning as a self and as a unit. (p. 45)

Leading and following, asserting personality, advising, directing, doing, blend together.

Unlike many of the participants in this study, Fritsch, Gibson and Erickson are not wary

of care; they embrace the messiness, blurred boundaries and mashing of identities

implied by care in their descriptions (see also Hamington, 2004; Price & Shildrick, 2002).

Arguably the participants in this study do so as well, although implicitly at the point

where chameleon and responsive strategies merge into a unified approach, or dance, as

Erickson describes. In a poem dedicated to her "other bodies" Panzarino (1996)

articulates the relational ontology of attendant work:

> I spend more time with you than with my lover.
> Our boundaries blur with painful necessity
> as I know when you are hungry, but saying you're not,
> or constipated, or doubting yourself,
> and you suffer my medical abuses as if they were your own,
> Just as you know my everything
> from my love of chocolate, my bank balance, and what
> brand of tuna I buy
> to how my twisted body must be placed at night so
> that we both get a good night's sleep. (p. 85)

In another piece of poetry, Stacey Milbern (2009), also known as "Cripchick," offers a

sexually charged description of getting dressed, only revealing she is writing about an

interaction with her attendant in the final stanza. She writes:

> today i notice how loud our lungs
> heave. our breathing
> a pattern of its own,
> complete synchronicity
>
> new partners in a familiar dance
> we are always in experiment
> gliding, sidestepping,
> mixing new techniques with old maneuvers

Erickson, Panzarino and Milbern all identify as queer women with disabilities, and

Milbern adds she is a woman of color. These women eloquently describe the relational

ontologies forged in attendant work and embody complexity. They do not reduce

themselves, nor attendant work, to simple or singular definitions. The weaving,

conflicting descriptions of 'arms and legs', prosthetics and complex relational work

managed through mutually respectful deference deeply challenge the power imbalances

and dependencies linked to care.

Closing thoughts

While Independent Living echoes strongly in the descriptions of attendant services as 'not care,' the picture painted of personal assistance also resonates with feminist descriptions of care. That is, the distinction between caring for/caring about that separates the instrumental side of *caring for* from the emotional sense of *caring about* sounds quite similar to the task-based 'arms and legs' descriptions and to the ambiguous, but mandatory relational work (Finch & Groves, 1983; Grant et al., 2004). So then, what makes personal assistance different from care? Is it 'mere semantics'?

In many ways, personal assistance is not care. We cannot ignore the push away from care represented in this study and others, and this is primarily why the caring for/about distinction cannot be directly employed. From the descriptions in the interviews, directing or being directed to do a certain task (whether it happened at one point in time, or ongoing), for example putting on socks and shoes, changes the nature and experience of the task for both recipient and attendant. This is the case even if the end result is the same (i.e., you end up wearing your socks and shoes), and the experience can only be accurately described as 'not care.' Care encompasses too much in this situation, it has too much "baggage" as Tracy Odell says; it is much simpler to talk about concrete tasks, and stress the importance of 'consumer-direction.' For attendants, being directed instead of making decisions in the 'best interest' of your 'charge' (Kittay, 1999; Wong & Millard, 1992) changes the experience of performing the tasks in significant ways. In fact, the attendants may not want the decision-making

responsibility and the onus to make the 'right decision' or as Tronto (1993) terms,

assume the "taking care of" element of care (p. 106). Calling attendants 'arms and legs'

is a reminder that the self-manager is in charge and is liable, but this does not deny the

existence of a whole self, or even combined self as revealed in the relational labour and

relational ontologies developed.

In terms of the mandatory relational work, attendant services can be

distinguished from other descriptions of caring about in important ways. Primarily, while

a fondness for the self-managers makes personal support smoother, friendship or

familial forms of relating are not required. In fact, the relational work that does take

place is much more complicated at times. As most clearly demonstrated by the

comments of parent-advocates, 'care' is not enough to describe these aspects. New

relational terms are established within each attendant-relationship, and renegotiated

through each interaction, as demonstrated by the chameleon/responsive self-manager.

Attendants and self-managers may relate as 'friends' in one instance,

employee/employer in others and this constant shifting of roles requires skilled

relational work. This work helps to avoid confrontation and clashes in personality and

takes into account gender, age, and life position. Arguably relational work is involved in

care, as generally understood; however, the personal assistance environment under

Direct Funding highlights the role of the self-managers in doing this work. This relational

work is an active, two-way process that must be done by both the attendants and the

people who require support, does not require as much 'acting' as other service jobs, and

for these reasons, among others, it cannot be adequately explained with the concept of emotional labour. For the self-managers, the relational work includes making attendants feel at ease and appreciated, building rapport in order to instill a sense of responsibility when outside the work environment, and a constant vigilance to shield against potential forms of abuse and the legacies of institutionalization. The self-managers' relational work builds on critiques of care, by asserting agency through directing their attendants, being vigilant against potentially dangerous and abusive situations while still trying to maintain a home environment that is not institutionalized.

In summary, Direct Funding is not care because the responsibility is in the hands of the self-managers, relational work is two-way, mandatory, and more complex than forming friendships or family-like relationships. At this point, it can appear as though, just as the description of attendant services at CILT, care does not happen here. However, the resistance to care was not universally expressed through the course of the interviews; there were a few participants who were surprised that care was rejected and almost all participants used the word 'care' at some point during the interviews in a relatively neutral fashion. Many (in fact, as many who firmly rejected care) expressed indifference towards the word on the condition that personal support is done in an Independent Living manner. There is some ambivalence around care even within this paradigm example of Independent Living, as well as a sense that care does not disappear with the advent of Direct Funding. Care still happens, 'out there,' 'somewhere

else' and occasionally, it does happen 'here' within Direct Funding as we will explore the

next chapter.

Chapter Five

Exploring the "authentic times to care": The places where care belongs

Even though the majority of participants in this study reject the term 'care' in some way,

this rejection does not mean that care completely disappears. Further, very few of the

participants completely abandon the term, and some imply there are places where care

belongs, as demonstrated in the title quotation from community advocate Judith Snow.

Care emerges as an ambiguous and at times unwelcome set of actions and attitudes

that we all have to tolerate at some points in our lives and are necessary and even

appropriate for certain people, particularly people who are sick and people who cannot

self-direct. In this chapter, I outline the picture of care presented by the participants. As

I speculated in my theoretical chapter, and as forged through the second accessible care

bridge, care is a tension between a number of competing definitions and the concept of

'access' helps to connect this tension to material and discursive experiences.

The process of refining and containing the meanings of care complicates debates

between feminist care researchers and disability perspectives. In brief, containing care

demonstrates the debates should not be framed in terms of independence versus

inter/dependence or care versus support. Disavowing care within Independent Living

frameworks, even to the extent of removing it from public documents, does not

eliminate care. This discursive move does make it difficult to see "what happens" to care

and thus care and independence become the distracting focal points in debating perspectives. Moving the concept of care away from Independent Living, but allowing it to remain in other areas, changes the meanings of care and reduces its oppressive potentials. Before further expanding on this argument, I explore four key areas that still count as care, that is, care is: an intricate form of oppression; linked to medical and social professionals; a necessary set of actions during times of illness, for specialized medical treatments and highly intimate needs; and finally, an approach to supporting people with intellectual disabilities and others who cannot self-direct.

Care as oppression

Just as disability studies' literature argues, for some participants in this study care is a complex form of oppression that must be removed from the Ontario Direct Funding program. There are three key aspects of this oppression identified in Chapter Two, namely, the erasure of agency for those who require support, the legacies of institutionalization, and to again cite Fine's (2007) term, the "dark side" or potential for abuse and coercion, all of which surfaced at various points in the interviews (p. 4). One of the strongest critiques of care highlighting its oppressive side comes from key informant Vic Willi, a long term disability leader, former Executive Director of CILT, and centrally involved in the establishment of the program. Willi states:

> Care is […]a Western concept where it's like a false kind of love. It's the *ersatz* model of love, in other words, like coffee made out of chicory. It's not real love and it's not real care. Care is where someone else is responsible for you. And that's the most important concept of the word 'care.' They care for you. And to

this day my family still thinks that these attendants care for me, the locus of control, then, is with the care giver, the locus of responsibility is with the care giver. And the disabled person, the object of care, becomes an invalid, or "invalid" and has no control over their own body functions in the sense of their own needs or are at least limited control. And we wanted to get away from the word 'care.' Care is for sick people that can't help themselves. That's where it belongs properly, so it's an extraction from the medical model. That's our biggest enemy and it always has been, the medical model, 'cause we are conceptualized by the general public as needing care.

From this quotation the idea of care entails "when someone else is responsible for you" or an erasure of agency. Even in this passionate rejection of care Willi alludes to the fact that care does not completely disappear. Willi states "It's not real love and it's not real care" implying there are some forms of care that are "real" and times and places where it "belongs properly." Just as there is imitation "coffee made out of chicory" there are also false forms of care directed at people with disabilities. The existence of *ersatz* coffee, however, does not eliminate the possibility of real coffee, although it leads to a widespread suspicion around the authenticity of all coffee, or care, that one encounters. What remains to be seen, however, is what "real" care is. How can we recognize when coffee is authentic, especially if one has only had *ersatz* coffee? Ironically, "real" care, accessible care, may be in fact Independent Living models of support, which as we know, explicitly reject the idea of care. Or, as Cheryl, a self-manager puts it: "I guess Independent Living is, um, it's, it's what takes care of me."

As proposed in the theoretical chapter, any definition of care must include an acknowledgement of its oppressive sides, including the potential for abuse and coercion of those who require support and those who provide it (Fine, 2007). Behind all of the

positive evaluations of Direct Funding in Canada and elsewhere (e.g., Glendinning et al., 2000; Maglajlic et al., 2000; Yoshida et al., 2004), there remains an ever-looming oppressive side to care. Even in this small study, participants alluded to the vulnerability of self-managers and attendants, and some directly recount instances of crisis, financial, physical, verbal, and sexual abuse to varying degrees of severity.

The most prominent form of vulnerability came up in nearly every interview. The participants spoke about the risks of self-managers being "stranded" because an attendant does not show up, or unexpected needs arise. This ranges from minor to more serious examples. On the minor end, Rita, an informal support, describes her main concern with Direct Funding:

> [...] If she's...say for instance she's writing or typing and she drops something. And she needs it. Who's gonna pick it up?

This situation is annoying, but it is not life threatening, painful or even uncomfortable. Those using Direct Funding are implicitly, and sometimes explicitly, drawn to the Independent Living model that builds on deinstitutionalization. In addition to promoting living in the community in non-medicalized environments, IL presumes that the freedom to make seemingly mundane decisions is a necessary component of full inclusion. One of the most dehumanizing aspects of institutionalization is the lack control over daily decisions and the imposition of routine (Goffman, 1961). When the Direct Funding model cannot logistically account for some of these decisions (e.g., wanting to pick up something that has dropped) it is a substantive critique that references the legacies of institutionalization.

There were also accounts and concerns about more serious vulnerabilities and forms of oppression inherent in Direct Funding. Jason describes a situation dating back to when he had just started using Direct Funding:

> [...] I'm still really fresh and new at this and [the attendant] misses her third shift. She calls me about two hours before her shift and asks if she's working tomorrow. And I'm like, "No, you work tonight." And she's like, "Oh 'cause I'm [out of town] so I'm not gonna be able to get in tonight." So I freaked out and I had no idea what to do, right? Like this is the first time anything like this has happened, and my mom wasn't there and here was that moment of panic [...]. So it's that moment of like, I'm not going to be able to survive. I'm not going to be able to do this. And um, so I slept in my chair that night. And uh, I didn't sleep very much, you know it's pretty hard to sleep in an electric wheelchair.

Ever-looming beyond the increased flexibility and freedom associated with Direct Funding are minor and substantial vulnerabilities that can lead to experiences of oppression, particularly for those who live alone. Other self-managers describe the importance of emergency back-up systems, as well as a sense of unease and even panic when attendants do not show up. One self-manager recounted terrible experience of an attendant missing a morning shift, forcing him to soil the bed. The unease and panic came up frequently in interviews and undergirds the experience of Direct Funding. Indeed, this side of attendant support is part of why Saxton and colleagues (2001) argue for an expanded definition of abuse, where stranding a person with a disability would be included.

Unfortunately, accounts of more typical forms of abuse also emerged in the interviews, again revealing the oppressive sides of care that are not mere metaphor. These accounts were more commonly described in reference to attendant

arrangements other than under Direct Funding. Under Direct Funding, there were

mostly examples of financial abuse such as stealing money and belongings from the self-

managers. One self-manager recounts a story of physical and financial abuse:

> ... I had a friend who got kicked off of Self-Directed Funding because he had an attendant who was abusing him and he didn't know what to do. He didn't know who to talk to or where to go. And the attendant stole a ton of money from him. A lot of it was from the self-directed fund where she made him sign cheques for her, she would just empty out his attendant care budget basically and he was too shy and too afraid of this woman to say anything. And so they kicked him off Self-Directed Funding when everything came unraveled. They were like, "Well, clearly you're not capable of directing your own funding because you were just taken for thousands and thousands of dollars by this woman." It's a situation where there was violence and that, and it would, it would never happen to me because I would call the cops.

Some of the discussions of abuse took on a distinctly gendered tone. A female self-

manager vaguely recounts an instance of abuse:

CK: Yeah. Do you ever have a man as an attendant?

Self-manager: Yes I did. And which I, he, I had to make him leave too.

CK: You had to make him leave too?

Self-manager: He was abusing. Abusing.

CK: Oh I'm sorry. That's terrible.

[...]

Self-manager: Yeah. But he was an abuser a long time. He's been in prison for abusing.

CK: Oh God.

Self-manager: But you don't know that.

CK: Did you report him to the police?

Self-manager: Ah no because they didn't...okay what happened was [I] went to Independent Living for, to help for that, to make him go. But I didn't have any attendant. But my thinking was not all there. I was so tired emotionally and physically and all that. Like I didn't think of anything so. But being that they were gonna bring me to a shelter for a while. But there was no shelter for disabled people available at that time, so.

As other researchers have found (Millen, 1997), it was difficult to open direct discussions around gender; however, there was one notable exception in the case of discussing men working as attendants for female self-managers. All of the female self-managers in this study expressed some degree of concern about having male attendants. Some expressed quite strongly they would only hire women, while others report they permit male attendants to assist with tasks that are not considered 'personal care' such as housework, help with meals and eating. For example, a female self-manager describes: "I kind of care [about the gender of my attendants] for some things, for like going to the washroom." It was implied or directly stated in most cases that this preference was not only out of concern for privacy or modesty, but also for potential abuse. For example, one female self-manager says:

You're giving them a key to your house. Um. So what I found is that, um, I'm not necessarily comfortable in giving some random male stranger I don't know a key to [my] home, knowing full well that if, you know, who knows what can happen. I mean it's, it's, you know... yeah. Women can do, [inaudible] abuse too, but chances are, we know statistics, it's gonna be a male.

Attendant/self-manager interactions include power differentials that the IL approach attempts to address; that is, attendants have a form of physical power over the self-managers and the self-managers counter this with the power associated with

making decisions and acting as an employer. The power differentials are precariously

negotiated in and out of balance through the difficult relational work outlined in the

previous chapter. These delicate differentials can be easily pushed out of balance when

the attendants occupy powerful social identities, for example, when an able-bodied

male attendant supports a *female* self-manager. During help with the most intimate

needs, the female self-manager feels exposed, and self-conscious at times, and

experiences a heightened sense of vulnerability to abuse. While the female attendants

largely feel they could work with either male or female self-managers, with a couple of

exceptions, the male attendants felt varying degrees of discomfort about the idea of

helping women. Attendant Mathieu:

> It's just a risky situation. Especially since you're going to be doing this [inaudible]
> privately in a room somewhere and this involves you taking off some vulnerable
> person's clothes and helping them. And anything could happen, where you feel
> you're helping them and that person feels that you actually touched them
> inappropriately. But, obviously if you're helping them in the washroom then
> might be a chance that you might touch them somewhere they wouldn't want to
> be touched.

There is no formula to predict when the differentials will be more or less pronounced. It

is easier for women self-managers to categorically exclude hiring men as attendants

than to attempt to predict and negotiate these complex imbalances on an individual

basis. This wholesale exclusion, which is sometimes the policy in other attendant

arrangements, can offend some of the long-term attendants:

> I discussed this with one of the administrators [at another place I worked]
> because I thought it was sort of assuming that male attendants are going to
> behave badly or sexually assault the people that they're helping. And I was kind

of offended by that actually because why is it more likely for a male attendant to do that than it is for a female attendant?

The balance can be offset in other ways; for example, in situations where service

recipients are supported by women of colour, workers can experience forms of racism

(Neysmith & Aronson, 1997).

Under Direct Funding, the self-managers are willing to take on these major and

minor vulnerabilities and potential sites of oppression, gendered and otherwise, again

gesturing towards the legacies of institutionalization. While self-managers (and those

who support them) do not want the constant surveillance, structure and systemic

exclusion, among many other atrocities associated with institutions, there is a

protection from specific vulnerabilities, namely, being stranded, that comes along with

institutionalization. Institutions certainly do not protect from the risks of abuse, and, in

fact, there is a higher risk of various types of abuses for people with disabilities in

institutions than there is in community arrangements (Rajan, 2004). The potential sense

of security linked to institutionalization is acknowledged more among mental health

perspectives. For example, branches of the Canadian Mental Health Association and the

Psychiatric Patient Advocate Office provide information on crisis hospitalization,

Community Treatment Orders and long-term care housing, suggesting that for some

people temporary and voluntary stays ranging to long-term, repeated and involuntary

stays in places that could be categorized as 'institutions' can be an integral part of

recovery and management of painful disabilities (Canadian Mental Health Association,

2011; Psychiatric Patient Advocate Office, 2011). This is unsettling, particularly in light of

adamant rejections of all forms of institutionalization that resonate through disability communities and accounts of how institutionalized and medical approaches to mental health have immense iatrogenic effects, and exacerbate the negative aspects of mental health crises (Morrison, 2005). This conundrum between protection and vulnerability, revealed in the accounts of being stranded and even in the brief comment about what might happen if a self-manager "drops something," demonstrates the paradoxical complexities of care, that is, in a single instance it can be empowering, risky, oppressive, healing, and secure.

While the instances of abuse are disturbing, the participants urged that experiences of this aspect of care were uncommon. However, if we are using the expanded definition of abuse proposed by Saxton and colleagues (2001) that includes being stranded, this form of abuse was very common and represents a limitation of the Direct Funding program. I want to be careful not to blame attendants for "not showing up." This type of work can be physically and emotionally demanding, with no employment benefits, particularly sick days. The issue of attendants missing work, while serious and an important concern, also highlights some of the problematic working conditions that accompany this model of support.

The common experience of being stranded accompanied with mild to profound anxiety becomes a harsh 'dependency check.' There are moments where the environment fails to accommodate physical differences and thus, as the social model of disability would suggest, these moments create experiences of disability (Oliver, 1990).

During these moments self-managers must face the systematic oppression against

people with disabilities embedded in structural environments. Isabelle, a self-manager,

demonstrates the idea of the dependency check:

Isabelle: [We've had] situations where we've needed to hire and we
             haven't been able to find anybody and it's ticking down, you
             know, the time's ticking down [...] or people that have quit all of a
             sudden.

CK: So you didn't have any warning.

Isabelle: [...]. You know, we've had those kind of situations where I think,
             that's not, there's something wrong. When the money's there, yet
             we can't have basic needs met because you know? That, that, I
             worry about that. But it's...[...] No, it's not very often. It doesn't
             happen often, but it takes one time to think, "Wow, we are really
             dependent." Right? Like!

CK: You only notice when the system breaks.

Isabelle: Exactly. Exactly.

CK: You know it's going along fine, everything is going well, and then
             all of a sudden...

Isabelle   It's like the van. When my van breaks down, you don't, I don't
             notice my disability until my van breaks down and I can't take, you
             know, the bus or [the accessible bus service] whatever because
             I'm not going to get to work on time. [...] Um, that's when I notice,
             ok I am disabled, okay? Right? Or the scooter breaks down, see I
             don't notice it until my infrastructure doesn't work.

There is a profound aversion to these moments. The dependency check reveals the

power dynamic that Independent Living and the Direct Funding program work so hard

to subvert and happens in reference to technology breaking down or attendants not showing up for work. In recent work, Garland-Thomson (2011) presents the idea of the "misfit" to move the social model of disability forward. According to Garland-Thomson (2011): "The discrepancy between body and world, between that which is expected and that which is, produces fits and misfits" (p. 593). The dependency check for self-managers includes moments when the "discrepancy between body and world" becomes an uncomfortable reminder of an environment that presumes a mythical autonomous, able-bodied norm.

In many cases the attendant ultimately holds a form of power over the self-manager, who is dependent on the attendants to meet everyday basic needs, and this power contains a high potential to veer towards abuse or coercion, especially in terms of leaving someone stranded. This dynamic is sometimes disrupted for those who have informal supports sharing the same living space in the form of a partner, spouse, child, roommate or relative who can fill in when needed. Just as the issue of attendants not showing up is more complicated than it first appears, the aversion to the dependency check affects the attendants as well. As we will explore further in the next chapter, attendants express a high degree of responsibility outside of the work environment. They often come in to work to prevent the self-manager from experiencing a dependency check when in other types of employment they would take the day off (e.g., due to illness). The dependency check demonstrates that even in the most emancipatory models of support, the vulnerabilities of care do not disappear.

The oppressive side of care is two-way as a few attendants reported instances of
abuse, mainly verbal in nature. For example, Andrea, an experienced attendant,
recounts a difficult situation in which another attendant was sneaking around behind
the self-manager:

CK:	... that must have been awkward for you. Like did you say something [about this other attendant to the self-manager] or not?
Andrea:	No I didn't say anything 'cause she was so abusive it was hard.
CK:	Is it like verbal, was it verbally abusive?
Andrea:	Yeah, like, that I have a horrible laugh, I wasn't allowed to talk loudly, she was gonna shoot me down, like constantly...

Other attendants spoke about abuse, but not in the first person and again outside of

Direct Funding. For example, one attendant says,

> More often I should say, as an aside to that, there was more incidents of
> attendants being put into positions where they felt uncomfortable or being
> propositioned or what not. It went that way a lot more than it ever, I mean I
> didn't hear a single client who had been in any way abused by an attendant, but
> it did go the other way.

Another attendant,

> I guess just 'abused' in that [attendants are] talked down to and there's
> disparaging remarks made. Um that same client that I was talking about earlier
> [...] who had a conflict with me, who accused me of stealing things, he actually
> ended up getting...I guess essentially kind of squeezed out of [the living
> arrangement] because there were just too many incidents in which he was just
> making too many inappropriate comments to the female staff.

In addition to the abstract sense, oppression, abuses and vulnerability are a very real

part of care for people in this study and in broader disability perspectives. Further, for

those who reject the term 'care,' sometimes the oppressive sides become equated with care in its entirety and translated into "what we don't want" or "not what happens here." At times, care is seen only as oppression; but definitions are fluid, and this meaning does not hold for long. There are other concepts linked to care, for example, professionalism, responsibility for health and personal needs and support for people with intellectual disabilities. Rejecting care and its oppressive potentials does not eliminate these other elements as there are increasing moves to professionalize and regulate workers, people with physical disabilities will have health-related needs that push the boundaries of home care and people with intellectual disabilities also require attendant services.

Professionals and the Ontario Direct Funding program

Dejong (1983) defines Independent Living as a "paradigm shift," and highlights the influence of self-help and demedicalization trends on the emerging model. Both of these elements push against the idea of the 'professional' and make room for the agency of the service-recipient. In Independent Living and other movements with anti-professional sentiments, care professionals are seen as privileged people who, through education and work experience, presume to know what is in the best interest of a passive client. In some ways, this sentiment remains in the interviews in this study, although there are points where it wavers. The anti-professional sentiment stands in stark contrast to the political galvanization to professionalize developmental service workers as seen in the

Ontario Ministry of Community Social Services (2008) *Transformation* initiative and the

related Bill 77 ("Bill 77: Services for Persons with Developmental Disabilities Act," 2008)

as well as the proliferation of Personal Support Worker (PSW) training programs at

Ontario and Canadian colleges, which will be explored in the subsequent chapter.

According to Adams (2010) the concept of 'profession' is difficult to define, and

varies across time and context. Even medicine, the "epitome of professionalism" is

"intrinsically intertwined with the values of society within which doctors practice" (van

Mook et al., 2009, pp. 81-82). Adams notes that a "trait approach" dominates literature

from the 1950s and 1960s, and Hwang and Powell (2009) operationalize such an

approach in their study of professionalism in the nonprofit sector. In trait-based

definitions of professions, items such as training, professional associations, regulation,

protection of jurisdiction and ethics are used as criteria to determine what is considered

a profession (Hwang & Powell, 2009). Adams (2010) advocates for a focus on regulation

to identify what constitutes a 'profession,' suggesting the significance of moves towards

regulating support workers. Adams (2010) further adds the role of status and power,

which are not included in trait-based definitions until the 1980s. When groups and

individuals critique the notion of 'professionals,' such as views expressed by disability

advocates, the concern seems to be with an unfounded expertise and power to assert

that point of view. Hwang and Powell (2009) comment on the idea of professional*ism*:

"Beyond the numerical expansion of professionalism, more diffuse notions of

professionalism – such as commitment to work and dedication to improve one's

capabilities – have become pervasive in contemporary society" (p. 268). There is thus an additional behavioral component, as some researchers explore how to teach professionalism in medical school (Cruess & Cruess, 2006) and how to identify when medical professionals behave "unprofessionally," inferring a sense of politeness and formality (Hickson, Pichert, Webb, & Gabbe, 2007). Resisting forms of formal professional behaviour is a manifestation of larger critiques of the power and privilege associated with professions.

Community advocate and self-manager Audrey King was involved in a consultation exploring the possibility of regulating PSWs; she recounts:

> ...there was a marvelous woman there who was from the Older Women's Network, anytime she would open her mouth some of the professional people would look at her and smile and say, "Isn't she cute?" And I would say something and the RNs and the professionals would be very whatever. [My friend] who is an RN, who is very Independent Living consumer-oriented, would say the same thing but because she is an RN they would listen to her.

In King's account, professionals are given more respect and authority than the self-advocates. It is noteworthy that her friend who is a Registered Nurse may or may not identify as a disabled person, but has an IL orientation. Care professionals have the power to "speak for" people with disabilities but may or may not have the "right" perspective to do so. Frank Wagner, former senior manager for the Ontario Ministry of Health and current bioethicist for Toronto's Central Community Care Access Centre, explains:

> Whenever home care starts seriously thinking about a direct funding model, which they have to some day, but it's such a medical model and in that case the disabled community is correct. Nobody wants to give up that control. Health

professionals are trained, they're risk-adverse and they're trained to make decisions for other people in spite of the fact that they say they don't do that, that they get consent.

There is a perception and a reality that health professionals "make decisions for other people." Just as other scholars find (e.g., Caldwell & Heller, 2003; Matthas & Benjamin, 2008), some self-managers in this study prefer to hire people with no prior attendant experience, and particularly take issue with those who graduate from PSW programs. For example, Mike Murphy, Executive Director of Independent Living Centre Kingston, notes, "Yeah we get people in [with PSW diplomas] and we have to un-train them and then train them again." This brief statement implies attendants do require training, but not the training provided in standardized, credentialed programs. While representatives of Independent Living often speak about attendants as 'arms and legs' it is implied that these extremities are not interchangeable; the skills required to be a good attendant cannot accumulate or be universally taught in a formal program.

PSWs are seen as representatives of the medical model. Medicine is the "epitome of profession" (van Mook et al., 2009, p. 81), and as Vic Willi said earlier on: "That's our biggest enemy and it always has been, the medical model." Other participants echo this same sentiment through the sense of wanting to prove medical care professionals wrong. Teresa, an informal support and mother of a self-manager, reflects back on advice given to her when her son was first diagnosed:

> I don't know why they [the doctors and professionals] tell you that anyway. You know, just let you deal with what they've, the news they've given you to begin with. They don't need to tell you that your marriage isn't gonna last and that

your son should be in an institution like. Yeah but anyway, so we proved them wrong.

By "prov[ing] them wrong" self-managers and their supports can reveal the limited

knowledge of care professionals. Marilyn Dolmage, a mother advocate whose son,

Matthew, had profound intellectual and physical disabilities, recounts an instance when

her son was being assessed by professionals:

MD: So we applied to I think two agencies somebody told us about. They came to interview Matthew to determine whether he could "direct his own care." We had been agents of that. And there'd been people who knew him in a lot of different ways, who understood how he directed his own care with us in the picture. So, it was a really tough morning when that woman came. I was really tense. I was really sure that they were gonna say he wasn't able to direct his own care, 'cause they wanted to interview him privately.

CK: Oh my gosh.

MD: I was getting really tense, and Matthew must have picked that up. We're all in the living room waiting for this person to come, and he turned on the most babyish cartoon show that he never ever watched. It was like Teletubbies or something. And he never watched that, he always watched-

CK: -adult shows?

MD: Well, he'd watch cartoons, but they were always of the more cerebral type. And I was like, "That's really making me mad! This person is gonna assess!" I didn't wanna say anything, but I was communicating it, and he was like "Screw you, I don't care to be assessed." And my husband Jim said, "Well, they can't interview him 'cause they don't know sign language." So the woman came and Jim says, "Do you know sign language?" "Oh, no, no." "How would you interview Matthew privately if you don't know sign?" -even though Matthew had some other methods but they were always interspersed with sign. So, it was like "Oh I can't! Ok, well, you stay in the room then." So, we had a sort of interdependent assessment, and he passed.

This story is saturated with the sense of needing to convince the professionals to get the required services, rather than seeing the assessment as fair and objective. Dolmage and the actions of Matthew imply the professional assessment is unlikely to capture the creative, complex and relational ways of directing and communicating that the family had cultivated over a long period of time. Matthew and his family, who experientially and deeply know how attendant services work in their household, are pressured to present this intangible information in an acceptable format that will result in a sufficient amount of services.

Eva Feder Kittay (2010) passionately urges moral philosophers to express "epistemic modesty" (to know what you don't know) and "epistemic responsibility" (to know the subject who you claim to speak for) in the context of moral philosophers debating the value of the lives of people with profound disabilities; some participants in this study take this even further by implying professionals cannot practice epistemic responsibility in relation to attendant services. This is further supported by the material from the previous chapter around the difficulty in describing the nature of attendant interactions, where attendants and self-managers are the only people who "truly" understand the Direct Funding program.

The "real" experts are the people with disabilities and their family members. Indeed, while there is a thread of anti-professional sentiment in this study, it does not require a rejection of expertise, but rather a redefinition of expertise. In Adams' (2010) historical review of 'professions' in Canada, she observes as definitions flux, different

occupations vie for inclusion, thus constantly stretching and reducing the parameters of

what constitutes a 'profession.' In the Ontario Direct Funding context, there is a push

away from formal credentialed training as people with disabilities are regarded as the

experts in their needs while attendants become experts in individual people. It would be

unfair to claim the attendants are not "professionals" as arguably an aspect of using the

'attendant' terminology attributes status to this role. But 'professional' in this context is

redefined; the attendants cultivate expertise in responding to the needs of specific

individuals and this expertise is gained on the job directly from a self-manager, closer to

an apprenticeship model. Attendants are not internally or externally regulated, do not

undergo standardized educational requirements or testing, do not have a large amount

of power associated with their positions, and do not have a professional association. It

appears as though the form of professionalism endorsed by the Independent Living

framework hones in on the status component.

Many of the participants admit there are some skills that self-managers cannot

direct attendants in. For instance, self-manager Michael explains when directing breaks

down:

> And I find there are a few things that I *can't* direct them, like we had a couple of
> people here who can't tie shoes, and I can't tell [them how] to tie a shoe
> because I've never tied one myself!

Vic Willi explains how there are a few techniques and skills that might be taught

formally in a classroom setting, but the most important and challenging elements of

being an attendant are more abstract:

VW: There are some good things [about PSW training], like they tell them how to live properly. There are a number of good things, how to clean properly, proper hygiene techniques.

CK: But the philosophy isn't there?

VW: The philosophy is that you're caring for a patient. What I'm trying to say is, you don't need it to be a good attendant. The experts will teach you. We have our own experts.

This is the same logic behind the unique five-week, low cost, Personal Attendant Community Education program developed by the Independent Living Resource Centre in Winnipeg, which will be further explored in the following chapter. Being an Independent Living attendant is primarily a philosophical approach to disability that cannot be easily taught in a classroom setting and has few transferable skills. Yet ironically, many attendants in this study transition into work in related fields, such as physiotherapy, occupational therapy or into more formalized attendant service settings, eventually becoming the abhorrent 'care professional.' From the outside (e.g., perhaps on the receiving end of a university application for a physiotherapy program), attendants may be read as experienced care professionals, while within the Direct Funding program good attendants demonstrate an alternative positioning on disability and become important allies to people with disabilities. While many self-managers expressed disdain towards professionals, particularly towards care and medical professionals, they did not take issue with their attendants, friends, and family members working in these positions. Just like the RN friend in King's account, it appears as though training in Independent Living philosophy is the primary transferable skill gained by attendants,

and this perspective may be powerful enough to slowly change the meaning and implications of care and medical professions from the inside out.

Illness, medical interventions and personal care

The strong anti-professional and anti-medical messaging of Independent Living does not lead to advocating for the eradication of medical institutions, but, just as with attendants going on to become care professionals, an implicit desire to change some of the foundational assumptions of these fields. Thus, while care is "not what happens here" it does not completely disappear. Two areas where the term 'care' continues to apply and is reluctantly tolerated are in reference to illness and assistance with medical needs and in reference to the most intimate aspects of attendant services.

The notion that "We are not sick, we're disabled!" echoes through the history of disability movements in North America and resonates in contemporary Independent Living organizations and programming. It is important that people with disabilities are not assigned to the "sick role" in our society, thereby excusing them from citizenship duties such as employment and decision-making, decreasing expectations and opportunities for social participation, and culturally assigning disabled people to the fringes of society (DeJong, 1983). The anti-medicalization thread in the disability movement is an important and powerful one, although it marginalizes the experiences of people who are "sick" with terminal, chronic or acute curable diseases (e.g., people with HIV/AIDS, cancer) who might otherwise feel an affiliation to disability communities

(Driedger & Owen, 2008). In spite of the cultural and rhetorical significance of this message, many people with disabilities are prone to illnesses and sometimes have complex health issues. If attendant services aim to support people with disabilities with the tasks of daily living, the question becomes where do we draw the line between daily and health needs?

In this study, there is a sense that assistance during periods of illness and medical procedures can be considered care, and these aspects are never desirable or enjoyable, but are necessary and must be tolerated. Carolyn, an attendant, describes:

> Um, whereas when it comes to care, I go to the hospital because I don't, because I might need to be cared for for some kind of medical situation that, that I don't know about or that I'm unfamiliar with or that I don't have an expertise with.

Care is a form of medical support, where the person in need is often not feeling well and another person works to alleviate discomfort and assist the sick person to opt out of social responsibilities. This may require the expertise of a medical professional, or in more common examples, can be provided by a family member or friend (e.g., bringing soup). Under the Independent Living approach, on the other hand, attendants help people with disabilities to participate in life. This is a philosophical commitment; however, as we will see in the next chapter there are not enough hours under the Direct Funding program to participate in all desired activities.

Care still takes place, in times of illness and injury, birth and death, in the hospital by a professional or informally at home. Community activist, Judith Snow:

> Well, the, the authentic times to care for people are when they're born or when they're dying [slight laugh]. You know, when they're suffering deeply in some

way. It's not... it's great in its rightful place, but it locates us as children or sick or dying, one way or the other.

Self-managers and informal supports in particular recount narratives about crises of health, including bouts of serious injury, infection, surgeries, and complications related to the underlying impairments of the self-managers. I will not disclose the specifics of these narratives, but detailed accounts of illness and injury emerged in 36 of the interviews. The detail and frequency of these narratives suggest the significance in the lives of the participants, and is interesting considering that the interviews focused on attendant services, and not on medical care. The Canadian Council on Social Development (2004) finds "persons with disabilities tend to have higher rates for a wide range of health conditions than do those without disabilities" (p. 1). Alongside the increased susceptibility to health conditions and the narratives of health crises, participants insist on a distinction between medical needs and attendant care (i.e., "we are not sick, we're disabled"). For example Jason, a self-manager declares:

> I don't have crazy medical requirements really. Um not like on crazy machines, stuff like that. It's pretty straightforward stuff.

Another self-manager, Ryan makes a similar statement: "...I don't really have any underlying health problems or disability."

At first glance it appears as though the distinction between crises of health (which require varied levels of informal and professional care) and the tasks of daily living, which require attendant services, can be clearly defined. This is reflected in the Ontario policy landscape, where attendant services are largely separated from home

care. Hazel Self, a community advocate, talks about the difference between attendants

and hospital workers:

> [This committee I was involved in] was to assess whether the attendants' work was comparable to working in a hospital environment, and it's not because of several factors. One is that *I'm* directing the work being done, my needs are routine, stable, life-long, self-directed, and they cease to be medical needs at that point. I don't need someone's trained judgment. I know what I need. Unless I get sick or I can't tell what I need, then I need nursing services which are different to attendant services.

John Lord, a researcher with extensive community involvement, agrees and endorses

the political separation of these functions and helps to articulate some of the

ambivalence around professionals:

> ... like a woman I know who has got a fabulous son, he's 12 years old, she needs a nurse 3 times a week for him because he gets clogged. He's got some very serious medical issues. He needs a nurse 3 times a week. But that's nursing care, or that's physiotherapy care, or whatever you want to call it. That care, it seems to me, should be a separate function but related to the life of the person but not part of the individualized funding, so it should be separate funding. 'Cause it's true, if a physiotherapist comes in ... because this is a specialized service, all I can do is tell the physiotherapist that I feel clogged in my chest. This person has studied for 2 years or 4 years or whatever. They're going to know what my chest needs and they're going to recommend things to me. I can say yes or no. "Can I pat on your back?" "No I don't want a pat on my back." So the person still has a say but it's a little bit different, right?

Attendants assist with daily needs, professionals and informal supports help

during temporary illness depending on severity, and health professionals provide

"specialized service[s]" that may be needed on an occasional or regular basis. The line

between health needs requiring a care professional and everyday needs that can be

managed by a self-manager and an attendant is not so clear from the point of view of

the attendants, who are sometimes required to do tasks they do not feel qualified for.

Long-term attendant Andrea explains:

> Andrea: Even, sometimes it's really uh almost medical, like the things that you have to do. You're surprised, that you're not qualified to do them. But it's still very informal.
>
> CK: You think "I can't believe I'm allowed to do this", is that what you mean?
>
> Andrea: "I can't believe I've been asked to do this" sometimes, yeah.

For some self-managers, and implied through the current policy framework in Ontario,

the distinction between attendant services and health needs is clear and easy to

identify, but it is the attendants who must navigate this fine line on a daily basis,

sometimes resulting in performing tasks that make them uncomfortable.

One aspect of the daily needs component is categorized by interview

participants as 'personal care.' For example, self-manager Cheryl explains:

> Cheryl: Uh well, when I think of care I think they, they have to turn me in bed and when I go to bathroom, they have to wipe my butt. I hate that. But it has to be done. And I think that's care. Is that what you mean?
>
> CK: Yeah. So you're not...
>
> Cheryl: It's personal.

Cheryl cuts me off, finishes the conversation there. Personal care is necessary, but not

enjoyable and is extremely private. It seems as though these are the activities most

commonly thought of in reference to care, that is, hands-on physical assistance with

toileting, bathing, dressing, grooming and can be likened to Twigg's (2000) notion of

"body work" or Tronto's (1993) "care-giving" phase of her definition of care (p. 107).

This is distanced from help around the house, and, I found, even from help with eating.

Personal care includes the daily routines that require touch and nudity and the

moments when self-managers feel the most vulnerable. These activities are described in

terms that go beyond intimate and are seen as the crux of attendant services.

During the most personal and perhaps complicated interactions, attendants

must behave more formally and professionally. The joking and the banter stop, as

attendant Adam explains,

> I guess at a certain point when you're doing something, let's say you're helping
> someone in the washroom. You might be talking with them beforehand and it
> comes time to do some work, and during that space of time both the
> client and the attendant sort of go into a space where this is a job that has to be
> done, and it's not pleasant and nobody likes it. The attendant doesn't like it and
> the client certainly doesn't like it but it has to be done and it gets done. Then
> you go back to talking again. So maybe there is a space in there where that role
> becomes a little more black and white.

During these intimate moments, the attendant behaves *professionally*, perhaps

becoming a care professional. The most personal and concrete assistance is named and

tolerated as a form of care.

While the lines between illness, specialized interventions and daily needs are

sometimes ambiguous, a common place emerges where the formality and knowledge

associated with professionals regains prominence and power. Some activities, such as

personal care or specialized health interventions are too delicate, precarious and

beyond intimate for the relaxed interacting sometimes associated with attendant work.

The attendant or health professional is expected to focus and the person in need

reluctantly and temporarily enters the role of the 'passive patient' in order undergo physical interactions that can be uncomfortable and can be called 'care.' The informal working spaces of Direct Funding are not always relaxing, and, in fact, can be distressing for the self-manager during personal care (e.g., when Cheryl says "I hate that.") and medical needs. Self-managers and experienced attendants describe being formal with each other at the beginning of a relationship, and relax as they become more involved. If the required need is not physically painful or beyond intimate, for example help with cooking and eating, the attendants and the self-managers are more likely to have informal, friendly interactions distanced from the idea of care.

Attendants can temporarily transform into care professionals when providing personal care; parallel, yet more distressing, attendant services can literally transform into health care when the attendant service system fails. Some of the most significant dependency checks are in fact serious health crises. Tracy Odell, community advocate and self-manager explains:

> It was hard for me to find another attendant and I started to get in a real bad situation, it was starting to look like I would end up going into a hospital because the service was falling apart, and you can't have it fall apart for very long. Like how many days can you go without going to the washroom? Or without getting out of your chair and going to bed? So I was kind of in a crisis situation, and anyways, then I ended up moving into another shared attendant service.

Isabelle, a self-manager shares her crisis situation:

> It's really, really tricky. So even when I, you know when I first [lived in a supported living arrangement it] was not very good. Um they just, the way they ran it wasn't very good. I don't think they have it there anymore actually. Um I just couldn't get the hours that I needed [...] um, I, so I ended up doing more

physically than I should have been doing and I got very sick .... I had a major flare-up.

These are not isolated experiences, as demonstrated by the Executive Director of CILT,

Sandra Carpenter, in reference to the waiting list issue in Ontario:

> No we don't jump [people in the waiting list]... well, I mean we jump once in a while if there's a real crisis that we have to deal with right away. But time is becoming more and more problematic because the longer people wait, the closer they get to a crisis. So, I'd say the majority of the people on the list are pretty much close to being in crisis.

Major failures of the system resulting in personal and physical crises are a standard

feature of the attendant service landscape in Ontario, and a major policy limitation of

the current options for people with disabilities.

The concept of care continues to apply and is tolerated in reference to times of

illness, medical interventions as well as the highly intimate 'personal care.' Care is

permitted in these activities, and formality and professionalism are drawn upon as tools

to help ease the social discomfort around intimacy, autonomy and bodies that

misbehave. Care is also required when the attendant service system fails and self-

managers experience personal and often physical crises of health, completely collapsing

any separation between health and attendant services.

Care and people with intellectual disabilities

As described in Chapter Two, the third bridge built by accessible care helps to explore

tensions and hierarchies within disability studies and communities, namely in this case,

tensions between people with intellectual disabilities and people with physical

disabilities. In the interview process, one of the earliest and most consistent themes

that arose is that care is for people with intellectual disabilities and for those who

cannot self-direct. Coupled with the other strong theme that care is a complex form of

oppression that encompasses patronizing viewpoints, institutionalization and many

types of abuse, one questions whether it is therefore acceptable to oppress people with

intellectual disabilities. Indeed, this line of thinking was distressing to me as a researcher

since I did not want to represent some of the research participants as prejudiced against

people with intellectual disabilities and parent advocates (Fine, Weis, Weseen, & Wong,

2000). Some comments do replicate the well-documented tension between self-

advocates with physical disabilities on the one hand, and people with intellectual

disabilities and their supports (often immediate family members) on the other (Douglas,

2010b; Hillyer, 1993b; Ryan & Runswick-Cole, 2008). There were comments from

community advocates representing people with physical disabilities about distrusting

parent-advocates and needing to distance from them. Further, there were comments

that directly or indirectly revealed the cultural phobia of irrationality and dependency so

often linked to people with intellectual disabilities. For example, a number of self-

managers and informal supports recounted relief when realizing the self-managers

"only" had physical impairments and no apparent intellectual impairment as young

children. For example, comments included [his/her] "eyes were bright, intelligent, there

was no dullness." There were other comments more directly offensive to people with

intellectual disabilities. For example, in reference to whether the Direct Funding

program could work for people who may not be able to self-direct, one self-manager

said:

> Well, I guess if they have intellectual disability, I mean you have watch them [so]
> they don't set fire to the couch kind of thing [slight laugh].

Many of the attendants expressed discomfort in theory or in practice in working with

people with intellectual disabilities as mentioned in Chapter Four in relation to the

preference to being directed. There was a concern about "knowing what to do" if the

person could not direct you verbally, a testament to the success of implementing

Independent Living philosophy under Direct Funding.

The picture being presented is problematic: care is not acceptable for me, or my

job, but it is acceptable for "them," that is, people who cannot self-direct. Cam

Crawford, ally and community-based researcher with the Canadian Association of

Community Living muses:

> But I still think that people with intellectual disabilities are at risk of being looked
> down upon because like rationality is so highly prized in our society. You know
> like all, "I've got my mind dear," you know? Like it's like so foundational to how
> we conceive of the human person that any kind of detraction of that is
> sometimes perceived as a diminishment of a person's humanity which I don't
> believe, but that's the way things often get played out. So, there's probably
> vestiges of that that are still there within...well, there are vestiges of that that
> are there within the disability community as in the society more generally.

Indeed, there is some contempt for people with intellectual disabilities and a

valorization of rationality and independence revealed in this study. Yet this first reading

and early analysis of the material is too simple. There are other comments and

sentiments that complicate the scenario.

A few of the interviews that stood out in terms of notable variation on messages from interviews with people involved with the intellectual disability community, in particular parent-advocates, Marilyn Dolmage and Harry Pott, academic and community researchers Cam Crawford and John Lord, who also has a daughter with an intellectual disability and Judith Snow. These conversations often transcended the dichotomous valorization of autonomy over dependence, rational thinking over alternative modes of expression (see also Kittay, 2002). For instance, Harry Pott explains how his son can direct people to provide support, even though he would not be eligible for the Ontario Direct Funding program:

> He came up to me this morning to bring me to the kitchen and he had already gotten the eggs out but he's not allowed to turn the stove on, 'cause he's done that too many times when it shouldn't have happened probably. So he'll come and get you, or when he wants to leave. Often when I come here he thinks he's going to my place 'cause I often take him up there so he'll grab me and he'll take me to where his boots are, and he can put his boots on himself. It's just his way of saying "Ok let's go." It's his way of communicating 'cause he can't speak. So yeah, he's pretty good at telling you what he wants [laughs].

Hearing and validating "his way of saying" unhinges the centrality of verbal, linear communication yet still acknowledges that he is in some ways directing his care. The example of the assessment discussed earlier by Marilyn Dolmage conveys a similar perspective.

The more complex positioning around 'directing' also emerged in a few interviews in reference to aging. As will be discussed in the next chapter, many self-managers have a significant fear of being de-qualified for the Direct Funding program as a result of the strong emphasis on the ability to self-direct, an ability that may diminish

as one ages. Tracy Odell, self-manager and community advocate speaks about wanting

to expand who is eligible for the Ontario program:

> Which is another reason why I'd like to see it expand 'cause if people are used
> to, like my family members are used to what services I need, if for some reason I
> couldn't direct anymore or do that, but my family member could provide that. I'd
> much rather have my Direct Funding continue so I could be living at home as
> opposed to them having to look at me living in an institution again.

Similarly, Katie Paialunga, Executive Director of the Ottawa Independent Living Resource

Centre, describes a time when she may need attendant services:

> I think personally, you know, if I'm all there when I'm 80 or 90 years old I would
> love to have something like this. I'm worried about going into some kind of home
> where I have no choices.

Significantly, when the participants were asked if Direct Funding should be expanded to

include people with intellectual disabilities, many of the responses highlighted gaps in

the current administration that would make it untenable for this group in addition to

noting the program is already strained by a long waiting list. This emerged in a

conversation with Vic Willi:

> CK: So you think it should be a separate program, though? That Direct
> Funding shouldn't expand?

> VW: It's a totally different concept. You have to care for somebody that can't
> care for themselves. The thing about care, I know you're interested in
> that, is it only comes up in the one situation where you mentioned the
> parents of children with intellectual, children or adults with intellectual
> disabilities. That was the one place where it came up, and they were after
> us quite a few times to allow their people onto our model, but it doesn't
> fit. It doesn't fit our model. And so we basically encouraged them, I
> remember wanting to help them, to have their own model, but they
> won't do it.

At present, the program is designed in a way that excludes people with intellectual disabilities from accessing it. Nick, a self-manager, sums up the main tension:

> CK: ... Do you think it changes if, if [people with intellectual disabilities] are allowed in?
>
> Nick: Ya! I thought you had to self-manage!
>
> CK: Well, you do right now, they haven't changed it yet.
>
> Nick: I think they, they should call it something else.

It is no longer Direct Funding if the person cannot self-direct. That is, it is not just a policy mechanism that delivers funds but in fact a manifestation of Independent Living philosophy. It is not about receiving funds, but about individual autonomy.

Despite this clear distinction, the consensus is that people with intellectual disabilities should have access to a similar sort of program with the right safeguards and mechanisms in place. For example, Mike Murphy the Executive Director of Independent Living Kingston notes:

> I think Direct Funding as a model can work. I think for people with disabilities it should be them in control first and foremost, and if they can't be in control there could be supports set up, whether that's the parents, whether that's in Ontario we have adult Protective Services Workers, whether an informal support circle could be developed and a structure supported so that that happens.

Developing infrastructure and safeguards is an important detail because it unsettles the logic linking oppression and people with intellectual disabilities. By containing care to certain areas the participants change its meanings and diminish the oppressive potentials of care. Providing care for people who cannot make decisions independently or completely "self-direct" as defined by Independent Living, does not grant permission

for abuse or even encroachment on their agency. It requires safeguards and variations to the implementation. People with intellectual disabilities do require some care and careful planning when designing a similar model.

Closing thoughts

Through exploring what care is not and what care is, the meaning that resonates the strongest is care as an outlook on disability with the potential to lead to experiences of oppression. In this context, care is not merely the concrete "body work" nor the relational negotiation that takes place between attendants and people with disabilities, even if we sometimes use the word 'care' to describe these items. Care is rhetorically framed as a wrong and oppressive outlook on disability based in tangible experiences. This is a clear political message that condemns speaking for others, the power of the medical institution, pity and regulating people with disabilities to the margins of society. The terms used around attendant services thus become signposts to indicate who endorses this position. Establishing a community of those who "really know" what care is all about does not completely eliminate the oppressive sides of care, but attempts to address them.

Pushing care into certain realms, as discussed in this chapter, shifts the focus within direct funding arrangements to the broader social and cultural exclusions linked to care, asserting "this is not what we do here." Care, in the agency-denying, abusive, oppressive sense, is no longer an all-encompassing response to disability, but is limited

and its power differentials are leveled in some aspects. Certainly saying that 'care' applies to people with intellectual disabilities does not mean that abuse or institutionalization is condoned, but rather acknowledges there are some instances where someone, perhaps a care professional or family member must make decisions and to speak on behalf of those who cannot always do so, at least in conventional ways.

The rhetoric around care in this study encapsulates more than the competing values of independence and interdependence as so often documented in academic literature as the central tension between disability and feminist perspectives (Beckett, 2007; Hughes et al., 2005; Kröger, 2009; Watson et al., 2004). Many feminist care researchers argue that focusing on independence, as happens in the Direct Funding program and Independent Living, masks the interdependency of our social worlds, or even "inevitable dependencies" as Kittay (1999, p. 14) claims. However, containing care to the worlds of professionalism and illness, medical interventions and personal care and reserving it for groups with alternative modes of communication does not mask inter/dependence, but moves it. This move sometimes literally results in the removal of the notions of inter/dependency in public documents linked to Independent Living, but it does not deny the value of these concepts nor the existence of times of "inevitable dependency." The spaces of inevitable dependencies, where care is required, are reserved and respected. Self-managers reluctantly enter these spaces when necessary, that is, in times of health crisis, for specialized medical treatments, or day-to-day during the most intimate personal care, sometimes accompanied by an attendant and other

times a health professional. Independence and inter/dependency, care/not care, are not

in competition, but flash in and out of prominence depending on the circumstance,

relationship, life stage and individual. Chattoo and Ahmed (2008) had similar findings in

relation to the fluidity of in/ter/dependency, although without reference to

Independent Living, in their study exploring care provided by family members in the

advanced stages of cancer. Chattoo and Ahmed explain:

> Rather than implying that self and significant other(s) are seamless, we
> suggested that, for both the carer and person needing care, self is constantly
> reconstituted as a balance between notions of interdependence or legitimate
> dependence on the one hand and independence on the other. (p. 561)

In parallel, independence, as manifested through consumer-direction and a rejection of

care does not universally "win" under the Ontario Direct Funding program; rather, it is

re-asserted as an important value that people with disabilities should have access to.

Direct Funding creates the conditions for independence to be expressed in relationship

with others, most often attendants. Meanwhile, the spaces where care still takes place

are also changed; the oppressive potentials of care diminish (although certainly are not

eliminated) by containing care and reducing the authority and reach of the medical

institution and professionals.

Chapter Six

A web of influence: Policy implications of Direct Funding

After cautiously handling the interview material in Chapters Four and Five in relation to

the theoretical discussions of care, a conflicted journey I explain in Chapter Three, I now

turn to the more tangible implications of the process of re/moving care from the

Ontario Direct Funding program. While the theoretical contributions to care scholarship

matter in the powerful realm of cultural meaning-making there are also more concrete

implications of this process in the broader policy landscape. Thus, we travel back across

the first bridge built by accessible care and outlined in Chapter Two, that is, from theory

to experience. I continue to include conversations with the participants throughout the

present chapter, but aim to build on the argument from Chapters Four and Five; these

chapters document instances in which participants in this study and the related

documents reject and transform the concept of care, a process that helps to reduce and

address the oppressive potentials of care. In this chapter, I demonstrate how elements

of the re/moving care process can: obscure other policy issues, convey a complexity that

overwhelms some policy discussions, and diverge from other approaches to disability

policy questions.

Various elements of the re/moving care process can obscure policy issues,

namely the limitations of the program and the availability of disability supports. As

discussed in Chapter Four, the Direct Funding program includes mandatory relational

work and unique relational ontologies that are not considered care. The mandatory

relational work instills an unusually strong sense of obligation in the attendants that is

used to address, and in some ways hide, limitations of the program, in particular the cap

on hours and the availability of back-up support. The relational ontologies help frame

the work environment as 'not like work,' and create informality that is highly valued by

attendants while changing their expectations around working conditions. There is also

an under-recognized fear among self-managers of being de-qualified or having funding

taken away. The availability of services is obscured in some respects by the 'arms and

legs' characterization of attendants, which resonates with the rationale behind the

Accessibility for Ontarians with Disabilities Act (2005).

Two of the places where care is moved create complex messages that

overwhelm or short circuit the policy landscape. Reserving care for professionals while

rejecting the power they hold, leads to an ambiguous and nuanced position around

professionalism. This has implications for the push to professionalize attendants

through Personal Support Worker (PSW) training and discussions around provincial

regulation. Further, seeing care as tied to health and intimate needs reveals the

limitations of a social/health policy divide, implicating which Ontario ministry houses the

Direct Funding program as well as the upcoming renegotiation of the Canada Health

Transfer and Canada Social Transfer.

Finally, reserving care for people with intellectual disabilities reveals a notable

difference in the political and cultural messages conveyed through the Direct Funding

program compared to other recent turns in disability policy. While practically, Direct

Funding fits among a number of policy trends as identified in Chapter One, it appears

incongruent with recent developments in the disability sector, such as the Ontario-

based *Transformation* of developmental services as well as the UN Convention on the

Rights of Persons with Disabilities.

Obscuring program limitations and availability of services

A number of known and new limitations of the Direct Funding program emerged in this

study, including ensuring salaries are comparable to other attendant arrangements and

difficulties in recruiting and retaining attendants, especially for short or overnight shifts.

Many participants suggested increasing or even doubling the hourly wage and

compensating attendants for mileage as the most immediate ways of improving the

program. There were also some complaints from self-managers about the amount of

administrative work required, the length of the waiting list (4-5 years), and the

application process being dated (e.g., instructions to use a typewriter).

Two of the most urgent limitations of the Direct Funding program have links to

the mandatory relational work that attendants and self-managers participate in,

namely, the cap on hours and need for reliable back-up support. The Ontario Direct

Funding program has a daily maximum of six hours. There are some exceptions made on

a case-by-case basis including: extra hours (sometimes through Outreach agencies) for

people using ventilators; access to an emergency fund during times of acute illness; and

extra hours to support self-managers with young children (CILT, 2000). This does not include additional home care hours for specialized medical needs, such as treatment of pressure sores, which can be arranged separately through local Community Care Access Centres. In many cases, up to six hours a day is sufficient, particularly for self-managers who live with another self-manager (as a spouse, roommate, etc.), as it makes it possible to pool hours, for example, during meals. Some self-managers in this situation would like to be able to combine the funding in a joint bank account or go through the Direct Funding program interview together, which might be an interesting proposal for CILT to consider. However, for other self-managers who live on their own, the six-hour limit can be quite restrictive. For these individuals, the first areas to cut back are recreational activities, social events and travel. Ironically, improved access to these types of activities is cited as one of the key benefits of this style of service delivery (Parker et al., 2000; The Roeher Institute, 1997). One self-manager explains: "[I need to] fill in the gaps of Direct Funding because I don't have, I don't have enough funding to go work out or go play [sports]." Self-managers must, in key informant Sandra Carpenter's words, "pick and choose" what they use their hours for. Another self-manager explains:

> With six [hours], think [I'm] about two short a day give or take. Um, certain days are worse than others. Fridays are good days for me, I play wheelchair [sports] on Friday nights. That's two hours alone. Saturdays would be nice as well. It would be nice to be able to go grocery shopping, something I'm not able to do apparently.

Sandra Carpenter and other administrators explained why increasing hours for self-managers is not a straightforward request; the Ontario Direct Funding program has

had only one major injection of capital since 1998 when the Pilot program became a

full-fledged program (Parker et al., 2000). The recent injection of 1.7 million dollars will

allow for approximately 50 additional people to become self-managers, using the same

eligibility and limitations that currently operate (personal communication with

Katherine Janicki, Direct Funding Clerk from CILT, November 15, 2011). Carpenter and

others in this study note that the needs of people with disabilities can increase over

time due to aging or progressive impairments. Thus, self-managers are required to do

more with the same amount of hours. The administrators must be vigilant about the

fixed amount of money; giving one self-manager more hours means potential users will

remain on the waiting list, increasing the possibility of reaching a crisis. Unfortunately

for the administrators and users of the Ontario Direct Funding program, it is a zero-sum

system.

Community advocate and self-manager Tracy Odell makes an important

clarification to the availability of hours:

> There's a concern that every person with a disability is automatically going to want 24 hours of people around. So there's this fear that it will be an endless request, like a bottomless pit of requests, but I don't think so, because you also want your privacy and you also want your own time. You don't want to have an attendant with you constantly. ... Most people will just ask for what they need and that's all they'll ask for.

In this study, self-managers greatly appreciate attendants and see them as important

people in their lives, but they also want to maintain a semblance of privacy, particularly

self-managers with families (see also Malacrida, 2009).

Self-managers "fill in the gaps" through work-based accommodations while

others informally rely on co-workers, friends, family and even strangers; continuing to rely on informal supports while using Direct Funding was also documented in the early evaluation of the pilot project (The Roeher Institute, 1997). As mentioned in Chapter Three, many self-managers insisted they did not want their informal supports included as participants in this study, perhaps downplaying the inadequacies of the Direct Funding program. Most commonly, self-managers in this study draw on the relational component of attendant services to fill in the gaps. Self-managers work hard to build rapport and instill a deep sense of obligation in their attendants, sometimes resulting in attendants working without pay. For example, attendant Madison explains:

> ... if you're doing the bedtime shift, then it makes up for [working extra earlier in the day], if you're not then, you know, it does, it does kinda feel like I just did an extra half hour of work that I'm not getting paid for. If, if I was working McDonald's I wouldn't even do that, I'd just walk out. But you know it's, it's different 'cause you know [the self-manager] is like, you know, he's a buddy.

Long-term attendant Rob explains how the relationships are his primary reason for working under Direct Funding, a job that is not "an ideal system":

> So I helped two friends of mine who had disabilities who were, who received Direct Funding largely because they needed the assistance. I didn't mind going to visit my friends so to speak, and I just went and also helped them out because they needed, they, they needed the assistance. So, but quite frankly I don't think it's an ideal system only because it's hard to find staff to work such short shifts.

The same sense of obligation based on relationship is drawn upon to avoid the dependency check, that is, instances where the self-manager is stranded. Attendant Melissa recounts:

Melissa:	... There was one day that [the self-manager] calls me, it's like at one o'clock in the morning. He's like, "My attendant hasn't showed up yet, can you come put me to bed?" [...] So I get out of bed, I get dressed, I start going. I'm on the [bus and he] calls me again, "Oh, don't bother coming. My attendant just showed up." I was like...
CK:	Thanks.
Melissa:	Fuck! So I jumped off the bus, went back home and back to bed. It's like things like that, like you just can't just leave them stranded, right?

Self-manager Ryan articulates the connection between relationships and the gaps of the program:

> Because I'm not going to like everything everybody does because everyone has their own little way of doing it. And if I start nagging at them to do it my way, then then, we lose that that, um friendship. And it would become more of an employee/employer relationship. They will only come in for that hour and a half and leave right away. Whereas if we develop a rapport or a friendship, if I want to eat a little more dinner and then we can do that and I won't feel bad about keeping them a little more.

Feminist researchers have long discussed the distinctions and connections between "caring for" and "caring about" (Grant et al., 2004). In this study, cultivating *caring* or emotional attachments can be drawn upon to compensate for a shortage in hours or to prevent dependency checks. Excluding the concept of care from public rhetoric around the Direct Funding program obscures this strategy to some extent. Caring relationships are transformed into an integral component of the daily operations of the program and make it appear to be running more efficiently than it actually is; this component is difficult to account for or commodify in discussions of care work (Lynch et al., 2009) and

even more so when care is so fervently rejected in the public discourse.

Relational ontology and the evaluation of working conditions

The relational ontologies created under Direct Funding, categorized as 'not care,'

connect to a lack of criticism and evaluation of the working conditions by the

attendants. Many attendants expressed their jobs are 'not like work,' particularly young

attendants who work/worked for self-managers of a similar age. For example, attendant

Kristina explains, "But, grocery shopping and do some cooking and I'll vacuum or

something, but you know we talked a lot and we got along really well so I didn't, you

know, it didn't feel like work and I didn't dread going." Attendant Adam concurs:

"Sometimes it doesn't seem like a job at all. [...] After a while you're going to hang out

with your friends and every once in a while they need a hand." Similarly, attendant

Hailey says: "It actually worked out really well because we ended up like being friends, it

didn't really even feel like a job." This was a strong theme, particularly reflected from

attendants who worked while attending post-secondary education, and is a part of why

the attendants enjoy this type of work. Self-manager Jason explains how the sense of

'not like work' may be intentionally cultivated:

> ... I like the informality of it. I like, it does not, does not [have to be] really strict,
> like the casual nature of it. 'Cause that's my house, you know? I don't want my
> house to feel like a place of work, even though it is.

Self-managers want to maintain a sense of home, as discussed in Chapter Four, to help

temper the feeling of being "on" all the time when attendants are present. Self-

managers work diligently to create a relaxed, informal work environment, where the

attendants feel at ease. The informality is created not only by the home environment,

but through the relational ontology of attendant work, in the spaces between the

attendants and the self-managers. The relational ontologies and epistemologies of

attendant work starkly contrast the independent, worker-unit model employed in many

contemporary work settings, and help prevent attendant services from medicalization.

The sense of 'not like work' extends beyond the attendants' personal reflections

and the self-managers' efforts to legal definitions. In a discussion of why the wage gap

between Direct Funding attendants and attendants employed in other settings may

have increased in recent years, Warner Clarke from the Ontario Ministry of Health and

Long Term care explains:

> The fact that even though a self-manager is employing attendants, it's not
> considered to be a "workplace" for the purposes of the pay equity legislation. So,
> in the same way that the workers working for an individual can't organize a
> union for example, it's considered the classification of a worker under the Direct
> Funding program is really basically the same as a domestic, you know if you're
> hiring a nanny, if you're hiring somebody to work in your own home. So, it's a
> class of workers that were excluded from pay equity legislation.

The resulting informal work environment protects the sense of home for the self-

manager and creates an appealing job for attendants who may wish to avoid more

formal work; however, it unintentionally maintains the status quo of the material

working conditions. The sense of 'not like work,' in combination with isolation from

other attendants prevents attendants from evaluating the working conditions unless

prompted. The standard expectations for other work environments do not seem to

apply. Perhaps since Direct Funding, as advocate and self-manager Audrey King terms it,

"removes all of the layers," the workers have a sense of owning the means of

production, of opting out of the capitalist system to some extent.

This logic masks some of the problematic material working conditions related to

the Direct Funding program. While many self-managers stressed the need to increase

wages in order to attract and keep attendants, many of the attendants expressed

satisfaction with the wages. For example, attendant Jillian:

> I thought [the pay] was great [laugh]! I don't remember exactly what it was. I
> want to say it was around $13 an hour or somewhere in that vicinity. Um, but it
> was definitely more than minimum wage, which is what I would be getting
> probably anywhere else I had worked at the time. So, yeah, I thought it was
> fantastic.

This is possibly connected to how attendants see this work in their career plans.

Attendant work is seen as temporary, something "on the side," and the majority worked

as attendants while students, thus had access to medical and dental benefits tied to

their post-secondary institutions, or parents or partners. Attendant work thus becomes

the "perfect job for a student" (Jillian). Indeed, 12 of the 15 attendants interviewed for

this study started (and some finished) working as attendants while attending post-

secondary institutions. Additionally, advertising at colleges and universities was cited by

eight self-managers as a recruitment strategy. The highly variable hours were seen as a

benefit that could be reconciled with school obligations. Madison sums up this situation:

"So it, I think it's pretty fair and I think it's, like I don't have any complaints. But, on the

other hand, I don't live off it." In the final evaluation of the pilot project, it is noted at

74% of attendants surveyed had begun post-secondary education, with 47% completing

a college diploma or university degree (The Roeher Institute, 1997, p. 51). While dated,

these numbers may suggest the sample in this study is skewed; however, the numbers

may also infer that the demographic has changed since the pilot and that Direct Funding

attracts different workers than other care settings (Lyon & Glucksmann, 2008).

While nine attendants at one point received income only from Direct Funding, it

was unsustainable and they ended up moving on or piecing together additional work in

related and unrelated fields. Not one of the attendants in this study could work under

Direct Funding as a primary means of income for a sustained period of time. I am not

convinced that the fear of attendants being drawn away from Direct Funding jobs into

more institutionalized settings (commonly cited in reports and advocacy comparing

wages and benefits) is founded. There were only three attendants who seemed to be

making a career out of this type of work, and they simultaneously tried to maintain

Direct Funding obligations while working elsewhere. In this sample, most of the

attendants *specifically* liked the informality and flexibility of working under Direct

Funding, for a limited period of time, and did not necessarily intend to work in other

long-term care arrangements.

The apparent satisfaction with relatively unsatisfactory material working

conditions (note, the subjective, relational benefits and informal environment were

highly prized job perks) helps cement the anti-union sentiments present around the

Direct Funding program. Reports and information surrounding Direct Funding seem to

discourage unionization, perhaps overstating the impact this might have on the

program. There is a historic tension between Ontario unions and Independent Living,

including Direct Funding advocates (Cranford, 2005). Some advocates identify issues

with unionized workers and downplay the possibility that self-managers can be abusive

(e.g., Parker et al., 2000, p. 16). For example, "organized labour" is identified as a barrier

to the establishment of the program in a report published in 2000 with no resolution at

the time of publication (Yoshida et al., 2000). According to the authors: "In prior years,

there have been consumers who have complained about problems encountered with

unionized workers, for example, refusing to lift or transfer them" and this report implies

the concerns of organized labour are unfounded as self-managers represent "vulnerable

employers" (pp. 25-26). The concept of vulnerable employers infers that disabled

people are incapable of abuse and exploitation, which does not fit with the findings of

this study. The rhetoric about disability suddenly changes from empowerment and

independence to less progressive terms; for example, one key informant explains:

> [The unions are] really vicious, mean people who threatened to fight against the
> program because, when pushed to the wall for the reason why, they said
> "Because we cannot trust you not to abuse these attendants." So, they're
> accusing us disabled, hapless, paralyzed people who are absolutely dependent
> for our life and going to the bathroom and everything else, of being potential
> abusers of the staff!

Attendants in multiple environments are vulnerable to abuse, although not nearly as

vulnerable as self-managers (Matthias & Benjamin, 2003; Saxton et al., 2001). Another

example:

> if [unionization] did happen I think, from the consumer end, I think we'd be back

> to that situation where we'd be in the fallout of labour disruptions and that kind
> of thing. Like we'd be held hostage for that kind of thing because people are in
> their own homes they'd be all the more vulnerable to being abandoned if
> somebody just walked out and couldn't help them, or if they were on strike,
> people would be extremely vulnerable because how would you get around to do
> the basics for people?

Yoshida and colleagues (2000) ambiguously claim that the results of the 1997 evaluation

(The Roeher Institute, 1997) suggest "that labour's concerns were positively addressed"

(p. 26).

Cobble and Merrill (2009) argue "not only that service workers are 'organizable'

– a premise which had long been in doubt, but also that they are the future of trade

unionism" (p. 154). They suggest it is integral to use nontraditional organizing strategies

that, in the case of the Ontario Direct Funding program, may help to dispel the

stereotypes and resistance to unionization. Drawing on the example of home care

workers who organized in California, Cobble and Merrill (2009) highlight the importance

of "creating a unionism which could help solve the problems of both service produces

and service consumers," particularly essential in the case of the provision of ongoing

attendant services (p. 162). Unionization is only one possible option for improving the

working conditions as well as the quality of service for disabled people under the Direct

Funding program; however, the anti-union sentiments may stifle discussions about

working conditions.

Graduate students in the field of disability studies as well as a coalition made up

of, and representing, people with intellectual disabilities living in group homes articulate

a more nuanced perspective (Rinaldi & Walsh, 2011). This perspective developed in

relation to the unionized developmental service workers who undertook strike action

outside of the group homes where they worked. Rinaldi and Walsh (2011) explain:

> [Bill 83, the Protecting Vulnerable People Against Picketing Act] honours union members' right to strike, yet would prohibit striking at a particular kind of location. An inappropriate location would be outside the homes of people with intellectual disabilities, those who during the '07 and '09 strikes reported feeling antagonized, unable to leave their homes, and incapable of daily living when replacement workers were delayed from getting to work on time, all due to picket lines on the premises.

As will be further discussed in relation to intellectual disability, at times the Direct

Funding program can diverge from developments in other policy spheres. The

informality of attendant work is seen as an important job perk, but also creates the

sense of 'not like work' shifting the focus away from attempts to change the material

working conditions and potentially drawing more students into this work than the

demographics associated with other attendant settings (Macdonald & Merrill, 2009).

The re/moving care process can be linked to another limitation, that is the self-

managers' fear of losing funding.

Care as oppression and fears of losing funding

Underemphasized in my reporting, perhaps because it is so well-documented

elsewhere, is that direct funding styles of attendant services are associated with high

levels of user satisfaction, increased sense of control and empowerment, and more

flexibility and freedom in comparison to other arrangements (e.g., Blyth & Gardner,

2007; Caldwell & Heller, 2007; Parker et al., 2000; Stainton & Boyce, 2004; The Roeher

Institute, 1997; Williams et al., 2003; Parker et al., 2004). Certainly in this study, self-

managers expressed their satisfaction with the Direct Funding program, particularly in comparison to other attendant arrangements. Eighteen out of 20 self-managers utilized at least one other type of attendant services prior to receiving Direct Funding, and 10 of these people utilized two or more types of attendant services before Direct Funding. The self-managers unanimously preferred the Direct Funding model over the past arrangements for a variety of reasons, including choice of attendants, flexibility, control over schedule, etc. (see citations above). Unquestionably, self-managers in this study are grateful to have access to Direct Funding. It is important to note here, however, that these results, as well as the studies listed above, do not consider the "satisfaction" of people on Direct Funding waiting lists, those ineligible for the program, or those who have been rejected by the program.

In the process of re/moving care, care is framed as a form of oppression. The satisfaction of self-managers are linked to personal histories of more oppressive attendant service arrangements that include accounts of abuse. Likely related to these factors, the self-managers expressed a strong fear of losing Direct Funding. One self-manager approached to participate in this study declined because of this fear. Near the end of our interview, self-manager Jason candidly expresses:

> ...I have no idea if this is real or not. Or maybe it's just me, something in my head. But, I always had a feeling, um, that you know deep down, if I'm going to be totally honest with myself and honest with you, um, it's always been a bit of fear for me of Direct Funding, that is like keep your head down. Don't ruffle, don't, don't rock the boat. [...] Try to fly under the radar. It's good to be under the radar, 'cause they will take your funding away if you're in the radar. And there was a real fear for me that you know if I ever have a problem with one of my [attendants], a situation that I don't know how to deal with, the last person

I'm gonna call is Direct Funding. [...] But my fear, my big deep dark secret fear is that they're gonna see that as weakness, that you're not able to, to deal with the funding. And say, oh, you don't know how to handle that situation, well, you shouldn't be directing your own funding.

The personal histories of more oppressive arrangements combined with satisfaction with Direct Funding confirms that self-managers have "a lot to lose." Losing Direct Funding would mean going back to less than ideal living arrangements with more of a caring (i.e., 'oppressive' in this instance) approach to disability, less control, flexibility and perhaps higher risk of abuse, as discussed above.

The fear of losing funding is linked to the materials and Direct Funding interview process facilitated through the Centre for Independent Living in Toronto. For example, the *Financial Administrative Start-up Package for Self-managers and Bookkeepers* (CILT, 2008), a document given to all approved self-managers, details the complicated reporting requirements and yet ultimately recommends self-managers hire bookkeepers and a payroll service. There is strong, disciplinary language, with many sentences using directives, for example beginning with "You must..." and "You need..." along with repeated reminders of the consequences for "failure" to manage the funds properly. After reading the document, one feels overwhelmed at the complex and rigid requirements. There were many challenges in initially securing approval for the Direct Funding program (Yoshida et al., 2004), thus it is likely that CILT's documents reflect concerns about the organization losing this hard-won funding. The political landscape in the global north makes these more individualized forms of service delivery a probable direction of the future, but this must be balanced with the consistent underfunding of

non-profit organizations, particularly those linked to social movements (Incite! Women

of Color Against Violence, 2007). CILT currently exists in a tenuous context where core

funding is almost nonexistent and organizations are highly dependent on project-based

opportunities and service delivery programs, such as the Ontario Direct Funding

program. CILT, just like the self-managers, has "a lot to lose" related to Direct Funding.

The qualification interviews are extolled as different from professional

evaluations since they are conducted by a board of peers (i.e., people with disabilities,

often self-managers), but may, in fact, contribute to the fear of losing funding. Self-

manager Marc recounts:

> Because if I have a job interview and I fail at a job interview, then there's going
> to be another job interview. But, if I failed at the Direct Funding, then I can't live
> in my house. I can't continue with my job. You know my entire life would have
> changed. So, I had to pass this interview. And since it was the first time that I
> ever did something like that, I didn't know how strict they were, I didn't know
> what the criterias were, I didn't know. You know it's the first time, I had no
> details about it so. I was extremely stressed for that interview.

The application and interview process is intense and designed to determine if the

potential applicant has the skills required to legally act as an employer. The final

evaluation of the pilot project makes ambiguous references to a "standardize[d]

assessment of self-management skills" developed by CILT that potential self-managers

are scored on during the interview (The Roeher Institute, 1997, p. 32). The model is

committed to accommodation, inclusion, and consumer-control; as such, it is concerned

that CILT does not publicly publish the criteria for the assessment, and further, that

people are evaluated and scored (presumably) on their intelligence and learning skills within a cross-disability organization.

Framing care as oppressive can be tied to a fear of losing funding as other arrangements are depicted and reported as being less empowering; however, this detracts from an important exclusion embedded in the eligibility requirements for the program. The ability to self-direct is emphasized throughout the material on Direct Funding released by CILT, an ability that may diminish as one ages. Perhaps the urgent tone and emphasis on self-direction in the documents are unnecessarily amplified as other direct funding programs, notably the UK model, operate differently. In the UK, there is a push from governments as well as the disability community to get *more* people on Direct Payments[1] (Barnes, 2007) with whatever supports are needed to make this feasible. The emphasis for the UK model is not on reporting, accountability and self-direction, but rather on solutions to make Direct Payments suitable for different individuals (Leece, 2000; Maglajlic et al., 2000; Ridley & Jones, 2003). As I explore in the concluding chapter, the Direct Funding program is central to Independent Living in Ontario, almost shorthand for Independent Living, leading to substantial anxiety around the possibility of losing the program funding. Elements of the re/moving care process thus obscure limitations of the program, including the cap on hours, need for reliable back-up support, tenuous working conditions, and the exclusionary aspects of eligibility

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[1] Direct Funding is referred to as "Direct Payments" in the United Kingdom.

criteria. On the broader landscape, aspects of the process also obscure the availability of disability supports.

The AODA and 'arms and legs'

As established in Chapter Four, attendants are frequently characterized as the 'arms and legs' of the self-managers, and the work they do is not considered care. In this discourse, attendants become disembodied replacement parts that can correct unaccommodating environments and prevent the feared dependency check outlined in Chapter Five. An attendant corrects, as Garland-Thomson terms it, a "misfit," and facilitates a "fit," which "occurs when a harmonious, proper interaction occurs between a particularly shaped and functioning body and an environment that sustains that body" (2011, p. 594). As long as attendants are available and familiar with Independent Living philosophy they can help mitigate the social and physical effects of disability. Positioning attendants as 'arms and legs' helps to emphasize the necessity of their work (i.e., as necessary as an arm) but objectifies attendants to some extent, and draws attention away from the availability and adequacy of attendant services.

This unintended consequence can also be seen in the efforts of various Ontario and national groups from the disability sector that are centrally involved in the establishment of the Accessibility for Ontarians with Disabilities Act ("Bill 118: Accessibility for Ontarians with Disabilities Act," 2005). This legislation sets out to: "achieve accessibility for Ontarians with disabilities with respect to goods, services,

facilities, accommodation, employment, buildings, structures and premises on or before

January 1, 2025" through the development and implementation of standards in five

arenas with which the private, non-profit and public sectors are legally obligated to

comply ("Bill 118: Accessibility for Ontarians with Disabilities Act," 2005). This is

markedly different from prior approaches to disability policy in Canada (Chivers, 2007;

Neufeldt, 2003) and resonates with the Americans with Disabilities Act in the United

States. The first standard, the Customer Service Standard, has been in effect for the

public sector since 2010, with the remaining standards rolling out in an integrated

format over the next 10 years (Ontario Ministry of Community and Social Services,

2011).

The AODA is an ambitious and urgent undertaking, and the topic of attendants

(termed "support persons" in this document) occasionally comes up. What stands out

in, and what I argue is linked to characterizing attendants as 'arms and legs' is that

attendant services are presumed to be already in place, operating smoothly and

effectively. For example, in the Customer Service Standard, support persons are

discussed in section 4, grouped together with service animals ("Accessibility Standards

for Customer Service," 2007). Both attendants and service animals are framed as

assistive technology correcting inaccessible environments and mitigating disability, or

"misfits" (Garland-Thomson, 2011). For example, in relation to transportation, the

AODA's Integrated Accessibility Standards declares:

> No conventional transportation service provider and no specialized transportation
> service provider shall charge a fare to a support person who is accompanying a

person with a disability where the person with a disability has a need for a
support person. ("Integrated Accessibility Standards Regulation," 2011, section
38.1)

It is assumed support people are available to travel for short or long distances

with the person they are supporting and presumably paid to do so. In reality, the

Ontario Direct Funding program and other arrangements have long waiting lists, with

the Attendant Services Advisory Committee reporting a 4-10 year range (OCSA, 2008).

For those who do have access to attendant services many options are tied to the

building where they are delivered (with the exception of Direct Funding). Even with

Direct Funding, this study found self-managers did not have enough hours for many

activities deemed 'extra' including local transportation and overnight trips (see also

Church et al., 2004).

In Charles Beer's (2010) Independent Review of the AODA, he comments:

Let me make an observation concerning the availability and importance of
American Sign Language (ALS) interpreters and Langue des signes québécoise
(LSQ) interpreters, real time captioners and attendant care workers. In my own
consultations we experienced challenges in scheduling sessions as a result of the
limited supply of these necessary services across the province. It became clear to
me that it is critical for these resources to be available in order to make it
possible for people with various disabilities to fully participate in public forums,
especially where the issues being discussed relate directly to accessibility. As we
move to 2025, strategies to increase the supply of these critical human resources
need be considered. (p. 16)

In the sweeping, multi-sector approach of the AODA, there is a glaring oversight

identified here. How can Ontario be considered 'accessible' by 2025 if the necessary

services are unavailable or have long waiting lists attached to them? Calls for more and

improved services come from outside work around the AODA and the Direct Funding

program, as seen in efforts to establish a Canadians with Disabilities Act[2] and work

around the UN Convention of the Rights of Persons with Disabilities, to be discussed

shortly. Further in Ontario, representatives from CILT and other community

stakeholders established the Attendant Services Advisory Committee through the

Ontario Community Support Association, to advocate around issues related to attendant

services (OCSA, 2008). This work takes place separately from the Direct Funding

program and from the galvanization around the AODA. Indeed, by framing attendants as

'arms and legs' who do not perform care, attendants become assistive devices, and

discussing access to these devices becomes "out of the purview" for many disability-

related organizations, policies, legislation, and, as we will soon see, government

ministries.

Short-circuiting policy discussions

As outlined in Chapter Five, there are four key areas in this study that still count as care,

including care as oppression, explored above. At times, care figures in discussions of

professionals, in reference to health and personal needs, and when referring to support

for people with intellectual disabilities. The final use is perhaps the most significant; at

first it may seem as to devalue people with intellectual disabilities (and there are some

elements of this), but it also reveals how care is transformed by the process of clarifying

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[2] Current calls for a national act have diminished with the exception of a small Ontario group with an independent advocate, Scott Allardyce, at the helm (personal communication, Scott Allardyce, ongoing 2010-2011). Most other Canadian disability groups, including the Council of Canadians with Disabilities, presently focus on the UN Convention on the Rights of Persons with Disabilities, which has the potential to serve a similar function to a national act.

what it is and is not. That is, even though care can be a form of oppression, this is not the same 'care' used in reference to other arenas. Building on the feminist political ethic of care, complex definitions of care should be at the centre of our public conversations, such as those represented by the re/moving care process (e.g., Robinson, 1999; 2011; Williams, 2001). Yet, unfortunately, the nuanced perspective conveyed through the Direct Funding program is marginalized in discussions of worker regulation and in social/health policy divisions.

Struggling to stay in the conversation: Regulation of care professionals

Care is linked to the notion of 'professionals' in this study, with some ambivalence around their roles. Care professionals are not welcome to work as attendants under Direct Funding; self-managers are framed as the true experts who are able to train attendants to become specialists in their support. The training under Direct Funding has as much (or perhaps more) to do with conveying Independent Living philosophy as with technical, transferable skills. On the topic of attendant regulation, self-manager Isabelle says,

> Well, I think we're getting away then from the whole philosophy of Independent Living. I think regulating, then you're risking unionizing and you're, you're, what you're saying is you have to have certain credentials to do attendant care and you're looking, and it's more institutionalized. [...] I mean Direct Funding, and Independent Living, and directing your own attendants is all about, I think, all about, you hire who you want. It doesn't matter what their credentials are, it's who clicks with you in terms of personality.

"Institutionalized" in the above quotation does not refer to a physical building, but the more abstract sense of a patterned and controlled life. Part of the establishment of the program included securing exceptions under the *Regulated Health Professions Act* which, as initially proposed, would make services classified as "controlled acts" illegal offences if performed by a uncertified professional; many of the originally proposed controlled acts are commonly provided by attendants (e.g., catheterization) (The Roeher Institute, 1997; Yoshida et al., 2004). Professionals remain respected for their knowledge and skills for specialized medical needs and at times of crisis. As such, care is removed from the Direct Funding context, yet not eliminated; rather care, and care professionals, are contained to certain contexts.

In contrast to this perspective, there are a growing number of Personal Support Worker training programs in Ontario colleges including a number of programs offered through dubious private career training colleges (Servage, 2008). Further, there have been public conversations around regulating PSWs and individuals engaged in similar work (e.g., CBC News, 2008, 2011). Bridging into the developmental service sector, there are recent efforts to define the "core competencies" (a human resources concept), develop apprenticeship programs, and regulate Developmental Service Workers under Bill 77 ("Bill 77: Services for Persons with Developmental Disabilities Act," 2008). It is noteworthy that people hired under the Ontario Special Services at Home program, a form of individualized funding to assist families of children with physical or intellectual disabilities, are even less regulated than those employed under

Direct Funding. There is no set wage, employer requirements or mechanisms to mediate

disputes. The push to regulate support workers aims to attribute higher status to these

positions, improve the quality of service (sometimes a euphemism for 'weeding out'

people who do not speak English as a first language), and prevent abuse of both

recipients and workers.

As in other arenas, the Independent Living perspective presents an unusual

narrative in the policy debate. Disability advocates in Ontario have yet to formally come

out as opposed to PSW training and the possibility of worker regulation, and, in fact, at

times serve as consultants, guest speakers, and researchers in college programs and

government committees related to regulation (e.g., Church et al., 2004). Given the

recent political emphasis on these issues in Ontario and Canada, the Independent Living

critique and the benefits associated with the informal, unregulated model may be

trampled by a dominating health discourse that includes a preference towards

credentialism.

Resting between these two trends is a somewhat controversial, low-cost, five-

week attendant training program run by the Independent Living Resource Centre in

Winnipeg, [3] termed the Personal Attendant Community Education or PACE (Independent

Living Resource Centre, 2010). This program is "a recognized curriculum developed,

designed and delivered by people with disabilities to promote consumer choice and

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[3] Notably, ILRC Winnipeg is unaffiliated with the national network of Independent Living centres, partially due to efforts to license the PACE program. It continues to operate in an Independent Living framework (personal communication, Steve Carroll National Director of Independent Living Canada, August 2011).

control in daily decisions that impact their lives" (Independent Living Resource Centre,

2010). The curriculum includes Independent Living philosophy first and foremost,

followed by technical skills and legal issues, essentially creating a community-based

form of attendant credentials. The success of instilling Independent Living philosophy

through the PACE program varies, largely related to the degree of regulation in the work

environments in which the students end up, and the predominant role of 'choice' in the

philosophy, which leads to varied interpretation of how it should be applied in daily

interactions (Kelly, 2010a). Yet the PACE program stands out as a unique compromise in

debates around worker regulation.

Given the push behind regulation and the expansion of PSW/DSW programs,

formalizing the attendant services field in Ontario may be inevitable and actually have

some benefits such as eliminating more dubious programs and false credentials;

however, Independent Living risks being left out of this process. The PACE program in

Winnipeg and the words of self-managers using the Ontario Direct Funding program

challenge the professionalization of attendants in a sophisticated way. In debates

around credentialism, education and care there is an underused capacity of people with

disabilities, Independent Living centres and other disability-related organizations.

Disability communities in Ontario, however, must clarify their positions on

professionalism as well as their positions on older people, people who cannot "self-

direct" and people with more complex health needs, issues which current PSW

programs address. IL positioning on this final issue, health, reveals another policy

discussion that is short-circuited by the complex position represented by the Ontario

Direct Funding program.

A social model in a medical system

Declaring personal support as 'not care' under Direct Funding distances it in part from a

medical framework and distances disability from illness; indeed, in this study various

health needs are considered appropriate applications of care. As we saw in the previous

chapter, theoretically the line between health and daily needs is clear, but in practice,

particularly for the attendants, the distinction can be ambiguous and results in

attendants performing tasks past their comfort levels.

The shifting boundaries around health have implications beyond the daily

interactions as the Ontario and federal government structures are also divided along

health/social lines and the program emerged during a period of health care reform

(Yoshida et al., 2004). Ontario's Ministry of Health and Long Term Care, formally the

Ministry of Health (1999), currently funds the Direct Funding program. Previously, there

was a brief period during which a separate Ministry of Long Term Care existed and

funded the program (July 27, 1998-June 17, 1999, led by former Minister Cam Jackson,

interviewed for this study). Prior to this, the Ministry of Community and Social Services

(MCSS) funded attendant services, and during the development phase of Direct Funding,

much of the background research, political push and the legislative changes required

were led by this ministry (Yoshida et al., 2004). MCSS continues to address the needs of

people with intellectual disabilities (with the exception of people on the autistic

spectrum, who are under the MOHLTC) and children with all types of disabilities, and is

the government branch responsible for the implementation of the Accessibility for

Ontarians with Disabilities Act. While this may appear like administrative shuffling, the

issue of ministerial placement of Direct Funding was discussed on multiple occasions,

particularly by the key informants. Community advocate, Scott Allardyce, explains:

> SA: ... My ultimate hope is that the Ministry of Health and Long Term Care will get out of the business of attendant support services. That I believe that it is a community based funding model and therefore the Ministry of Community... of communities?
>
> CK: and Social Services?
>
> SA: ...and Social Services has to be involved directly. The Ministry of Health and Long Term Care deals with patients. It deals with people who are institutionalized in a patient setting. If we want to break the mold of the patient setting we have to move all the funding and all the programs out of that ministry that deals with attendant support services. And how do you do that? You move it to the ministry that deals with Community and Social Services.

Tracy Odell, community advocate, agrees:

> CK: So what are some of the current advocacy issues related to attendant care, generally, or Direct Funding, specifically?
>
> TO: I guess the first is to position it not as care but as a service. From my perspective that's like a mindset that people need to understand. So if it's under Health and Long Term Care it automatically gets considered care.

The program aims not only to address a need for attendant services, but also to convey

a strong cultural message about care, disability and independence. Many key

informants, with the notable exception of Cam Jackson, former Ontario Cabinet

Minister, expressed that attendant services should not be funded through the health system. During the establishment of Direct Funding, Jackson was "trying to convey to the government of the day that [attendant service was] not a social service, this was a fundamental health service that the quality of your life was dependent on this health service." Some additionally felt uncomfortable with the "welfare" undertones of the MCSS, suggesting other ministries and options.

The restructuring of programs, ministries and funding in the 1990s was not only administrative reorganizing, but was connected to the considerable change in the amount and method of federal transfer payments to the provinces. The Canada Assistance Plan (CAP) was transformed into the smaller Canada Health and Social Transfer in part to help balance the budget, but this switch created a difficult environment for social approaches to health to survive (McIntosh, 2004). The subsequent split into the Canada Health Transfer and the Canada Social Transfer (yet another example of the health/social split in government organization) cemented the priority of providing funding to initiatives linked to healthcare. With the advent of CHST in 1996, and even more so with the CHT/CST system in 2004, more funding, in both cash and tax credits, became formally available for health-related services and was bolstered by widespread public and political support due to the almost iconic status of the Canadian healthcare system (Mahon, 2008; see also Armstrong, 2001). Long-term care and attendant services in particular were not adequately addressed in the Romanow report, a centrepiece of the reform (Shapiro, 2003), suggesting further ambiguity

around whether they should be considered health or social services. It is noteworthy

that amid messages that Direct Funding is 'not care,' the waiting list is too long, there

are not enough hours for self-managers, and attendants need higher wages, there is

simply more money available for healthcare in Canada. Whether or not attendant

services and home care are identified as priorities and if these areas are considered

health or social priorities also has the potential to substantially change the Direct

Funding program during the upcoming renegotiation of the CHT/CST in 2014.

Some concessions must be made to the medical model in order to access

funding from the health system. One interesting area that the program managed to

sidestep is the push to centralize and regionalize many health services through Local

Health Integration Networks (LHINs), introduced in 2005 (Ronson, 2006). Centralizing

health services aims to reduce costs and streamline access, but also limits the mobility

feature of health care. Presently, the Toronto Central LHIN tracks the overall budget of

the program and reporting may eventually flow through the LHINs system, but the

funding for the program will likely continue to flow directly from the Ministry. Direct

Funding has a provincial jurisdiction, making it an anomaly that pushes against the

localization of services the LHINs model represents.

The placement of the program, whether viewed as fiscally strategic or as

ideologically problematic, has unintended community consequences. Unfortunately,

funding the program through the MOHLTC reinforces community divides between

people with physical disabilities and people with intellectual disabilities, and their

related organizations and allies. Even if the political and community will was present to

expand the program to include people with intellectual disabilities, the ministerial

separation between physical and intellectual disabilities further complicates the

likelihood of this happening. The people most affected by this divide are those who have

both physical and intellectual disabilities, who are left to awkwardly bridge multiple

systems and occupy diminishing policy spaces. As community advocate and mother of a

son with profound physical and intellectual disabilities, Alison Ouellette, describes:

> People with developmental disabilities were kind of shunned over in one direction because a lot of the people with physical disabilities felt that it coloured their image in the world, because people might think that people with physical disabilities also had developmental disabilities. They weren't able to distinguish that just because a person has a physical disability doesn't always mean they have a developmental disability. It made it hard for people like Dave to get what he needed in the physical disability world because he always kept getting shunted into the developmental disability world. We were jumping on both sides of the fence.

The tension between attendant services as 'not care' and health needs as care offers a

valuable critique of the medical system but requires more clarification within the

community. The ambiguity places attendant services on the edges of funding

discussions since they do not fit neatly in a health or social framework.

Diverging from approaches to intellectual disability

The final arena considered care in the Direct Funding program is support for people with

intellectual disabilities, which can include support with decision-making. *The Final*

Evaluation Report of the Pilot Project conducted by the Roeher Institute (affiliated with

the Canadian Association for Community Living) in the mid-1990s notes:

> "Self-management capacity" as defined for the purposes of this Project might
> unnecessarily exclude individuals who may need assistance in self-management
> because of a lack of management skills or because of a deteriorating condition.
> Self-management, at least in theory, does not appear to be at odds with a
> recognition of the need for support. (The Roeher Institute, 1997, p. iii).

The exclusion of people with intellectual disabilities from the Direct Funding program,

solidified by the movement of attendant services from MCSS to the MOHLTC stood out

in the early days of the program and it continues to depart from developments in the

disability field, as demonstrated through the both the provincial *Transformation* of the

developmental service sector and the UN Convention on the Rights of Persons with

Disabilities.

The *Transformation* initiative in Ontario, situated in the Ministry of Community

and Social Services, alongside but peculiarly separate from efforts around the AODA,

began with closing the doors of the last large scale institutions in the province in March

2009 (Community Living Ontario, 2009). Deinstitutionalization in Ontario, like in many

other places, was pushed and heralded by the disability community, especially those

from an intellectual disability perspective (Community Living Ontario, 2009; Stroman,

2003). Through this historic process it became apparent that existing legislation was

outdated as it assumed institutionalization as the preferred response to disability and

employed some language considered offensive by contemporary standards. Thus it was

necessary to "transform" the legislation and practices of the Ontario developmental service sector.

A significant portion of the *Transformation* and related Bill 77 builds on past advocacy around the Special Services at Home program (SSAH Provincial Coalition, 2011) and the work of the Individualized Funding Coalition for Ontario (2008) proposing individualized funding to support people with intellectual disabilities. There is a dynamic relationship between the Direct Funding program and individualized funding, as SSAH served as a precedent in the early days of establishing Direct Funding, and Direct Funding currently serves as model to support requests for more substantive individualized approaches. Theoretically, and in practice under SSAH, individualized funding provides funds to families to use for a variety of purposes, although the amount under SSAH is much less than the funds available under Direct Funding. The money can be used creatively, in hopes to address a wide array of issues related to living with an intellectual disability. For example, Marilyn Dolmage explains what her family used SSAH for:

> ... But because it was individualized funding, we could be flexible with it, so we developed, I had to think back to my days as a civil service manager, how do you structure a budget? You ballpark it, and then you don't have to stick to that as long as you can explain how you diverged. So we put in a certain amount for the staffing and we wanted to pay those people well once we got them. There was some money, it could go for training them, it could go for Matthew to go somewhere with them to hear a presentation about meaningful day or whatever, it went for mileage for our vehicle [...] His YMCA membership came from the budget, his rental of his assisted devices computer because they wouldn't pay it 100%, they paid for wheelchairs 100% but they wouldn't pay for devices, so that went in there.

Similarly, John Lord describes how individualized funding works for his family and in the

bigger picture:

> So, for example, if I think about my own daughter who is 30 now and she has a
> couple of pockets of individualized funding, she has Special Services at Home,
> she also has Passports Funding. She's living with a friend in a house. For her to
> really manage that money and use it effectively requires some facilitation
> support, it requires somebody to spend time with her, help her figure stuff out,
> spend time with her figuring who she's gonna hire, when and how, how to follow
> up on her dreams. I think the assumption in the Independent Living movement is
> that the person can do it themselves, can do all those things. The assumption in
> the individualized funding movement, where it's more family driven and more
> around people with developmental disabilities, the assumption is more that
> people are going to need some facilitation support to go with that, so the piece
> that I've been working on a lot in the last few years is trying to figure out, both
> research, and practice and training, what would that support look like?

Individualized funding is a substantial portion of the proposed changes in the

Transformation process and requirements to independently self-direct are

conspicuously absent. Ironically, people with physical disabilities will be excluded from

accessing any funding resulting from the *Transformation*, which may actually end up

requiring less administrative work and provide more flexibility than the Direct Funding

program.

Building on this, the second example where Direct Funding appears to diverge

from approaches to intellectual disability is in the context of the UN Convention on the

Rights of Persons with Disabilities. The Convention was adopted by the UN General

Assembly in December 2006 and opened for signature in March 2007, where "Canada

was among the first countries to sign it" (Foreign Affairs and International Trade Canada,

2009). The central aim of the Convention is to "protect the right to equality and non-

discrimination for persons with disabilities," which quickly branches into issues of reasonable accommodation (MacQuarrie, 2010). It is acclaimed as the fastest negotiated international convention and Canadians played a substantial role in this negotiation, in particular, through representatives from the Council of Canadians with Disabilities and the Canadian Association for Community Living. Currently, the Convention has 153 signatories and 106 ratifications (United Nations Enable, 2011). Many of the ratifications include reservations and interpretative declarations, and in the Canadian example, the federal government has an interpretive declaration on Article 33 item 2 to clarify that monitoring of the Convention will account for Canada's federated structure. More significantly, the government put forth a limited reservation and interpretative declarations on three items under Article 12.

In essence, by declaring people with disabilities shall "enjoy legal capacity on an equal basis with others in all aspects of life" (12(2)) and be supported to do so (12(3)), Article 12 of the Convention codifies an interdependent understanding of personhood and autonomy. Mégret (2008) argues aspects of the Convention may actually determine new rights for disabled people, namely around this highly debated Article 12. It is not coincidental that the Canadian Association for Community Living has expertise in the area of legal decision-making, recognized both nationally and internationally for the *supported decision-making model,* which is often discussed in the context of research ethics and is apparent throughout this controversial article. The supported decision-making model recognizes all people make decisions with consideration for and with the

help of other people, and thus people with intellectual disabilities should not be dismissed as entirely incapable of making complex decisions (Bach & Rock, 1996). The supported decision-making model "presumes capacity" and refuses to categorize some individuals as "sub-human" (Bach & Rock, 1996, p. 6). This approach resonates with recent philosophical work as seen in Eva Feder Kittay and Licia Carlson's edited collection *Cognitive disability and its challenge to moral philosophy* in which various authors passionately assert new forms of personhood and methods for enabling participation of those with different ways of being in the world (Kittay & Carlson, 2010).

Article 12 acknowledges as feminist theorist Grace Clement (1996) puts it, "relationships, and specifically caring relationships, are a necessary precondition for autonomy" (p. 24). More concretely, it presents a direct challenge to substitute decision-making models such as power of attorney and guardianship typically employed in legal settings, including in Canada. As written, Article 12 requires a substantial revision of the legal system, arguably commands the elimination of small and large-scale institutions that often preclude the conditions for substitute decision-making, and challenges some foundational social values around independence and self-determination. Michael Bach, Executive Vice-President of the Canadian Association for Community Living, renowned for his work on supported decision-making, writes:

> Yet, along with many other people with disabilities, there is a large group of people with more significant intellectual disabilities whose legal capacity, and therefore full personhood before the law is questioned and often removed only because of their ascribed disability status. Article 12 of the Convention demands an end to this systemic discrimination. (Bach, 2009)

This innovative approach seems to directly challenge the approach of

Independent Living and the values behind Direct Funding. For example in the *Direct*

Funding general information could be interpreted as one place where the "full

personhood" of people with intellectual disabilities is questioned:

> In addition to the ability to self-direct, they must be able to self-manage. A self-manager is a person in control of his or her own situation and not easily manipulated. A self-manager is a person who knows what services he or she wants and needs, someone with plans-- perhaps to move, work to study – or simply a clear desire to take responsibility for improving his or her own services. Self-managers are capable of interviewing, training, hiring and if necessary, firing attendants, and handling the financial and reporting duties of an employer. They are willing to take risks in return for the choice, flexibility and control over their attendant services made possible under [Direct Funding]. (CILT, 2000, p. 2)

In this passage, it is implied that most people with intellectual disabilities or who require

support with the tasks described cannot be considered 'self-managers.' The UN

Convention endorses a nuanced perspective that directly challenges major societal

institutions in order to enable inclusion for people with an array of capabilities, while

Direct Funding is designed to work only under certain conditions, for certain individuals.

These two arenas, the provincial *Transformation* initiative and the UN

Convention, indicate that rejecting care through the Direct Funding program and

reserving it for people with intellectual disabilities may end up leaving Independent

Living and people with physical disabilities behind or on separate paths. Indeed, these

two processes perhaps represent future policy approaches to disability, and yet seem

separate from the AODA (arguably with more links to the physical disability world),

Independent Living and the once cutting edge Direct Funding program.

Closing thoughts

In this chapter, I demonstrate the broader policy implications of the seemingly isolated

process of distinguishing what care is and is not under the Ontario Direct Funding

program. Generally, this process funnels attention in certain directions, sometimes to

the benefit of self-managers, attendants, and Independent Living, and other times

unintentionally obscuring certain policy issues or setting Direct Funding apart from

developments in disability policy.

The areas that are 'not care', that is, 'arms and legs' operations, mandatory

relational work and the relational ontologies between attendants and self-managers,

have a number of implications. The 'arms and legs' descriptors situate attendants as

assistive devices and is a similar approach to accessibility legislation, such as the

Accessibility for Ontarians with Disabilities Act. This process unfortunately makes the

actual provision of the services "out of the purview" for the various stakeholders and off

the table during vibrant negotiations and discussions of how to implement this

important legislation. Indeed, by considering attendants 'arms and legs' the focus

becomes how to make space for the extra limbs, and not how to ensure the initial

presence of the limbs. The mandatory relational work is integral to the daily operations

of Direct Funding; yet, classifying this work as 'not care' and limiting discussions of this

aspect of the work in lieu of employer/employee language, obscures the ways in which

relationships serve to fill in the gaps of the program. Finally, the informal, relational

ontologies developed in Direct Funding arrangements contribute to the sense that

working as an attendant is 'not like work' and thus expectations around working conditions do not seem to apply. Attendants surprisingly do not complain much about the pay, lack of benefits, or short shifts, perhaps because of the student-demographic attracted to this line of work and the highly valued relationships that form.

There are also links in the areas that remain care. By holding on to the sense that care is also a complex form of oppression, self-managers and perhaps the Independent Living movement broadly have a fear of losing funding and returning to more oppressive, "caring" approaches to disability. Secondly, by linking professionals and care, Independent Living perspectives risk exclusion from the potential regulation of support workers in Ontario, since it could be interpreted as 'having nothing to do with you.' Third, the link between care and health and efforts to distance Independent Living from health has had concrete implications in terms of funding and ministry placement both past and in the future. The ambiguity of where Direct Funding fits in unfortunately moves it to the edges of these important discussions. There are many areas of need within the Direct Funding program, forcing administrators and advocates to concede to the fiscal and cultural reality that more funding opportunities and public support are linked to the healthcare system in Canada. Finally, distancing from care and intellectual disabilities has the unfortunate consequence of making Direct Funding diverge from some of the most cutting edge work around disability, including the *Transformation* of the developmental service sector in Ontario and the UN Convention on the Rights of Persons with Disabilities, both of which allow for interdependent models of decision-

making and personhood, directly challenging the self-management emphasis explicit in Independent Living.

The Direct Funding program thus plays a complex role on the Ontario policy landscape, despite its relatively small size and scope. It has a unique cultural role that challenges common understandings of disability and care and works with rather than against the precarious economic landscape (Vosko, 2000) by drawing on workers who prefer the flexibility and informality of attendant work. The cultural role is a benefit and a detriment to the functioning of the program, as it can distance the program from some policy discussions but makes it stand out as a program that is not merely serving a material need, but also a cultural one. I now turn to some conclusions around Direct Funding in terms of contributions of this study, implications for Ontario and Canadian disability movements, while also considering the effects for Killian, who has been present, with a different pseudonym, in the previous three chapters.

Chapter seven

Re/Moving care: The story behind the story

This study set out to explore contemporary conceptualizations of care through the lens

of the Ontario Self-Managed Attendant Services-Direct Funding program. This program

is affiliated with the Ontario Independent Living movement and includes strong

messages rejecting care, thus allowing me to contribute to debates about care between

disability scholars and feminist researchers and ethicists. Yet, a few self-managers,

attendants, and 5 of the 6 informal supports demonstrated that not everyone cares

about the term 'care.' For example, an exchange between myself and Teresa, an

informal support:

CK:	I've gotten some very sort of angry reactions. Like people, some people just hate the word 'care,' they feel it's so offensive, almost, but some people just...
Teresa:	But that's what you're doing.
CK:	Well I...I don't know.
Teresa:	I don't get that.
CK:	Well, it's the medical and the kind of charitable history of the term....
Teresa:	Yeah...[...] Now I, I have no problem with that term at all. I, I, I don't find it, it doesn't anger me at all. I use it all the time. And that's what they're doing. I mean they are, they are taking care of [him]. You know they feed him, they toilet him, they put him to bed. Like, that's what you do when you care and you're their caregiver.

In parallel, self-manager Nick comments "I think I prefer 'services.' But I'm not, it doesn't bother me either way." For some people in this study, debates around care have become an issue of semantics. This can appear to be the case when only considering the messages conveyed through formal documentation around the Direct Funding program. The less-visible picture includes defining what care *is* with many far-reaching implications. It can be difficult to see the entire process, even for those who are deeply engaged in the community and/or the related academic literature. The sense of 'not caring about care' also reveals some political and cultural strategies to the anti-care messages from the Centre for Independent Living in Toronto, and related movements throughout Canada and elsewhere. There is other evidence demonstrating a strategic element, most significantly, changes in the discourse when referring to people with intellectual disabilities. That is, while care does not happen under Direct Funding because it is primarily an oppressive outlook on disability (so the message goes), it is not exclusively an oppressive outlook. The participants reserve care for those who need support making decisions and at the same time, do not condone oppressing people with intellectual disabilities. Further, while the anti-care messages seem unshakeably anti-medical at times, various leaders concede to funding under the Ministry of Health and Long Term Care, again indicating a strategic function to the rhetoric. To be clear, however, the rejection of care is not only a strategy for challenging cultural conceptions of disability, but in fact alters the way attendant services are delivered and experienced, among other ramifications.

In this brief conclusion, I explore the strategic and non-strategic components of the re/moving care process. I outline the major contributions of this study, including empirical, theoretical, and methodological contributions as well as the implications for policy and practice. While doing so, I review the findings and central arguments of the dissertation and draw connections throughout to the bridges built by accessible care. I then look ahead and outwards to explore the broader implications for Independent Living as a network of non-profit organizations and a social movement in Ontario, and present some areas for future inquiry.

Contributions

The research process and findings of this study make a number of key contributions, including methodological, empirical, and theoretical contributions with implications for policy and practice.

Methodological contributions

My commitment to reflexivity and multiple connections to people with disabilities and disability organizations creates openings for discovery beyond the data. For example, in addition to past and ongoing experiences working as an attendant, in the regular course of my life, I often witness self-managers and attendants interacting with each other, including some of the participants from this study. These experiences greatly helped contextualize the formal interviews and challenged my initial analysis on a number of

occasions. For example, in light of material from CILT and even some of the interviews, I may have argued that formal employer/employee relationships are the standard in attendant services; however, I knew from personal experience as an attendant and from seeing Killian with his attendants that informal relationships and even friendships can sometimes form.

Intimate access to insider knowledge is an invaluable source of data and insight, yet how we handle this knowledge is an ethical balancing act. As invaluable as these community connections can be, we must be careful not to claim ownership over all experiences or change our scholarly approaches to protect our connections. Feminists and disability scholars encourage researchers to be accountable to, and involved with, the communities we research, which must be tempered with applying a critical lens to our topics. This proved to be a difficult endeavor, particularly when dealing with issues of representation in the writing stages, which I discuss in Chapter Three.

More specifically, through my methodological approach I reframe the idea of 'key informant' by highlighting the role of Killian, a close friend of mine. Killian voluntarily expressed a deep and ongoing interest in the project from the outset, echoing a participatory action approach without demanding this from all participants. Sometimes in "ideal" approaches to participatory research, expectations around participation "can become a tyranny if not held lightly and flexibly" as the researcher may be disappointed with the level of commitment and involvement of participant-

researchers (Wicks & Reason, 2009, p. 258). Making room for varied and fluctuating roles for research participants is thus beneficial for both the researcher and participants.

As a key informant, Killian also helps demonstrate the benefits of drawing on friendship in the research process. Friendships can be pre-established, created, or deepened through the research, but like the friendships that can form between attendant and self-managers, are not mandatory. Including friends as well as strangers created a rich data set, where important information was exchanged and created because of a pre-established friendship at times, while at other times, just as significant information with a distinctly different tone was shared because we were speaking as strangers. Thus, like Taylor (2011), I endorse the inclusion of a "mix of intimately familiar and unfamiliar informants" when possible and appropriate to the topic (p. 15).

This study also highlights the role of relational-standpoints in data collection and analysis, which are forged not only through interaction with the research participants, but also based on past and ongoing experiences with disability. This applies to the experiences of researcher, as I have discussed throughout in reference to Killian and my community involvements, as well as to the interpretation of the research material. Many of the findings of this study emerged in the spaces between participants. For example, as discussed in Chapter Six, many self-managers stress the importance of raising the hourly wage for attendants, while attendants report they are generally satisfied with the wage they receive. This difference does not mean that one opinion is "wrong" but helps demonstrate that the attendants' sense that what they do is 'not like

work,' the relationships between self-managers and attendants, and the anti-union

sentiments in Direct Funding material coalesce with unintended consequences,

including limiting discussions of the material working conditions. This series of findings

solidified by considering the symbolic relationships between the narratives, the more

literal relationships between the participants, and reflecting on my own experiences as

being a paid and unpaid attendant.

Empirical contributions

This study makes a significant contribution to care and disability studies literatures by

documenting the re/moving care process. Through the official documents published at

CILT (e.g., CILT, 2000; Parker et al., 2000), narratives of the interview participants in this

study, and other contextual information, a distinct, previously undocumented process

emerges under the Ontario Direct Funding program. Combined, this material defines the

parameters of what is and is not care instead of the well-known message that attendant

services are simply 'not care.' Chiefly, care does not happen in attendant services

influenced by Independent Living, especially the quintessential manifestation of

Independent Living philosophy, Direct Funding. What does happen is often publicly

described as attendants being the 'arms and legs' of the self-managers, appearing as a

form of assistive technology that (not "who") mitigates what Thomas (1999) terms

"impairment effects." Less publicly, this study documents both attendants and self-

managers engaging in complex relational work that does not necessarily mean

friendships. Attendants and self-managers describe deference to each other, revealing

unique relational epistemologies and ontologies, which are supported by scholars

exploring attendant services from a cultural theory perspective (Erickson, 2007; Fritsch,

2010; Gibson, 2006; Price & Shildrick, 2002). These features, 'arms and legs'

characterizations of attendants, mandatory relational work, and relational ontologies,

are firmly 'not care.' Removing care from Independent Living changes the daily

experiences of giving and receiving support, with some attendants reporting they would

only work in this model and self-managers unanimously preferring Direct Funding to

other arrangements. In some ways, removing care successfully addresses the history

and limits the oppressive potential of medical and professional "caring" approaches to

disability.

Claiming attendant services are 'not care' does not mean that care is eliminated.

In this study, the participants in particular revealed remaining meanings of care as well

as a few "authentic," as Judith Snow terms it in Chapter Five, venues and practices of

care. This aspect rarely appears in Independent Living public rhetoric or research, and is

exposed only through conversation with self-managers, attendants, informal supports

and key informants. Primarily, as alluded to in the removal of care process, for

participants in this study, care can be used to describe a form of oppression and can

mean a 'wrong' outlook on disability. This definition is urgent, serious, and not to be

dismissed. Indeed, acknowledging the oppressive side of care is the foundation for

building accessible versions of care, as I argue in Chapter Two. Secondly, the concept of

care is linked to the idea of professionalism and there are times when care professionals are acceptable and necessary. Further, while care professionals are not welcome to work as Independent Living attendants since self-managers are the true experts, experienced attendants may become "Independent Living professionals" whose primary credential is familiarity with Independent Living approaches. Attendants who go on to become more traditional care professionals bring this knowledge with them, a knowledge that has the potential to challenge oppressive assumptions of professional fields from the inside out. Care also refers to assistance during illness, specialized health interventions, and highly personal needs. In practice there is an ambiguous line between health and daily needs, but it remains appropriate to respond to these circumstances with care. Finally, care is reserved for people with intellectual disabilities and other people who may need help making decisions. The final application in particular reveals that the meanings of care are transformed through this convoluted process of defining its parameters. While the re/moval of care process is interesting in itself, it also makes substantial theoretical contributions.

Theoretical contributions

In Chapter Two I present the idea of accessible care, the first theoretical contribution of this study. Accessible care presumes access is "an interpretative relation between bodies" (Titchkosky, 2011, p. 3) that is constantly evolving; accessibility is a critical reflection on the connections between discourse, spaces and bodies. Care can only be

defined as a complex tension, one that *includes* the notion that care can be a form of oppression for both disabled people and the people who provide support. From here, accessible care builds bridges in four key areas: from experience to theory, across feminist and disability literatures, across divides within in disability communities and scholarship and finally, from the local to the transnational. The concept of accessible care is useful within the bounds of this study, but can be used more generally in other care-related studies.

·The first and second bridges help to uncover another theoretical contribution of this study. In this study, without the narratives of self-managers, attendants and informal supports, only a partial image is created, that is, that attendant services are not care because care is an oppressive outlook on disability. Without the experiences of the participants in this study, what care remains, and how the process of claiming boundaries for care changes its meanings, is lost. Indeed, the experiences shared for this research helped to create a rich picture, which adds significantly to academic theorizing.

The small body of literature that can be considered 'conversations' between feminist and disability perspectives seeks to identify the reasons for tensions; possible points of mutual "passionate commitments" (Watson et al., 2004, p. 341) and places of "common ground" (Kröger, 2009); and advice for moving forward. In this literature, a polemic is documented between an independent, "masculinist" approach of disability movements on the one hand, and feminist, interdependent approaches on the other, often focusing on the ethic of care literature. For example, as Hughes and colleagues

(2005) put it: "the [Disabled People's Movement] has adopted a pragmatic and

materialist interpretation of care that is commensurate with its masculinist ethic and

idealizes masculinist notions of autonomy" (p. 263) and

> Feminist theorists, by contrast, argue that the dominant model of the 'worker
> citizen' obscures the need for, and the potential of, the 'carer citizen'. The carer
> citizen also works but she will be drawn into emotional and pragmatic relations
> of interdependency, invariably and in embodied ways, throughout the life-
> course, most likely as both a carer and a worker. (p. 264)

I identify other approaches to care that do not fit into these categories in Chapter Two.

Authors working on 'conversations' attempt to point out that the approaches are not as

disparate as they seem and that the confrontational tone in some articles (e.g., Morris,

1991b; Silvers, 1997) and actual confrontations at academic conferences (Thomas, 2007)

may be overstated as there are places of common ground including: connections to

social movements, "a political and empirical concern with the problem of caring work"

(Watson et al., 2004, p. 341), revised definitions of independence, and inclusion of the

"concepts of citizenship, justice and rights" (Kröger, 2009, p. 415-6). Most authors

engaging in the conversation seem to conclude that the feminist approaches to care are

in some ways better or more holistic than Independent Living, which is depicted as

limited or narrow. For example, even Watson and colleagues' (2004) balanced analysis

declares "The solution lies, we argue, in exploring the emancipatory potential of the

concept of interdependence" (p. 340). In this study, however, the process of controlling

what care means is an effort to reduce its oppressive potential, acknowledge past

harms, and move inter/dependence to appropriate spheres in life. Thus, while the

theoretical literature documents a debate *between* independence and

interdependence, in which interdependence often seems to win out, I argue this

oversimplifies the cultural, political and material effects of the Independent Living

message. Furthermore, creating a situation where people with disabilities and their

organizations "lose" in an academic debate does not respect the incredible changes this

movement has attained in a relatively short period of history.

The process of pushing care out of attendant services, but not eliminating it,

changes the terms of the debate between feminist and disability perspectives, perhaps

most closely resonating with work around relational autonomy, for example Grace

Clement (1996) and work by Sangeeta Chattoo and Waqar Ahmad (2008). In my study,

community activist Judith Snow encapsulates this complex position on the changing

centrality of notions of in/ter/dependence:

> ...well I'm kind of making light of it, but literally I cannot live my day without
> being accompanied by somebody. Or if I did live a day, then six hours of being
> accompanied and not the rest of it, I would live an extremely limited life. And I'm
> just not interested in having a limited life. So it's always been sort of to me that
> it's about relationship and how it can one, justify/sustain/make a good use of,
> create a valuable opportunity for two people to go through life together or
> multiple twos of people to go through life together so that it's possible for full
> participation to be there, right? In my case, me plus one of six other people are
> going through my day together to live a valuable life. And, it always has to be a
> dynamic, it can't, I can't imagine that [my attendant] sitting here beside me and
> beside you is really not really there, right?

Snow critiques the six hour limit of the Direct Funding model and the idea of 'arms and

legs' by acknowledging her attendants as full humans who she "can't imagine" ignoring,

even rhetorically. Snow and her attendants "go through life together," demonstrating

relational ontology and epistemology. Yet Snow's unusual validation of interdependence and public admittance of dependency (i.e., "I cannot live my day without being accompanied by somebody") does not mean an abandonment of independence, or "full participation." Indeed, as Snow describes, in/ter/dependence is "dynamic."

I would further add that the new terms for this debate are not found exclusively in this study, yet can be often overlooked. For example, a quotation from Connie Panzarino's (1994) autobiography *The me in the mirror*:

> [my friend] Tom was really great. If he saw me struggling with something I couldn't reach, or writing when my hand had gotten tired and my words were beginning to look like scrambled eggs, he would say something like "Do you need a hand? You look like you're getting tired." Sometimes I accepted the help and other times I preferred to struggle. He was fine with both. (pp. 119-20)

This quotation is set in a different context entirely, that is, Panzarino is a college student at New York's Hofsta University in the late 1960s. Throughout the book, Panzarino endorses a consumer-directed, Independent Living approach to attendant services. The above quotation demonstrates, again, the adamant rejection of care and removal from attendant services does not signal a denial of inter/dependence, but serves a broader role in reclaiming authority and challenging long-standing medical and charitable institutions. Theoretically it is significant that care is both removed from Independent Living *and* transformed in the bigger picture. The theoretical literature on disability and feminist perspectives on care thus must focus on relocating care, respecting the disability critiques and attempting to discern what this process means both for attendant services and the arenas where care is transformed, or deemed appropriate

and left intact. The process identified in this study is empirically unique, theoretically significant, and has implications for policy and practice.

Implications for policy and practice

While there is a strategic element to the re/moving care rhetoric that conveys strong cultural messages, there are some unintended consequences that appear in a variety of policy spheres, as detailed in Chapter Six. Aspects of the re/moving care process can obscure other policy issues, can convey a complexity that overwhelms varied policy discussions, and can diverge from other approaches to disability. At times, the cultural message that "attendant services are not care" draws the focus away from issues such as the availability of services, the limitations of the program, and the working conditions for attendants. At other times, the messages conveyed through this process are so complex that they cannot be accommodated in the policy landscape. In particular, the complex positioning around professionals means that the narratives from Direct Funding do not fit into discussions around regulating personal support workers. Further, the (intentional?) ambiguity between health needs and daily needs serves to collapse false divides between health and social policy, but also means that Direct Funding is an enigma in ministry reorganizations and the upcoming renegotiation of the Canada Health Transfer and Canada Social Transfer. Being an anomaly can be a beneficial position (e.g., in the case where Direct Funding is permitted to bypass the Local Integrated Health Network system, obtaining exceptions under the Regulation of Health

Professions Act), but also a detriment when this point of view is marginalized or excluded in policy discussions since it is uncommon. Finally, the re/moving care process sets Independent Living apart from recent approaches to intellectual disability. Realizing these implications brings new layers of analysis to a variety of policy issues as well as for individuals using and working under the Direct Funding program.

Individual self-managers both benefit and struggle as a result of the Direct Funding discourse around care. Certainly self-managers experience feelings of empowerment, increased flexibility and control in their daily lives as a result of the Direct Funding program. Yet, there are also a number of drawbacks, some of which are exacerbated by the process of re/moving care. As discussed previously, the process of naming the parameters of care has implications in varied fields, but while self-managers stand to benefit the most when the message is effective, unfortunately they also bear the brunt when this message is too complex to be processed by the policy landscape. For example, it is the attendants who must live out the inattention to working conditions, self-managers who wait years on a waiting list, while both will feel the effects of being an unusual perspective in policy conversations about worker regulation and federal transfer renegotiation. Self-managers and attendants are quite literally left to fend for themselves, in terms of when to bend the rules, styles of management, what types of relationships are appropriate. Take for example this exchange with Killian:

CK: ...if your work didn't give you support, would you have enough
            hours? 'Cause your work, you said, paid for some...

Killian: No.

CK: ...Some of your hours...

Killian: I would only get two hours a day.

CK: Two hours a day?

Killian: At work. Or that's what I did before. For about 7 years I was alone all day.

CK: So what, what would you do if you had to go to the bathroom or something came, something suddenly happened?

Killian: Someone, it only happened to me a couple of times, and a co-worker asked me what's wrong or what...and they helped me.

CK: The co-worker helped you?

Killian: Ya.

At another point, Killian describes a period of severe illness when he was hospitalized and his primary concern was making sure his attendants were paid even though they were not providing his support "Because they have to make a living." With liberation comes risk, and at times isolation. Killian is left with a heavy responsibility, to look for attendants to work short shifts at unusual times, negotiate what he terms "awkward" relationships with attendants and fill in the gaps when the program falls short, by asking a co-worker or establishing rapport with attendants and drawing on this. Indeed, the most liberating aspects of Direct Funding are also the most cumbersome, and it is important that explorations of direct funding models account for these limitations. Moving beyond the specific contributions of this study, I now reflect on the shifting policy landscape for non-profit organizations such as IL centres and the Independent

Living movement.

Reflecting on Independent Living

One of the questions I set out to explore in this study is how the Ontario government

grapples with tensions between independence and care; the short answer is that it

leaves that work to the non-profit sector. In spite of the global recession in 2008 and its

likely return in the subsequent decade, we do not seem to be witnessing a turn away

from neoliberal approaches to social and health policy. Relationships between non-

profit organizations and governments are changing, and the Centre for Independent

Living in Toronto represents an example of this. We may be entering a period of hyper-

neoliberalism, where the primary function of governments is regulation of the work

force (e.g., of PSW workers, the *Transformation* initiative related to the developmental

service sector), monitoring the public and private sectors (e.g., the AODA and the UN

Convention), and administering funds for external agencies to provide services (e.g., the

Direct Funding program). The government is striving to leave the business of service

provision to the private and non-profit sectors, which are increasingly focused on

applying, administering and reporting on government funds (Hall & Banting, 2000). Non-

profit organizations with a social justice component or history in particular must turn

away from activist work that is "un-fundable" for lacking measurable, short-term

outputs (M. Smith, 2005). Various levels of government become "objective" regulators,

evaluating the very services they underfund. The evaluations are often further

outsourced to independent consultants, sometimes from within the communities

governments seek to monitor and regulate, for example, hiring The Roeher Institute to

evaluate the Direct Funding program (The Roeher Institute, 1997). These are early

observations on the relationships between non-profit organizations and Canadian

governments, a course that may change. The implications, however, for the

Independent Living movement and disability movements are significant, and less

tentative.

Independent Living as a social movement

In this shifting environment, the Direct Funding program stands remarkably still. In

many ways Direct Funding is the quintessential manifestation of Independent Living

philosophy as it was originally conceived; it embodies many of the philosophical tenets

as identified by John Lord (2010), including consumer control, cross-disability (to an

extent, in that it is not only for people with a certain impairment), peer-support,

integration and full participation, and non-profit. In the UK, Jenny Morris (1993)

identifies the central tenets of Independent Living as:

  (1) All human life is of value
  (2) Anyone, whatever their impairment, is capable of exerting choices
  (3) People who are disabled by society have a right to assert control over their
      lives
  (4) Disabled people have the right to participate fully in society. (p. 17)

While the cross-disability and the claim "whatever their impairment[s]" do not entirely

fit with the Direct Funding program, the emphasis on self-determination, consumer-

control, community integration and participation are defining characteristics of the

program.

In my interview with Mike Murphy, Executive Director of Independent Living

Centre Kingston, he explained how Direct Funding is the showpiece program highlighted

in requests for elusive, core funding:

> ...So we're developing a case for support [for core funding] and in there we've
> made a case in terms of how we align to a lot of what the government of Ontario
> is doing but we profile the Direct Funding program as one of the most concrete
> examples of Independent Living. So it's important to the movement for sure.

I read two versions of these requests, and it was noteworthy that the activist language

was toned down in the later draft. There is widespread agreement that Canadian

Independent Living has strong activist roots and should be considered a 'movement'

(Hutchison, Arai, Pedlar, Lord, & Yuen, 2007; Lord, 2010; Valentine, 1994). Further, aside

from the key informants approached for their involvement in community activism, many

of the self-managers and informal supports, and even a few of the attendants, reported

engaging in various individual advocacy efforts and collective actions. The participants

described times when they pushed against schools, businesses, governments and

workplaces for inclusion. Yet, Independent Living centres avoid engaging in activism or

advocacy. Part of this is due to the charitable status, which in Canada cannot be

assigned to organizations with "political purposes" including efforts to "retain, oppose,

or change the law, policy, or decision of any level of government in Canada or a foreign

country" (Canada Revenue Agency, 2011). Securing funding without charitable status is

very difficult, making applying for this status an appealing route for non-profit organizations.

The aversion to activism is also partially connected to the history of Independent Living in Canada. Lord (2010) notes "the Canadian Independent Living movement decided early on that it would stress individual advocacy (and self-advocacy), not collective advocacy. In part, this decision was made because [the Council of Canadians with Disabilities] and other national groups were already doing the collective advocacy" (p. 159). The distinction between individual, self and collective advocacy may not be as clear as implied in this publication as the self-advocacy focus creates a tension with the notion of Independent Living as a collective movement. Even the example of the messages rejecting care documented in this study could be considered a form of cultural activism, although the Ontario Direct Funding example lends itself to stagnation because the messages are necessarily "frozen" since they are enshrined in binding policy documents and eligibility criteria. Regardless of the rationale, IL centres and the national IL office tend to publicly promote self-advocacy, systems navigation and life skills rather than collective action.

This is one of the few features that distinguish Canadian Independent Living from American versions. Other features identified in studies include less confrontational tactics than the American counterparts (Chivers, 2007), early and ongoing location in the non-profit sector (Neufeldt, 2003), and a close and amicable relationship with the state (Peters, 2003; Stienstra, 2003; Valentine, 1996; Valentine & Vickers, 1996). Using

these criteria in addition to the philosophical tenets explored above, the Direct Funding program in many ways *is* Independent Living in Ontario. It emerged through advocacy and activism, but no confrontational tactics were used (or at least were not documented). It is situated in the non-profit sector and represents an ongoing relationship with the Ontario government as many politicians and public servants are identified as allies, not adversaries in the history. Indeed, Direct Funding is in many ways philosophically representative of the Independent Living approach and operationally reflective of the documented Canadian disability movements.

Yet, there are other branches of Canadian disability movements that are less-documented and discussed, as demonstrated through another project I was involved with at the same time as my dissertation research. I am a board member for Citizens with Disabilities-Ontario (CWDO), the Ontario affiliate and full member of the Council of Canadians with Disabilities (CWDO, 2011). In partnership with the Council of Canadians with Disabilities, a group of us fundraised and organized a Youth Activist Forum for approximately 40 youth with and without disabilities, held in Ottawa, June 3-5th 2011. As will be seen shortly, it is noteworthy that Independent Living Canada declined to partner on this project. We brought youth together in order to learn from established and emerging leaders with disabilities, and encouraged the participation of allies in order for them to see people with disabilities as leaders for all. This was also a participatory action research project funded by the Canadian Centre on Disability Studies, and results of this study are forthcoming. CWDO exists almost exclusively

online, does not have charitable status at this point, and our lack of resources and infrastructure at times works in our favour as there is room for varied projects to emerge, as long as there is a committed leader or group available to volunteer the time. We faced many of the same barriers as Independent Living centres, including the project-based funding landscape and the aversion to activism (e.g., if we hold an event in the future, it will be called the 'Youth Summit.')

Literature documenting the history and current state of Independent Living in Canada laments a lack of new leaders emerging (Hutchison, Arai, Pedlar, Lord, & Whyte, 2007; Lord, 2010; Prince, 2009). In my experience, it is not that the new leaders do not exist, as indeed we featured many at our Forum, but that the Independent Living model does not account for them, or make room for the issues and approaches they represent. For example, Michael Prince (2009) identifies five arenas that constitute the disability community in Canada: social service sector organizations (who may or may not have a progressive approach to disability); a policy community; a new social movement; a constitutional category of citizens; and a research and knowledge production network. In spite of including the category of new social movements and acknowledging that some cultural, identity-based organizing takes place, Prince does not provide specific examples from disability artists, or more relevant to my experience, youth leadership. Meanwhile, at the Youth Activist Forum, we featured people like Jes Saches, an Ontario artist with a disability most well-known for a large scale, culture-jamming ad campaign American Able (with photographer Holly Norris). Their campaign spoofs the company

American Apparel, a "socially aware company," which through highly sexualized

advertising, claims to represent "everyday women," yet does not feature women with

disabilities (Norris, 2011). Saches' work is known not only for its commentary on

disability, but also on sexuality, gender and normalcy. Similarly, sprOUT, a group of

youth with intellectual disabilities that identifies as gay, lesbian, bisexual, transgendered

or questioning from the Griffin Centre Mental Health Services (Griffin Centre, 2010) in

Toronto, also represent a highly intersectional approach and came to the Forum to

present their documentary *Our Compass* (for information on documentary see Art

Gallery of Ontario, 2011). We featured Jeff Preston, community activist who

independently organized the Get Mobilized! March (Preston, 2008) to protest the lack

of local accessible transportation, made a documentary about it, and is currently the

writer for the edgy and political webcomic *Cripz* (Madrenas & Preston, 2011). Preston

also spearheads a "stair bombing" initiative, where staircases that are inaccessible to

wheelchair-users are humorously closed with yellow caution tape, indeed, a

confrontational approach to addressing inaccessible built environments (Preston, 2011).

How do these creative youth leaders fit within Independent Living movement? Is there

room for individual, intersectional, radical, culturally-focused activism in the Canadian

disability movement?

In John Lord's (2010) recent book (notably written in partnership with and

published by IL Canada), he notes: "The initial principles of the Independent Living

movement are as relevant today as they were in the early 1980s. This is itself is quite

remarkable, considering that the movement has matured in some significant ways over the last 25 years" (p. 35) and "the core functions have changed slightly over the years, but the heart of the original four remain within all centres across Canada" (p. 55). In particular, the Direct Funding program has undergone very few changes to the eligibility criteria, the application package, number of recipients, and informational material since it was established as a full-fledged program in 1998.[1] Even the key informants identified by the centres are many of the same people involved in the formation of the program, rather than people moving it forward. Unlike Lord, I am unconvinced that this consistency is a positive feature and may represent a growing generational gap, linked to the shifting political landscape, that excludes youth leaders such as those identified above. The more inclusive and cross-issue focus of the youth leaders is marginalized particularly by the exclusion of people with intellectual disabilities from Direct Funding, the third, and broken bridge of accessible care. This reflects transitions in the women's movement from a second to a third wave "do-it-yourself" approach. Many second wavers comment on the apathy and lack of leadership coming from young women, when in reality, it is a misinterpretation of new forms of leadership and issues (Pinterics, 2001; Steenbergen, 2001).

In Canadian disability movements the generational gap is perhaps the most pronounced when examining the Toronto-based group DAMN 2025 (Disability Action

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[1] In fall 2011, I heard the Direct Funding program is receiving an injection of capital that will enable approximately 50 more people with disabilities to become self-managers, although the eligibility criteria and cap on hours will remain the same (personal communication with Katherine Janicki, Direct Funding Clerk from CILT, November 15, 2011).

Movement Now), another group featured at the Youth Activist Forum. DAMN 2025's

name is a direct reference to the AODA (which promises an accessible Ontario by the

year 2025), a policy that has been largely unchallenged and unanimously supported by

varying disability organizations (DAMN 2025, 2008; Henderson, 2007). DAMN 2025 has

an intersectional, grassroots and multi-issue approach; further, individual activists are

cautious not to speak for the group, but identify and situate their own positions.

Activists affiliated with DAMN 2025 have even organized critiques of the Direct Funding

program; some of these initiatives are directed at the Ministry of Health and Long Term

Care, while others are directed at the Centre for Independent Living in Toronto

(personal communication, Anne Abbott, 31 July 2011). Indeed, the current approach of

Independent Living in Ontario leaves the movement without new leaders and the youth

leaders without organizations.

I agree with Lord (2010) that the IL movement in Canada has an incredible

capacity for social innovation and a proven track record of entrepreneurial spirit.

Unfortunately, as seen through the example of the Direct Funding program, the

Independent Living movement is shaped and constrained by the tenuous funding and

political environment in Ontario and Canada. IL centres are forced to fit in with a

number of trends, which the Direct Funding program does quite well as explored in

Chapter One. Indeed the established relationships with Canadian governments may

constrain the IL movement from accommodating new leaders and issues, compounded

with the aversion to activism in spite of the history of Independent Living. The

programmatic responsibilities of Direct Funding, for example, dilute the cultural

messages and roles of Independent Living. This is seen in the concessions to the health

model, "freezing" program eligibility requirements, and the messages that seem out of

step with the emerging approaches to intellectual disability and those expressed by

youth leaders.

Future directions

The foundation of accessible care is an understanding of care as a tension and this

foundation has proved relevant in this study. Further, three of the bridges built by

accessible care have been acknowledged, that is, bridging experience and theory,

feminist and disability perspectives and divides among disability communities, most

notably a generational divide and divides along impairment lines. The fourth bridge,

from the local to the transnational, is conspicuously absent and is the first area for

future inquiry. As mentioned in Chapter Three, three attendants declined to participate

in this study because English was not their first language. As I included only 15 attendant

participants, three is a notable number and may suggest support for the final trend

identified by Fiona Williams (2001) in care research (particularizing, universalizing, and

transnationalizing). Scholars document how large scale economic factors create push

and pull conditions that facilitate the migration of female care workers (Misra et al.,

2006) and further, "Underneath the international division of care work, there is a

gradational decline in the worth of care" in reference to the families of the care workers

who are left behind in home countries (Parreñas, 2009, p. 139). What emerges as a

substantial gap in the literature and a limitation of this study are the places where the

transnationalizing trend intersects with the particularizing trend of Independent Living.

This reflects Meekosha's (2011) (and other authors) broader critique of much of

disability studies scholarship; she argues: "disability studies was constructed as a field of

knowledge without reference to the theorists, or the social experiences, of the global

south" (p. 668). Abstractly, a connection can be made through considering global

neoliberal developments, but work is needed to consider how these trends manifest

experientially for people with disabilities and attendants. How do attendant services

influenced by Independent Living account for new and temporary Canadians using the

services or working as attendants who may or may not speak English? Do the programs

target and encourage new and temporary Canadians to fill these jobs? When the self-

managers have more control over who is hired they often hire by word of mouth or

choose post-secondary students who benefit from an "ideal student job" but do newly

arrived Canadians lose out? Do new Canadians using the Direct Funding program hire

other immigrants? How do new Canadians change the values and manifestations of

Independent Living? What are the racialized implications of re/moving care? Indeed,

there are many remaining unanswered questions.

Secondly, amidst the sea of studies documenting user satisfaction with direct

funding programs in a variety of contexts (e.g., Caldwell, 2007; Leece, 2000; Stainton &

Boyce, 2004) and a few studies that have begun to complicate those messages

(Askheim, 2005; Pearson, 2000; Ungerson, 2004) there is a substantive need for studies that explore the "satisfaction" and strategies of people who remain on waiting lists for years, or who are ineligible to apply, or are rejected from a program. Further, there is a dearth of studies in Ontario exploring how people with intellectual disabilities and their families piece together pockets of individualized funding and how these experiences resonate with or differ from the Direct Funding experience, particularly the highly unregulated and undocumented individuals employed through these programs.

Thirdly, there is a need to document and collect demographic information from attendants working under the Direct Funding program and individualized funding models in Ontario and Canada. The example of attendant services under direct and individualized funding include the notion of 'not like work,' which could possibly be used to explore the nature of work in contemporary contexts.

Finally, there is a need for a more critical examination of Independent Living in Canada. It is difficult to critique non-profit organizations struggling in a hostile environment, particularly those with social movement roots; thus, the few accounts of Independent Living in Canada take a somewhat positive approach (especially Lord, 2010). Yet, there is room and a need for what Spandler (2004) terms in reference to Direct Funding "progressive critiques" that take a constructive approach to offering criticism. It is time for Independent Living in Canada to evolve in ways that reflect new approaches to intellectual disability as well as the issues and methods of youth leaders.

Concluding thoughts

This study is a testament to the story behind the story; there are nuances and complexities revealed in the narratives behind public documents; however, the lived and public narratives are not in competition, but rather serve different ends. The public messages around Direct Funding proclaim "this is not care," but the other part of this process, equally as interesting and potential transformative, is implied, made apparent only through conversations. As this exploration of the Ontario Direct Funding program demonstrates, public messages have elements of strategy and are often shaped in response to political and economic contexts or parallel initiatives in international arenas. Tying messages about disability and care to a practical, concrete solution like Direct Funding is a powerful combination resulting in substantive cultural and material effects. These include some highly empowering changes for individuals with disabilities using the program and altering the terms of academic conversations about care, disability and feminism. Yet, as largely seen through the narratives of participants in this study, there are also some unintended consequences of this framework, resonating through a variety of public policy issues, shaping which issues are highlighted and addressed within the program itself, and appearing within disability movements in Canada.

By moving care out of attendant services but not eliminating it completely, Independent Living creates spaces and conditions for autonomy and helps to position people with disabilities as active citizens. When considering the complete process of

re/moving care, it makes it possible for one self-manager to say, "I guess Independent

Living is um, it's, it's what takes care of me" without meaning that she, or people with

disabilities, need to be spoken for, managed or abused. By moving the concept of care,

Independent Living in some respects, represents a deeply caring framework that treats

disabled people fairly, respectfully and as full humans. Killian, when explaining why he

does not use the word 'care,' comments:

> Let's just say you are my attendant and you come in one night for dinner to help
> me with dinner and I say, "Oh Chrissy, would you mind helping me out tomorrow
> night? Because someone can't do it." I think it's, I think you would be more
> willing to do it than, than if I go, "Hey Chrissy I need care tomorrow night, would
> you mind working for me tomorrow night?" I try to take the institutionalized
> language out of everything I do.

Indeed, as Killian demonstrates, it is unusual to use the first person when referring to

needing or receiving care. It uncommon to be an active participant who declares "I need

care" or "I am cared for," as we are accustomed to talking about "providing care for" or

"taking care of" someone else. Care is indeed steeped in a myriad of meanings,

including oppressive ones. Efforts to move care away from Independent Living help to

limit its oppressive reach in practice and academic conversations while also contributing

in unexpected ways to discussions among policy makers. These efforts also influence

daily conversations between attendants and self-managers who, through living and

doing Independent Living, resist the legacies and mentalities of "caring for" while

transforming the meanings of care within their relationships and beyond.

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Appendix 1: Interview schedule for key informant interviews

1. How were you involved in the formation of the *Direct Funding program*?
    a) When was this process? How long did it take?
    b) Who else was involved? Advocacy groups? Politicians? Attendants?
    c) Were you involved in actually drafting the document? Who else/do you know who was?
    d) Were other Canadian or International policies used as precedents?
    e) Were there any outside factors that influenced this process (political pressure? Advances in medical or social science research? Activities in other provinces?)

2. I've noticed you use the term 'care' – what does care mean in a policy context? How does this differ from your own understanding of care?
    a) **OR** I've noticed you don't use the term 'care' when talking about this policy. Why not?

3. **[for program administrators].** Can you tell me about how the program worked at first? How does it work now?
    a) How does a person qualify?
    b) How is it monitored?
    c) How are attendants recruited/trained/paid?

4. What type of feedback have you received about the Direct Funding program? When was it?
    a) Was it formal or unsolicited?

5. Have there been any formal evaluations? If so, when/how many/who conducted them? What did they reveal?

6. From your perspective, what has changed about direct funding over the years? Describe key developments and events in relation to qualification, demographics of service users and attendants, monitoring, training/recruitment, rates of pay, # of care hours, etc.
    a) What were the impetuses for these changes?
    b) Is there continuing advocacy around the program? What are the 'asks' of this advocacy? Have the messages changed since the establishment of the Direct Funding program?

7. Do you think direct funding represents a policy shift in Ontario? Where do you see it fitting on the policy/program landscape?

8.   Do you think the Direct Funding program attracts different people as attendants as compared to other forms of attendant care?

9.   From your perspective, how does direct funding change the daily experiences of giving and receiving care?

10.   **[for advocacy organizations and key informants who are involved with IL]** How central is direct funding to the Independent Living movement in Ontario?

11.   **[for advocacy organizations and key informants who are involved with IL]** In your opinion, has the concept of *independent living* changed at all over the years? Has the movement changed? What is different about it?

12.   **[for advocacy organizations, particularly CILT representatives]** How has your organization changed as result of the establishment of the Direct Funding program?

13.   Shifting gears to talk more generally about care, do you think care work is valued enough in our current society? Why or why not?

14.   Do you find certain forms of care (child care, health care, elder valued, etc.) are more valued or receive more attention than others? Where does direct funding fit in public policy discussions?

15.   In your opinion, does direct funding change the value attributed to care work in our present society?

Appendix 2: Revised interview guide for self-managers, attendants and informal supports

1. Tell me about your current life – what do you do? Work? Hobbies?

2. Describe a typical day in your life

3. **(for family)** How often do you see _____ (pwd)? When did you first know (pwd) had a disability and would need extra support?
OR **(for pwd)** How much time do you spend with your attendants?

4. What term do you use when talking about the help you/pwd need?
    a) How do you feel about the term 'care?'

5. Tell me about your history of receiving help – what other programs have you used/how did they work?
    a) Can you describe some of the people who worked with you/who you have helped?
    b) Conflicts? Fond memories?

6. Changes associated with shift to direct funding
    a) How did you hear about direct funding?
    b) **[For family/friends/attendants]** Are you involved with the management of **[name of pwd]**'s direct funding?
    c) How does it compare to other programs (other similar jobs)?
    d) What are some of the problems you see with direct funding?

7. Attendants
    a) Recruitment/job search process for attendants
    b) How would you characterize the relationship between attendants and people with disabilities? (e.g., as friends, employees, or something else)
    c) How do relationships between attendants and pwd differ from or resemble other relationships?
    d) How are attendants trained?
    e) Conflicts?
    f) Do you find attendants are different from support workers in other programs? In what ways?
    g) **[for family members/friends]** How do you relate to **[name of pwd]** attendants?
    h) **[for all]** What happens when an attendant and a family/friend are at the same place/event with **[name of pwd]**, how do you negotiate who helps?

8. (more broadly) **[for attendants]** Outside of your job as an attendant, **[for all]** do you provide support for anyone else? Who? In what ways?
   a) How is this work different from or similar to being an attendant?
   b) **[for attendants/family]** Have you ever received physical care yourself?

9. What is your earliest memory of receiving help and knowing you were being helped? **(OR)** Tell me about the first time you worked as an attendant.

10. Do you think attendant services are valued enough in our current society? Why or why not?

11. Are attendant services different from support seniors might require? Or health care in times of illness?

12. Direct funding largely came about due to local and international advocacy work based on the principles of Independent Living. Are you familiar with the IL movement? Were you/are you involved with it? What are your opinions on it?

13. Do you feel there is a difference between the terms 'Independent Living' and independence?

14. Would you say your definition of independence has changed over the years? How?