The Work of Self-Managing Attendant Services: A Reflexive Ethnographic Study

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Graduate Program in Health and Rehabilitation Sciences  
A thesis submitted in partial fulfillment of the requirements for the degree in Doctor of Philosophy  
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Abstract

In self-managed attendant services, disabled people organize and manage their own personal support services. ‘Self-managers’ take responsibility to recruit, hire, train and manage ‘attendants’ in order to have greater autonomy in attendant services, and in everyday life. Where the tasks associated with self-managing attendant services are often represented as responsibilities, this research begins with the assumption that these activities constitute work. Following critical disability studies and critical feminist scholarship, work is defined broadly as efforts made to organize and manage attendant services within self-managed models. The research presented adopts a reflexive ethnographic methodological approach to explore multiple perspectives on the work self-managers and potential others contribute in the context of one self-managed program in Ontario, Canada.

This dissertation is comprised of four integrated manuscripts, in addition to introduction and discussion chapters. The first manuscript interrogates a reflexive account of my personal and professional experiences as an attendant working within a self-managed model and theorizes embodied reflexivity as an approach to the generation of practice-based knowledge. The second manuscript elaborates a critical disability studies theoretical framework and applies this framework to critically analyze official accounts of the Ontario self-managed attendant services program. The third and fourth manuscripts present findings from the ethnographic study, reporting on the work of self-managing attendant services and considering implications. The third manuscript presents an analysis of participant-reported tasks and responsibilities, highlighting the often-invisible character of self-managers’ work and discussing factors that may be implicated in rendering this work invisible. The fourth manuscript adopts a temporal theoretical lens to explore the relational work self-managers and attendants reported in the study, and to consider both the liberatory and marginalizing dimensions of such work.

This thesis contributes knowledge pertaining to social, economic and cultural factors that shape the work self-managers and others contribute through participation in self-managed attendant services. This research further contributes theoretically informed insights
about the work of self-managing attendant services, and opens a number of theoretical, methodological and ethical discussions. This work has implications for self-managers and others who participate in self-managed attendant services, for advocates and policy-makers, for professionals, and for health professional education.

**Keywords**

Attendant Services; Direct Funding; Direct Payments; Disability; Self-Management; Critical Disability Studies; Critical Feminist Theory; Embodiment; Reflexivity; Governmentality; Work; Invisible Work; Relational Work
Co-Authorship Statement

I, Erika Ruth Katzman, acknowledge that this thesis includes integrated manuscripts that evolved as a result of collaborative endeavors. In these manuscripts, the primary intellectual contributions were made by the first author who: a) led the design and execution of the studies (developed the ethics application; conducted the literature reviews, participant recruitment, data collection, transcription and coding), b) led the data analysis and c) led the writing of the manuscripts. The contribution of Dr. Elizabeth Anne Kinsella was primarily through the supervision of the research, theoretical and methodological guidance, reflexive dialogue throughout the process, and intellectual and editorial support in crafting manuscripts for publication. Dr. Jessica Polzer offered additional intellectual and editorial support in preparing manuscripts for publication. As members of the advisory committee are acknowledged as co-authors for the purposes of publication, the third and fourth manuscripts (Chapters 5 and 6 of this dissertation) are written in a first-person plural voice (i.e. we, our).
Dedication

This work is dedicated to Barb, Carolyn and Alessia.

Thank you for taking a chance on me,

for trusting me

and for all that you’ve taught me.
Acknowledgments

The crafting of this dissertation was, at times, a lonely endeavor; but the result is a product of countless relationships, pre-existing and borne of this doctoral process. I am grateful to the vast community of mentors, teachers, colleagues, family, friends and students who have supported me along this journey. Thank you, especially, to those who have taken a chance to open doors for me, and to those who have listened and offered encouragement.

Foremost, this research would not have been possible without the willing participation of the individuals who took the time to share their experiences and expertise with me. Thank you for teaching me and for entrusting me with your stories. I am grateful to the Centre for Independent Living in Toronto for your willingness to support this work, and to the many people who supported this endeavor by helping to spread the word. I gratefully acknowledge that funding to support this research was provided by the Social Sciences and Humanities Research Council, and by various bodies within Western University, including the Faculty of Health Sciences and the Department of Health and Rehabilitation Sciences.

To my supervisor, Dr. Elizabeth Anne Kinsella, I cannot imagine what it would have been like to navigate this process without your dedicated guidance. With wisdom, generosity and patience you have pushed me to complete a project of which I am very proud. The skills I have gained, and opportunities found through your mentorship are too many to name. Thank you for encouraging me to explore, and for allowing me to grow at my own pace. It has been my privilege to learn from your expertise. Thank you to my advisory committee, Dr. Jessica Polzer, Dr. Shanon Phelan, and Dr. Pamela Cushing, each of whom have supported my scholarship and professional development in tremendously helpful ways. I owe great thanks to Dr. Debbie Rudman as well, for your support in the role of grad chair in the Occupational Therapy program. I would also like to acknowledge Dr. Kathryn Hibbert, for many, many years of informal mentorship, for helping me find my way to Western, and for continuing to shed light upon the path along the way.

To my most loving and supportive family: thank you for holding me together through this wildly challenging chapter of our lives. Your confidence and encouragement give me strength to accomplish things I might not otherwise pursue. Thank you, David, Irene, Noah
and Leah, for all of the phone calls, visits, meals, walks and runs. I deeply value your unwavering willingness listen, and to offer support in various forms.

To my PhD family: Nedra Peter and Emily Knight, thank for reminding me to put down the books and have fun once in a while. Stephanie LeBlanc-Omstead, Susan Mahipaul and Helen Butlin, thank you for discussing my work (and life!) ad naseum; for so much validation and emotional support; and for teaching me the importance of self-compassion and balance. Melanie Stone, Rachel Pack, Tobin LeBlanc Haley and Nicole Dalmar, your solidarity on these last legs has been invaluable. And of course, to my beloved OT family, especially Katie, Calen, Kayla, Shannon, Saskia, Kevin, Peter and Josh: thank you each for the vital role you played in my survival from September 2013 – October 2015.

To Delaksh—who unwittingly fell into the role of live-in confidante and frontline support person—thank you for making me laugh, for keeping me grounded, for keeping me fed, and for growing along with me these past six years. To my dearest friends in the ‘real world’, who have also been here to celebrate the highs and to help me through the lows: Kelly, Robert and Mark, Lindsay, Becky and Syb, thank you for sticking by me, for always loving and accepting me exactly as I am. Alessia and Kirk, thank you for welcoming me into your lives, for supporting me like we’ve know each other much longer than we have, and for teaching me so much in such a short time. Awooo!

Lastly, I’ll extend special thanks to the Centre for Teaching and Learning at Western, whose stellar programming and welcoming community have fueled my newfound passion for leadership in teaching and learning. Thank you, too, to the students and wider scholarly communities at Western and at King’s who have welcomed me into their classrooms and allowed me to participate in their learning—a process that has most certainly been mutual.
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The encounter with dependency is, I believe, rarely welcome to those fed an ideological diet of freedom, self-sufficiency, and equality. It was, after all, as a rejection of dependency on the feudal lord that Rousseau (echoing the sentiment of his day) declared the equality of men [sic]. But the deeper dependencies of infancy and early childhood, frail old age, disease and disability, do not vanish in a revolution. We have no lords to fight for this independence. So we have built fictions. But these fictions damage us and with the demand of women to be included in the ideal of equality, we find the limit of an ideal based on our putative independence. Therefore we have to use our multiple voices to expose the fiction and rebuild a world spacious enough to accommodate us all with our aspirations of a just and caring existence. That is the thesis and method I am pursuing here.

Eva Feder Kittay (1999, p. 5)
Preface

In October of 2006, a woman with a high-level spinal cord injury hired me to work for her as an attendant. As a social sciences undergraduate student, I knew very little about living with disability and even less about the world of support work—both of which would soon become inextricable parts of my everyday life and being. In the beginning, I was a student. While finishing my undergraduate studies, I was also learning my way around a new world. A world much like the world I already knew, but in which people did things a little bit differently. A world at times seamlessly integrated with the non-disabled world around it, and at other times standing in stark contrast.

In many ways, attendant support communities function as distinctive subcultures in which everyday lifeworlds are navigated a little bit differently than in the dominant culture. My first employer and her team of attendants, hand-picked and trained by her to understand and work within the intricacies of her unique lifeworld, worked together to show me the way. My employer would describe, explain and instruct, or direct an attendant to show me a particular routine or skill. She allowed the other attendants to fill in the gaps, and occasionally an attendant would pull me aside to quietly share tips. This inculturation was never complete; I saw and learned new facets of this world every day. Forever a student in this increasingly-familiar but always strange world, I quickly became part of a team; a community that centred around my employer. As a neophyte in this world, I marveled at what appeared to be a finely-tuned machine.

My life as an attendant was fascinating, exciting, exhausting and emotional. I learned so much technical knowledge, about wheelchairs and other assistive technology, about manual transfers and mechanical lifts, about the human body, its bowels, bladders and skin. I learned so much about people, about the complexities of relationships with others, and about myself. And I learned about disability—the nuances of life with it, the challenges of living within often-unaccommodating physical and social environments, the inadequacy of my knowledge of disability hitherto.

My life as an attendant was filled with opportunities. It became my first longer-term full-time job, the first time I was really able to save and spend money, to support myself.
There were opportunities for travel: to new places and across social realms. I was constantly meeting new people. I spent hours each day with a woman twice my age who was sage and savvy, clever and kind; who had known real struggle in her life, but also lived with immense privilege, of which she was acutely aware; a woman who, in twenty-some years of relying on other people to support her physical mobility, had mastered the art of communication. I learned and grew so much that, no longer the neophyte, I began to ask questions. I witnessed mechanical failures in the well-oiled machine. I had ideas and wanted to contribute, to help make improvements to the systems that bound us all together. My employer was open, she validated my ideas. Many were welcomed, and some made valuable contributions to refine our routines. Sometimes, my ideas were off the mark; mine was, after all, just one among several perspectives. Ultimately, the questions and ideas that I had exceeded the scope of changes that could be made to finetune the everyday lifeworld I shared with my employer and her team of attendants. These are the questions I came to pursue in this dissertation.

For five years prior to the commencement of my graduate studies, and ongoing throughout this process, I have been employed as an attendant to a small number of physically disabled women who organize and manage their own support services. Before I began this research, I learned about attendant services from my employers and through experience. I learned that, for my employers, the opportunity to ‘self-manage’ attendant services represented an important opportunity to distance their everyday lives from the institutionalized supervision and guidance of agency-managed support services. I understood that, from their perspective, self-managed attendant services facilitated an increase in autonomy as compared to previous experiences with agency-managed services. During my time as an attendant I have heard a fairly consistent narrative of praise for this arrangement. Oftentimes, what I have seen and felt from my attendant perspective coheres with this optimistic view. At other times, I witness and experience this arrangement from another vantage: seeing the work that goes into the mundane tasks of organizing and managing a team of attendants and witnessing the emotional sways of a life that relies heavily on other people. Sharing in the stresses of life lived with an extra layer of unpredictability, with the potential to affect everything from physical comfort and well-being to social participation and relationships, I have pondered at length the hidden costs of self-managed models, despite
their certain benefits. This experience has led me to investigate the phenomenon of ‘work’ in self-managed attendant services.
1 Introduction

The aim of this research was to critically examine the work that self-managers and potential others (self-managers’ employees, families, friends and support networks) contribute to self-managed attendant services. This project explored work in the context of one specific self-managed attendant services (SMAS) program in Ontario, Canada: the Ontario Direct Funding program. Multiple approaches were taken to explore the primary research question: “What is the ‘work’ of self-managing attendant services?” Sub-questions included: “Who performs the various associated forms of work? When and where? Are they paid? By whom/with whose money?”; “How is the work of self-managing attendant services understood/represented by the people who perform it?”; “In what ways is work represented in ‘official’ accounts of SMAS?”; and, “What assumptions about disabled people do the policies reveal?” To capture a variety of perspectives and representations, data were drawn from numerous sources including: interviews, reflexive journaling and field materials (i.e. policy and program documents, work schedules, personal records). The purpose of this study was to gain a broad understanding of the work that various parties contribute to the organization and management of self-managed attendant services. In application of a theoretical framework informed by critical disability studies and critical feminist theory, this research sought to illuminate hidden operations of power (social, economic, cultural and other factors) that shape the distribution of this work.

This introductory chapter provides a brief overview of self-managed attendant services in Ontario, as well as the independent living movement and philosophy that instigated the inception of this and other self-managed models. These sections are followed by a review of the literature on self-managed attendant services, highlighting key themes and situating the current research. ‘Work’ is then elaborated as a key concept in the research. A summary of issues, a rationale for this research, and a purpose statement are then presented. The chapter concludes with an outline and brief descriptions of the studies that are subsequently presented in the dissertation.
1.1 Self-managed attendant services

Community-based models of service delivery, typically represented by agency-managed attendant services, are criticized from an independent living perspective for their lack of choice, flexibility and portability (Yoshida, Willi, Parker & Locker, 2004). Rather than transfer public funding for services to agencies, self-managed models transfer funds to disabled people directly with the intent that individual service users recruit attendants based on their own set of criteria, relevant to their own preferences and needs. ‘Self-managers’, as individuals who participate in the Ontario program are commonly called, then educate and train attendants according to their unique preferences and needs. Unrestricted by an agency’s scheduling constraints, self-managers organize attendant supports around their own schedule (Yoshida et al., 2004). In contrast to agency-managed models that may restrict the range of locations where attendant services are allowed to be provided (i.e. within an individual’s home), self-managers are permitted to make their support mobile, taking attendants to work or school, shopping, on vacation, or wherever else support may be required (Yoshida et al., 2004).

1.2 The Ontario Direct Funding program

The Ontario Direct Funding (ODF) program is a self-managed model for delivering attendant support services to physically disabled people in Ontario. The Ontario program is funded by the provincial Ministry of Health and Long-Term Care (OMHLTC), administered through a central Independent Living Centre (ILC) in Toronto, and governed by the Ministry of Community and Social Service (MCSS) Act (MCSS, 1994). The MCSS Act outlines the scope and eligibility for attendant services in the province. Attendant services are defined as assistance with “essential activities of daily living” (para. 2.2.f); physical tasks related to care for an individual’s body and their home, including: washing, grooming, dressing, toileting, breathing, eating, housekeeping, positioning and transferring, and “essential communication” (para. 1.2.8). The eligible person “is at least 16 years old” (para. 2.2.a) and “requires attendant services as a result of a permanent physical disability” (para. 2.2.b). Support needs “have been stable over a period of at least one year” (para. 2.2.d), and “met while the person resides in his or her home” (para. 2.2.e).
Conventionally, attendant services are delivered through an agency-managed model wherein the organization and management of attendant supports is carried out by agency-employed staff (Spalding, Watkins, & Williams, 2006). Self-managed attendant services, by contrast, transfers public funds to disabled people directly. Provincial policy characterizes an eligible self-manager as one who: “understands the nature of his or her disability and its impact on his or her ability to carry out the essential activities of daily living” (MCSS, 1994, para. 2.2.f); “is aware of the type of attendant services he or she requires, the times at which he or she requires the attendant services, the number of hours of attendant services he or she requires and the manner in which the attendant services should be provided” (para. 2.2.g); and “is capable of evaluating the attendant services he or she would receive and of communicating his or her evaluation to others” (para. 2.2.m). The Act further stipulates that self-managers “assume the responsibility and risks inherent in undertaking” (para. 2.2.n) a specified list of tasks, that include: “scheduling” (para. 2h), “training … supervising, instructing and otherwise communicating with attendant workers” (para. 2.2.i); “recruiting, hiring and dismissing attendant workers” (para. 2.2.j); “understanding and carrying out the responsibilities that he or she would face as an employer” (para. 2.2.k); and “managing and accounting for the expenditure of … funds” (para. 2.2.l).

Key distinctions between agency- and self-managed attendant services in Ontario rest in who performs support work and how they are employed. As direct employers of their own attendants, self-managers determine the criteria on which to hire staff. Frequently, self-managers prefer to hire attendants who have not been formally trained as ‘personal support workers’ (Kelly, 2016). In Ontario, formal personal support worker training programs are offered by public (government-funded) colleges, private (for-profit) colleges and regional school boards. Despite recent efforts to create an educational standard for formal training programs, personal support work is not currently regulated in the province, and the designation may also be claimed by workers trained on the job by employers (Kelly & Bourgeault, 2015). Many self-managers prefer to hire staff who have not received any prior training, since support worker training frequently espouses a medical model of disability (Kelly, 2016). Trained support workers may arrive with assumptions about disability and a sense of authority tied to their ‘expertise’; a quasi-
professional status that may interfere with service users’ attempts to act autonomously with a worker’s support. Self-managed models therefore create an important opportunity for self-managers to choose who they will hire, and to train employees according to individual preferences and needs (Yoshida et al., 2004). This arrangement is also noted to increase choice, flexibility and control over spatial and temporal considerations, since scheduling is negotiated between self-managers and attendants directly, and the needs of other service users do not need to be considered (Yoshida et al., 2004).

The ODF program was introduced as a pilot in 1994 in response to extensive efforts on the part of a local community of service users who demanded an alternative to conventional agency-managed attendant services. The pilot offered 100 physically disabled individuals the opportunity to self-manage their attendant supports (Yoshida et al., 2004). After receiving an overwhelmingly positive review by The Roeher Institute in 1997 (The Roeher Institute, 1997), a full program was launched in 1998. By 2004, the program had 691 participants, with 300 applications pending (Yoshida et al., 2004). By 2006, the program had 720 participants, with approximately 310 people on the waiting list (Spalding et al., 2006). In 2014, the Province announced it would expand the program, with the goal of delivering funding to 1000 self-managers by 2016 (OMHLTC, 2014).

1.3 Independent living

Service user activism that lead to the emergence of self-managed attendant services in Ontario may be understood as part of a broader independent living movement. The movement dovetailed with international disability movements that began in the 1960s in England and the United States. The North American independent living movements developed as disabled people fought to join an emergent global conversation about human rights. The concept of independent living is rooted in the idea that disabled people possess expert knowledge of their needs, and that physical impairment need not constitute a barrier to one’s ability to ensure one’s own needs are met (Yoshida et al., 2004). The independent living philosophy directly opposes “the ‘sickness’ or medical model of rehabilitation” (Lord, 2010, p. 16); the conventional understanding of disability as a pathological object of modern medicine. Independent living, by contrast, “was based
on supporting people to live in their chosen communities, rather than warehoused in an asylum or institution” (p. 16). Among other political struggles, the notion of independent living became one key aspect of the disability rights platform (Withers, 2012).

The origins of the independent living movement are often attributed to efforts by disabled university students to increase access to university campuses in Illinois and California (DeJong, 2001). The movement gained greater visibility and momentum with the creation of the Center for Independent Living (CIL) in Berkeley, California. The Berkeley CIL incorporated itself in 1972 as a self-help group to be managed primarily by persons who were themselves disabled. The center provides a wide range of services, including peer counseling, advocacy services, van transportation, training in independent living skills, attendant care referral, health maintenance, housing referral, and wheelchair repair (Brown, 1978; Stoddard, 1978). (DeJong, 2001, p. 8)

In Canada, the Independent Living movement gained momentum in the early 1980s, with the first Independent Living Resources Centres (ILRC) opening in Ontario, Manitoba and Alberta.

Exceeding the role of service provision, ILRCs were seen as instrumental to support a national redefinition of disability (Lord, 2010). Notions of de-medicalization, self-help and consumerism underpinned the independent living movement’s fight for the right of disabled people to exercise increased choice and control over the supports and services they require in order to live independently in the community (DeJong, 2001; Yoshida et al., 2004). Resisting a conventional medical or rehabilitation conception of independence as physical ability to act without supports, the independent living movement articulated a renewed definition of independence as “decisional autonomy” (Shakespeare, 2014, p. 180), emphasizing individual self-determination and service user direction and control of resources at the community level (Lord, 2010). These principles led to the development of self-managed models.
1.4 Self-managed attendant services in global context: research trends

Self-managed models exist across Canada, North America and abroad. Literature on self-managed attendant services in Canada is limited. At the outset of this study, two publications were identified to focus on the Ontario program. The first detailed social and political forces that led to its development (Yoshida et al., 2004). The second examined the program through a legal/policy lens, with a focus on implications for organized labour of support workers (Cranford, 2005). A third publication includes the Ontario program in a report on self-managed care programs in Canada (Spalding et al., 2006). During the course of this study, several publications emerged exploring tensions around the concept of ‘care’ in relation to the Ontario program (Kelly, 2016; 2014; 2013; 2011). Another recent publication reports on a study evaluating impacts of and barriers to participation in the Ontario program following a funding increase in 2011 (Lord et al., 2012).

Regional, national and international variations in language used to describe self-managed attendant services posed a significant challenge to the task of reviewing relevant literature. The Ontario program, for example, is variably referred to as Self-Managed Attendant Services, the Ontario Direct Funding program, and Direct Funding within policy, academic, and popular literature. At the same time, ‘direct funding’ is used in the developmental services sector in Ontario to refer to individualized funding that may not be self-managed. In the United States, ‘personal assistance’ describes both consumer-directed (self-managed) and agency-directed supports (Clark, Hagglund, & Sherman, 2008; Mattson-Prince, Manley, & Whiteneck, 1995). In the UK, direct funding is commonly called ‘direct payments’ (see for example Riddell et al., 2005; Shakespeare, 2014; Stainton, Boyce, & Phillips, 2009) and the phrase ‘cash-for-care’ is often used in reference to direct funding programs that may or may not be self-managed (Ungerson, 2004). Though used less frequently, and not always in reference to self-managed and direct funded attendant services, further relevant literature was found to refer to an ‘independent living’ model, ‘individualized’, ‘personalized’, or ‘self-directed’ attendant services. Further variations in vocabulary result from the diversity of populations served.
through direct funding models in some jurisdictions (i.e. older adult and mental health service user populations) (Spandler, 2004).

Existing studies that identify, describe and compare self-managed models in Canada (Spalding et al., 2006) and cash-for-care models in Europe (Ungerson, 2004) reveal significant variation across sectors and geo-political contexts. Given that the present study focuses specifically on self-managed attendant services, literature on non-self-managed direct funding models has largely been excluded. Due to the aforementioned challenges with vocabulary, an initial review of the literature failed to identify a significant international literature on direct funding models. Despite apparent differences in the organization and philosophical orientation of self-managed direct funding models in a global context, research on non-Canadian models and programs offers important historical context. Furthermore, literature on non-Canadian self-managed direct funding models (in particular, a substantial body of research on direct payments in the UK) demonstrates important philosophical development in theorizing around self-managed models. The following sections highlight key themes in the Canadian and non-Canadian literature on self-managed models.

1.4.1 A dominant narrative of praise

A narrative of praise dominates much of the earlier literature on self-managed models in Canadian (Yoshida et al., 2004) and non-Canadian contexts (Spandler, 2004; Stainton & Boyce, 2004). Praise for self-managed attendant services is commonly attributed to the potential for such models to promote the independent living principle of ‘self-determination’ (Spandler, 2004), a version of independence that foregrounds decisional autonomy over conventional understandings of independence as acting without support. Praise is commonly expressed via an emancipatory discourse (Scourfield, 2005; Stainton & Boyce, 2004) emphasizing choice, control and flexibility (see for example, Arksey & Baxter, 2012; Carmichael & Brown, 2002; Glendinning, Halliwell, Jacobs, Rummery, & Tyrer, 2000a; Yoshida et al., 2004); terms that reflect the independent living philosophy (Prideaux, Roulstone, Harris, & Barnes, 2009), and are variably adopted in the literature in reference to increased service user choice and control in hiring and training attendants, and flexibility to self-determine the time, place and particulars of supports provided. This
dominant narrative of praise is reflected in a number of studies reporting on user satisfaction with self-managed models, in which satisfaction is frequently reported in comparison to (previous experiences with) agency-managed models (see for example, Clark et al., 2008; Mattson-Prince, 1997; Mattson Prince et al., 1995; Stainton & Boyce, 2004). Other studies report positive impacts of self-managed models on health and overall quality of life (Hagglund, Clark, Farmer, & Sherman, 2004; Mattson-Prince, 1997; Mattson Prince et al., 1995; Yoshida et al., 2004); as well as improved lifestyle and vocational opportunities with related outcomes for identity and self-esteem (Glendinning et al., 2000a; Stainton & Boyce, 2004).

1.4.2 Challenges with implementation

Alongside a significant literature describing the benefits of self-managed attendant services, a growing body of critical perspectives urge a more balanced critique. A number of studies corroborate the afore-mentioned benefits of self-managed models but describe challenges and issues as well. One critique that surfaces recurrently in the literature addresses issues with implementation of self-managed models. Several studies cite lack of infrastructure, such as supports to assist service users and families with the self-manager role (Arksey & Baxter, 2012; Barnes, 2000; Carmichael & Brown, 2002; Glendinning et al., 2000a; Leece, 2007; Maglajlic, Brandon, & Given, 2000; Morris, 2004). Other studies discuss structural barriers to implementation (Leece, 2004; Pearson et al., 2005; Stainton, 2002), including ignorance or resistance among gatekeeper clinicians, service providing agencies (Glasby & Littlechild, 2008; Morris, 2004; Riddell et al., 2005; Scourfield, 2005) and local governments (Barnes, 2007; Priestly et al., 2007). Lack of public and professional knowledge and awareness of self-managed models was cited as another barrier to implementation (Carmichael & Brown, 2002; Glendinning et al., 2000a; Morris, 2004; Spalding et al., 2006). Among other structural barriers, insufficient funding was noted to constitute a barrier to accessing self-managed models (Slasberg & Beresford, 2015), and was highlighted as a factor preventing full realization of an independent living philosophy within self-managed models (Marfisi, 2002; Morris, 2004; Slasberg, Beresford, & Schofield, 2012; Spandler, 2004). Other factors noted to impact access include personal wealth (Leece & Leece, 2006), geographic location
(Barnes, 2007; Morris, 2004), type or severity of disability (Morris, 2004), and race (Clark et al., 2008).

1.4.3 Relationships

The literature addressing relationships in self-managed attendant services illustrates a complex web of benefits and challenges (Christensen, 2012; 2010; Glendinning, Halliwell, Jacobs, Rummery, & Tyrer, 2000b; Kelly, 2016; Spandler, 2004). Multiple studies note the potential for self-managed models to decrease the burden of care work responsibilities on families, thereby potentially improving relationships within families (Leece, 2004; Lord, 2012). Another noted benefit is continuity in support relationships (Leece, 2004; Yoshida et al., 2004). Several studies note the potential for deeper and more meaningful relationships to develop between self-managers and attendants (Glendinning et al., 2000b; Kelly, 2016; Stainton & Boyce, 2004). Alongside these benefits, persistent critique of self-managed models has highlighted a potential for overdependence and exploitation (Ungerson, 2005; 2004; 1997) in relationships that are at once professional and intimate (Glendinning et al., 2000b; Kelly, 2016). Several studies highlight issues with compensation for attendants (Kelly, 2016; Leece, 2010; 2004; Leece & Peace, 2010; Ungerson, 2005; 2004; 1997), while others raise the issue of organized labour, noting a lack of workplace protections for attendant workers (Church, Diamond, & Voronka, 2004; Cranford, 2005; Leece, 2010; Riddell et al., 2005; Scourfield, 2005; Spandler, 2004). Additionally, Marfisi (2002) discusses lack of recognition for the skilled expertise required of good attendants, as well as lack of opportunities for professional mobility among attendants.

The literature addressing attendant/worker issues in self-managed attendant services has met with resistance from scholars such as Morris (1997), who highlights incongruity between the intent of the independent living movement to liberate disabled people from oppressive professional ‘caring’ relationships and attempts in the literature on self-managed attendant services to reclaim and to valorize attendants’ work as more than a set of mechanistic physical tasks. Several scholars (Christensen, 2012; 2010; Kelly, 2016; 2011; Leece, 2010) acknowledge the fraught history of care as a construct in relation to disability, but argue its outright rejection disregards feminist care
scholarship—a literature of noted value as a means address the frequently feminized and racialized character of the support worker and attendant workforce (Christensen, 2012; Leece, 2004; Scourfield, 2005; Spandler, 2004).

1.4.4 Cost-effectiveness

Cost-effectiveness is a frequently-cited benefit associated with self-managed models. Few studies, however, elaborate or factually support this claim (Stainton et al., 2009). One American study by Clark et al. (2008) identifies system-level benefits owing to income tax contributions from both individuals who would have increased employment opportunities if they had portable attendant services, and from family members of disabled individuals who could work more if their disabled family member were able to afford more hours of paid assistance. The same study also describes a reduced need for emergency room and hospital care for individuals living with disabilities who experience improved health outcomes under a self-managed model of service delivery. Comparative studies have related cost-effectiveness to service user incentives to make efficient use of limited funding (Spandler, 2004; Zarb & Nadash, 1994), to the reduction in overhead administrative costs (Stainton et al., 2009), to lower wages paid to unskilled attendants (Clark et al., 2008), and to more efficient use of time by attendants who are motivated by relational ties (Stainton et al., 2009). Prideaux et al. (2009) critique comparative analyses that “have not taken account of the economic and social implications for informal ‘carers’, relatives and friends”; they urge “a more thorough and holistic analysis of the less acknowledged socio-economic costs and benefits of self-directed support systems for service users, their families, [attendants] and local/national economies” (p. 559). In addition to costs, Prideaux et al. highlight benefits such as opportunities for personal assistance skills gained by attendants through workplace experience and a reduced need for informal care work leading to increased opportunities for informal carers to work in formal workplaces.

Urging a more critical analysis of cost-effectiveness, Spandler (2004) describes cost savings at a “thorny issue” (p. 193). Spandler is one of a number of scholars to raise concern about broader social implications of self-managed schemes, noting in particular a tendency for market logic to trump the model’s social justice orientation (see also Hande
Critiques in this vein highlight the potential for direct funding to marketize, privatize and individualize social support services, potentially eroding social service infrastructure (Hande & Kelly, 2015; Mladenov, 2015; Scourfield, 2007; 2005), while at the same time advancing depoliticized self-managed models that move ever farther from their revolutionary principles (Riddell et al., 2005; Scourfield, 2005). Gendered analyses (Leece, 2004) link privatization of support work (see also Cranford, 2005) and processes that commodify care (see also Marfisi, 2002; Ungerson, 1997) to increased precarity of feminized labour. Additional critiques focused on the neoliberal economic context suggest that marketization as a route to cost-efficiency in neoliberal healthcare is achieved by downloading responsibility to individuals (Hande & Kelly, 2015; Scourfield, 2007), while “popular rhetoric is routinely employed to mask the twin goals of marketisation and austerity” (Mladenov et al., 2015, p. 311). Recent analyses challenge the validity of claims to cost-efficiency outright (Pearson & Ridley, 2017), and suggest properly implemented self-managed models may actually be more expensive than conventional models (Maldenov et al., 2015; Slasberg & Beresford, 2015; Slasberg et al., 2012). Slasberg et al. express concern that “While advocates of the current strategy continue to point to the success of the minority who are flourishing, other research is showing that life for the majority is poor and probably worsening” (p. 1033).

1.4.5 Work

In conventional agency-managed service models, support workers and the agency staff responsible to hire, train and organize support workers are constructed as the workers in supporting relationships. A defining feature of self-managed attendant services is the change in the service user role, from recipient to manager of services. A small number of studies have observed and discussed the work self-managers take on in this role. Several studies identify the added burden of paperwork and administrative tasks as a potential challenge to implementation and uptake of self-managed models and call for adequate measures to support self-managers in their role (Carmichael & Brown, 2002; Glendinning et al., 2000b; Morris, 2004; Stainton & Boyce, 2004). Some studies have described efforts required to manage boundaries in the unusual relationships that develop within
self-managed models (Glendinning et al., 2000b; Kelly, 2016; Leece, 2010); a responsibility Marfisi (2002) describes to require skill, and part of what Kelly (2016) has referred to as the ‘relational work’ of self-managing attendant services. Stainton and Boyce (2004) conclude that “While the administration and management demands were not inconsequential … they are not seen by disabled people as a significant barrier” (p. 453). Spandler (2004) urges a more nuanced analysis that moves beyond consideration of individual costs, suggesting that the focus on “[difficulties] relating to bureaucracy, paperwork and administration … has resulted in little acknowledgement of other more fundamental and complex difficulties” (p. 194).

More explicit discussions of self-managers’ work appear in a subset of literature that debates the character and significance of work in the context of self-managed attendant services. Drawing parallels to other forms of (usually paid) work, several scholars (Barnes, 2000; Morris, 2004; Prideaux et al., 2009; Rummery, 2006) name and describe the responsibilities of the self-manager role as ‘work’. These authors argue for recognition of self-managers’ contributions in relation to productivity expectations of citizenship in modern societies and encourage a reconceptualization of productivity to include the kinds of contributions disabled people can make in a self-manager role. Barnes highlights the potential for engagement in this work to positively impact identity and lifestyle, while Prideaux et al. discuss the potential to challenge the common social construction of disabled people as dependent or non-productive. While these authors argue to expand notions of social inclusion that recognize the productivity of unpaid work, Mladenov’s (2017) recent work bridges conversations about representation, work and cost-effectiveness: characterizing self-managed attendant services as “a transition from welfare to workfare” (p. 92) and challenging the social requirement of productivity itself.

1.5 Situating this research

This review of key themes in the Canadian and non-Canadian literature on self-managed attendant services reveals a body of scholarly work that is abundant, self-critical and actively growing. Attesting to the significance of self-managed attendant services as an historical achievement, praise for such models persists amidst significant and growing
critique of their challenges, pitfalls and shortcomings. Scourfield (2005), for example, concedes the widely-cited benefits of self-managed models are undeniable; but remains apprehensive of “[overoptimistic] messages—especially those from government—about the ‘transformative’ effects of direct [funding]” (p. 485). In my own experience, and in my review of the literature, I have found that there exists a dominant narrative of praise for self-managed models. However, my experience and observations also resonate with a critical subset of the literature on self-managed attendant services, which has found that “the situation is more complex and the solution not as complete as has been assumed in some of the disability studies literature” (Shakespeare, 2006, p. 148). While much scholarship in this area has focused on the benefits of self-managed models and challenges with implementation and uptake, an emergent literature with strong foundations is now applying critical theoretical perspectives to examine barriers to successful implementation of self-managed models, including attention to unintended and potentially detrimental consequences of a model with undeniably laudable intentions. As Hande & Kelly (2015) aptly note, critique in this genre is complicated, since “Direct Funding users in Ontario and in other contexts advocate strongly for this model and report high levels of satisfaction, including increased freedom, flexibility, and sense of empowerment, especially in contrast to other forms of service delivery” (p. 968). In this dissertation, I work with and build upon existing scholarship on self-managed attendant services to contribute a novel perspective with a focus on the work self-managers and others do in the context of such models. With full recognition and respect for the activist origins of self-managed attendant services and for continued reports of service user satisfaction, this research applies a critical perspective towards the ongoing project of improving self-managed models and the lives of those who participate in them.

1.6 Theorizing ‘work’

In this dissertation I explore multiple perspectives on the work self-managers and potential others contribute to organize and manage attendant services in the context of one self-managed attendant services program in Ontario, Canada. This research is informed by a particular conception of work, which includes certain assumptions about the work required to organize and manage attendant services. The conceptions of work
guiding this research stem from ethnographic, critical disability studies and critical feminist literatures. A foremost assumption about the work of self-managing attendant services is that the responsibilities self-managers accept, and the activities self-managers and their networks engage in to support them, indeed constitute work; and, that this work may unintentionally contribute to the perpetuation of cycles of marginalization affecting both disabled self-managers and those who support them.

In this dissertation, ‘work’ is understood broadly “to direct attention to everyday practices in which people engage and that their labour produces. This includes formal participation in the labour market and activities that people do that they might not normally think of as work” (Bisaillon, 2012, p. 620). This definition of work extends to include “what people do [but] it is also about the consciousness that necessarily goes along with doing”; “planning”, “thinking”, “deciding”, “coordinating”, and so on (Smith, 2002, p. 46-47). This definition encompasses the “complex invisible ‘work’—generously defined—performed by disabled people in every day/night life” which spans “becoming/staying corporately viable, the work of disabled people in managing their engagement with personal support workers, and the work of disabled women as they use clothing practices to mediate societal expectations around ‘normal’ female bodies” (Church, Frazee, Panitch, Luciana, & Bowman, 2007, p. 1). This definition readily includes the work self-managers do to recruit, hire, train and manage attendants, to maintain accountability to the local organization that administers their funding and to the Canada Revenue Agency. It also encompasses the work attendants and potential others (family members, friends, colleagues, acquaintances, health care workers) contribute to the organization and management of attendant services.

1.6.1 Dependency work

A specific definition of work that helped to shape this research is Kittay’s (1999) conception of ‘dependency work’: “the work of caring for those who are inevitably dependent” (p. ix). Kittay explains ‘inevitable dependency’ as a natural part of the human condition, involving “identifiable states of our life history in which dependency is unavoidable, either for survival or for flourishing” (p. 29).
The immaturity of infancy and early childhood, illness and disability that renders one nonfunctional even in the most accommodating surroundings, and the fragility of advanced old age, each serve as examples of such inescapable dependency. The incapacity here is determined neither by will nor desire, but by determinants of biology in combination with social circumstances. (p. 29)

Dependency work comprises the paid and unpaid work of attending to dependents. As work that women traditionally took on “as part of their familial duty” (p. 30), dependency work is either unpaid or “poorly paid labor” (p. 40). It is “most commonly assigned to those in a society with the least status and power” (p. 16). “In contrast to the visibility of the professional … dependency work [is] especially invisible” (p. 40); and, “While professional work is held accountable to publicly acknowledged ethical standards, affectional ties importantly sustain dependency work” (p. 40), “even when the work involves an economic exchange” (p. 31).

To conceive of the work that self-managers do as dependency work invokes tension with the independent living philosophy that underpins self-managed attendant services. One tenet of independent living includes rejection of ‘care’ as a practice that perpetuates traditional power relationships and situates disabled people in a passive role (Kelly, 2016; Shakespeare, 2006). From an independent living perspective, “the vital distinction was between physical dependency—not being able to do particular tasks—and social dependency” (Shakespeare, 2006, p. 139); in taking responsibility for the organization and management of their support services, self-managers are less socially dependent than disabled people who are traditionally ‘cared for’. The goal of the independent living movement was “to gain independence through being able to control how tasks are performed”; “From a disability rights perspective, the aim became autonomy, not self-sufficiency” (p. 139).

The independent living perspective embraces and maneuvers within dominant Western discourses of equality and autonomy. Kittay’s theorization of dependency work, by contrast, critiques notions of equality and independence, emphasizing the injurious
effects of “the fiction of independence” (p. xiii) upon those whose dependence is more limiting and those who do work to support them. She argues that

A conception of society viewed as an association of equals masks inequitable dependencies …. While we are dependent, we are not well positioned to enter a competition for the goods of social cooperation on equal terms. And those who care for dependents, who must put their own interests aside to care for one who is entirely vulnerable to their actions, enter the competition for social goods with a handicap. (p. xi)

Kittay locates a fundamental inequality in “discussions of political and social justice that take as their starting point the public lives of men” (p. 2); “a hypothetical being—usually male, unencumbered, physically and cognitively intact—enables the elaboration of patterns of rights and liberties which may bear little relation to the realities of life for the majority of citizens” (Shakespeare, 2006, p. 135). For Kittay (1999), “this starting point has determined not only moral, social and political theory; it also has determined the shape of public policy” (p. 2).

Dependency work was invoked in the framing of this research as a useful lens to consider the responsibilities disabled people absorb, and the work that goes into the execution of these responsibilities, when attendant services are organized and managed through a self-managed model. This research explores the work of self-managers primarily, but considers the contributions attendants, family members, friends, colleagues and other acquaintances may also contribute to the work of self-managing attendant services. It is an extension of Kittay’s original theorization to conceive of disabled people doing their own dependency work. After all, the very definition of dependence suggests that disabled people are incapable. As noted, however, the independent living philosophy distinguishes physical and social dependence. With this distinction, it is possible for some disabled people to execute some of the dependency work related to their physical dependence: the organization and management of attendants, and the self-direction of supports, amongst potential others. The definition Kittay provides of dependency work as low wage, if paid at all, typically relegated to marginalized people, relatively invisible
and vitally dependent upon affective elements and interpersonal relationships resonates strongly with the literature on attendant work and on self-managed models, and with my own personal observations and experiences working as an attendant. Viewing the labour that self-managers and their networks contribute as ‘work’ and considering it in light of histories of ‘dependency work’ informs this critical examination of work in self-managed attendant services.

1.7 Summary of issues

Self-managed attendant services evolved in response to an assertion that disability is not inherently medical in nature; that disability does not require constant medical attention, and that it is within both the rights and the capabilities of many disabled people to be primary, if not sole decision makers regarding the organization and management of their own attendant services, and their everyday lives (Shakespeare, 2014; Yoshida et al., 2004). A key element of the argument for self-managed models is that disabled people should be free to choose who will provide their attendant supports, when, where and how. Further, since the attendant support needs of disabled people are not necessarily medical in nature, attendant supports need not be provided by someone who has been formally educated to do so (Yoshida et al., 2004).

The structure of self-managed attendant services in Ontario grants some disabled people, meeting certain requisite qualifications, the opportunity to make decisions about the organization and management of their attendant services, including selection and hiring of attendants, and determination of attendants’ qualifications. This opportunity, however, also requires that disabled people accept responsibility for all administrative, organizational, management and human resources activities associated with their support services. This research attends to a disquieting trend in health and social services to adopt self-managed models in supposed satisfaction of a mandate to provide efficient and effective services, without acknowledgement of the unpaid work that marginalized people contribute.

By investigating representations of the work of self-managing attendant services in ‘official’ accounts and in the reported experiences of self-managers and their support
networks, this research critically examines the nature of this work and the realm of possibility that surrounds it (i.e. potential alternative ways in which that same work might be understood and constructed). Without denying the achievements of the independent living movement, and the frequently cited positive impacts (i.e. freedom, choice and flexibility) self-managers and others attribute to self-managed models, this research draws attention to the often-invisible “survival workload” (Pearpoint, 1990, p. 20) that disabled people and those who support them shoulder. The point is not to debate whether such work is desirable or advantageous, but to acknowledge that “it is work that must be done by someone” (Kittay, 1999, p. 16).

1.8 Rationale

Most available literature on the Ontario Direct Funding (ODF) program reproduces a dominant narrative of praise, emphasizing benefits and noting some challenges (Lord, 2012; The Roeher Institute, 1997; Yoshida et al., 2004). With the exception of Kelly’s recent work investigating constructions of care in self-managed attendant services (2016; 2014; 2013; 2011), little scholarship has approached the Ontario program through a critical lens. This research attends to this gap in the literature on self-managed attendant services in Ontario. With a focus on the work self-managers and others contribute to organize and manage attendant services, this dissertation also makes a unique contribution to the broader global literature on self-managed models.

This study adopts a critical theoretical framework informed by critical disability studies and critical feminist theory, focusing on dimensions of experience that may not be fully represented in existing scholarly literature and in ‘official’ accounts (i.e. policy and program literature) of self-managed attendant services. In particular, this study aims to elucidate the work that various parties contribute to the organization and management of self-managed models. In application of this critical theoretical framework, this project seeks to contribute to the expansion of current representations of the work of self-managing attendant services, by incorporating the perspectives of self-managers and those who support them towards a more comprehensive understanding of the work of self-managing attendant services. This knowledge has the potential to make a valuable
contribution to the creation and maintenance of policy that remains relevant, effective and accessible.

The initial questions taken up in this study arose from personal and professional experiences and observations during my employment as an attendant. The impression I was left with after several years of practical experience in this field was that self-managed attendant services represents a vital alternative to traditional agency-managed; however, access to what is often constructed as the *privilege* to self-manage attendant services entails an incredible amount of work—much of which does not seem to be recognized in policy and program literature. Since much of the (often low-wage or unpaid) work involved in self-managing attendant services falls on populations that may be disadvantaged (disabled people, women, people of colour, immigrants) (Cranford, 2005; Yoshida et. al, 2004), the Ontario program may unintentionally contribute to the perpetuation of cycles of marginalization affecting these groups. By incorporating accounts grounded in the experience of people whose work contributes directly to the organization and management of self-managed attendant services, this research generates a ‘textured’ account (Church et al., 2004) of self-managed attendant services, which represents various stakeholder perspectives and holds potential to inform policy that is directly relevant to the people whose daily realities are affected by it.

1.9 Purpose statement

The purpose of this research is to present a richly textured account of the work self-managers and others perform to organize and manage attendant services. The outcomes stand to make a meaningful contribution to the ongoing development of relevant and effective policy on long-term health and social care for Canadians with disabilities. The objectives of this research were: 1) to broadly understand the work that self-managers and potential others contribute to the organization and management of attendant services; 2) to produce a representative account of the work of self-managing attendant services that is relevant to the people who perform such work; and 3) to consider participant accounts in the light of existing ‘official’ accounts of self-managed attendant services.
1.10 Plan of presentation

This dissertation is presented in an integrated manuscript format. In this introductory chapter, I have introduced myself in relation to self-managed attendant services and the Ontario Direct Funding program. Through a review of the scholarly literature on self-managed attendant services, I have situated the Ontario program in relation to other self-managed models in non-Canadian contexts. I have outlined the particular conception of work taken up in this study, summarized the issue, provided a rationale for this work, and stated the purpose of the research.

The first manuscript (Chapter 2) interrogates a reflexive account of my personal and professional experiences as an attendant, adopting a critical feminist lens to theorize embodied reflexivity as an approach to the generation of practice-based knowledge. This chapter was published in *The Body in Professional Practice, Learning and Education* (Green & Hopwood, 2015), an edited volume that explores embodied ways of knowing and embodied forms of knowledge.

The second manuscript (Chapter 3) elaborates a critical disability studies theoretical framework and analyzes the Ontario self-managed attendant services program through this lens. This manuscript was published in *Neoliberal Governance and Health: Duties, Risks and Vulnerabilities* (Polzer & Power, 2016), an edited volume that critically analyzes the politics of health and social care systems in contemporary Canadian society.

The fourth chapter outlines the reflexive ethnographic methodological approach and relates this approach the critical disability studies and critical feminist theoretical frameworks. This chapter further outlines the study methods, quality criteria, ethical considerations, strengths and limitations, and plans for dissemination.

The third manuscript (Chapter 5) presents an analysis of participant-reported tasks and activities and points to how these are distinct from the responsibilities outlined in policy and program materials. The findings illustrate three ‘layers’ of work: the administrative work outlined in policy and program materials; the supplemental work self-managers engaged in to support completion of administrative responsibilities; and
the more abstract work self-managers undertook to navigate uncertainties; much of which appears to be invisible in official accounts and to self-managers. In this paper, I discuss factors that may be implicated in rendering this work invisible and conclude by considering implications of invisible work. This manuscript is currently in press in the journal *Disability & Society*.

The fourth manuscript (Chapter 6) adopts ‘crip time’ as a theoretical lens to explore temporal and other resources that self-managers and attendants contribute to the performance of relational work in the context of self-managed attendant services. These findings highlight a tension between potential liberatory and marginalizing effects of the work self-managers and attendants do to organize and manage attendant services. Implications for policy, practice and education are discussed.

A concluding seventh chapter discusses the emerging findings and implications of this research. Reflexive insights on the research process and directions for future research are also discussed.

### 1.11 References


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2 Embodied reflexivity: knowledge and the body in professional practice

2.1 Introduction

Embodiment and reflexivity both are concepts familiar to contemporary professional practice and education scholarship. The aim of this chapter is to explore the fusion of these concepts, considering embodied reflexivity as an approach to knowledge generation in the context of professional practice. In this paper I present reflexive writing about my own personal and professional experiences and observations over several years of employment as an attendant service worker. I aim to show how an embodied narrative about embodied experience can reveal embodied reflexivity, as a form of reflexivity that is felt within the body. I further suggest that attending to embodied reflexivity potentially offers an important avenue for knowledge generation: a path of access to the unique knowledges of individual practitioners, developed through embodied professional experience. As a preface to the reflexive account introduced later in the chapter, I begin by examining conceptual work on reflexivity and embodiment, to consider how a notion of embodied reflexivity may be a salient concept with respect to making tacit or invisible embodied knowledges more visible. It is my intent to demonstrate, by way of reflexive writing, how acknowledging and attending to embodied reflexivity offers a unique contribution to how we think about what counts as knowledge, specifically in the context of professional practice.

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2.2 Reflexivity: thinking critically about the generation of knowledge

The concept of reflexivity is relatively new to conversations surrounding professional practice. Some examples can be found in the literature on health and welfare (Taylor & White, 2000), social work (D’Cruz, Gillingham, & Melendez, 2007), education (Cunliffe, 2004; 2002), occupational therapy (Kinsella & Whiteford, 2009; Phelan, 2011) and nursing (Bellot, 2006; Cheek, 2000). Reflexivity is often described in terms of its etymological roots in the Latin reflexus, meaning ‘to bend back’. Reflexive ‘bending back’ is most commonly described as a critical cognitive process that is fundamentally concerned with “interrogating interpretive systems” (Sandywell, 1996, p. xiv). At an individual level, reflexivity is about recognizing ways in which the self is implicated in the social production of reality and of interpretive knowledge, and thus recognizing the values, attitudes, assumptions and prejudices influencing the thoughts and behaviours of individuals as actors or interpreters (Bolton, 2010). At a social level, reflexivity involves recognizing the socially constructed nature of many aspects of reality (Cunliffe, 2004), as well as “the sociality of the process of knowledge generation” (Kinsella & Whiteford, 2009, p. 251).

Bolton (2010) suggests that “The reflexive thinker has to stand back from belief and value systems, habitual ways of thinking and relating to others, structures of understanding themselves and their relationship to the world, and their assumptions about the way that the world impinges upon them” (p. 14); however she notes that “This can only be done by somehow becoming separate in order to look at it as if from the outside” (p. 14). Watts (1992, as cited in Sandywell, 1996), observes the impossibility of such a separation, stating that “if you and your thoughts are part of this universe, you cannot stand outside them to describe them” (p. 103). While Watts expresses concern at the interminability of the process of “thinking about thinking, thinking about thinking about thinking, and so ad infinitum” (p. 103), this appears to be the very nature of much of what is taken as reflexivity: an interminable process of critical questioning, in particular the interrogation of knowledge.
Reflexivity, understood in this way as an interminable process of critical questioning, parallels what Richardson (1994) has termed the postmodern “ideology of doubt” (p. 520). Indeed, at the centre of much postmodern/poststructuralist thought is an emphasis on reflexivity. Lather (2007) signals Nietzsche’s significant contribution to the philosophy of knowledge, stating, “Nietzsche invites us to … multiply perspectives toward an affirmation of life as a means of knowledge without guarantee” (Lather, 2007, p. 17). Sandywell (1996, p. 357) suggests a ‘Nietzschean reflexivity’, pointing out the influence of Nietzsche’s radical questioning of the notions of objectivity and absolute truth upon prominent poststructuralist thinkers, such as Foucault. Foucault’s genealogical writings, which are “aimed at unsettling established models of knowledge and epistemological presumptions” (Grosz, 1994, p. 145), at once address and demonstrate reflexivity. In his archeological work The Order of Things (1970), Foucault discusses the idea of reflexive knowledge amidst a reflexive analysis of the history of Western thought; he describes reflexive knowledge as “thought thinking itself” (p. 326). Foucault contends, “there is always something still to be thought … that everything that has been thought will be thought again by a thought that does not yet exist” (p. 372). In much the same way that Foucault’s methodological approaches challenge the essentialist assumptions inherent in methodologies that are concerned with the pursuit of absolute truths (Grosz, 1994; Scheurich & Bell McKenzie, 2005), reflexivity creates space for the identification and consideration of alternative ‘truths’; a space for thought about the potentiality that is stifled each time a claim to truth is made.

Perhaps the most crucial function of reflexivity in relation to the generation of knowledge is the capacity for reflexivity to draw attention to and demand awareness of the situated and partial nature of claims to knowledge. Acknowledging the social construction of knowledge, reflexivity reveals not just the incompleteness of claims to knowledge, but also highlights the tendency of truth claims to mask and serve particular interests. “Once it is acknowledged that truth itself is constructed not discovered, then specific interests – be they racial, class, sexual or gender – pertaining to the dominant agents of discursive power must clearly affect the content of that truth” (Shildrick, 1997, p. 22). Kinsella and Whiteford (2009) usefully employ Greene’s (1995) metaphor of a “cloud of givenness, of what is considered ‘natural’ by those caught in the taken-for-
granted, in the everydayness of things” (p. 47) to illustrate the way in which disciplinary knowledge, left uninterrogated, can appear natural, or without alternative. Reflexivity facilitates penetration of such normative conceptions of knowledge, exposing the subjective nature of claims to knowledge, including the values, interests and relations of power wrapped up within them, and thereby creating a space for the development of alternative interpretations.

**2.3 Embodiment: on (the generative potential of) the body and lived experience**

Reflexivity, in the tradition described here, is commonly conceived of as a cognitive act, an intellectual exercise of critical interrogation of processes of knowledge generation. My purpose in this section is to reflexively consider how conceiving of processes of knowledge generation as purely cognitive has the potential to obscure the possibility that processes of knowledge generation might also be embodied. I draw on writings about the body, primarily informed by phenomenological, feminist and poststructuralist perspectives, which suggest that constructions which frame knowledge generation as a purely cognitive process spring from a specific historical postulation; namely, the separation of mind and body incited by Cartesian dualism.

The notion that mind and body constitute distinctively separate entities stems from the Enlightenment era, and was famously and most clearly articulated in the writing of Descartes (Matthews, 2006). Descartes suggested that truth in the form of objective knowledge could only be achieved by thinking, via the cognitive function of the mind. While the philosophical bifurcation of body and mind had appeared elsewhere in history, “Descartes … succeeded in linking the mind/body opposition to the foundations of knowledge itself, a link which places the mind in a position of hierarchical superiority over and above nature, including the nature of the body” (Grosz, 1994, p. 6). Descartes doubted the reliability of the bodily senses as a means of capturing the supposed essence of reality, expressing an epistemological orientation that came to represent the philosophical foundation of modern science; in particular, modern science’s rejection of the body as a potential source for the generation of knowledge (Matthews, 2006). In the
words of Grosz (1994), “Descartes instituted a dualism which three centuries of philosophical thought have attempted to overcome or reconcile” (p. 6).

Embodiment is an emerging concept that is beginning to be taken up as a critique of the prioritization or legitimation of the mind at the expense of the body. “An embodied perspective begins with the assumption that our bodies are mediums through which we experience the world” (Kinsella & Park Lala, 2011, p. 78). Offering an alternative to Descartes’ framing of the body as distinct from the mind, phenomenologist Merleau-Ponty (1962) suggests a more integrated understanding of body and mind when he says that “The body is the vehicle of being in the world … I am conscious of the world through the medium of my body” (p. 94-95). For Merleau-Ponty, consciousness, perception and the mind are embodied phenomena: “The body and the modes of sensual perception which take place through it … affirm the necessary connectedness of consciousness as it is incarnated; mind for him is always embodied, always based on corporeal and sensory relations” (Grosz, 1994, p. 86). Theories of embodiment aim to recover and legitimize alternative accounts informed by and generated from within sensory experience.

Grosz (1994) links Merleau-Ponty’s emphasis on the primacy of lived experience to a similar vein in feminist contributions to the philosophy of knowledge. Harding (1991) suggests that different knowledges arise from different perspectives on and experiences of reality, pointing to the capacity of thinking from the perspectives of women’s lives to ‘make strange’ what had previously appeared familiar. Grosz finds in Merleau-Ponty three key insights relevant to feminist perspectives on the relationship between experience and knowledge: 1) that experience at once produces and is produced by knowledge; 2) that experience “is not only the starting point of analysis but also a kind of measure against which the vagaries of theory can be assessed” (Grosz, 1994, p. 95); and, 3) that experience is at once cognitive and corporeal, and “can only be understood between mind and body—or across them—in their lived conjunction” (p. 95). A focus on the body and attention to lived experience as a path to knowledge highlights and challenges the dominance of cognitivism or intellectualism as the sole avenue for the
production of knowledge, and offers an epistemological alternative to Cartesian rationalism.

While some phenomenological and feminist approaches to the generation of knowledge argue that we need to begin with the body, Foucault’s poststructuralist critique of rationalism intentionally decentres the subject, preferring instead to approach analyses by focusing on language and discourses (Scheurich & Bell McKenzie, 2005). While the body and lived experience tend to be downplayed in postmodern/poststructural analyses, Grosz (1994) locates critiques of the absence of the body in the work of Nietzsche:

For Nietzsche, consciousness is a belief, an illusion … a convenient fiction. … Knowledge, mind, philosophy, as that activity supposedly concerned with reason, is the discipline most implicated in a will to ignorance … philosophy is based on a disavowal of its corporeal origins and its status as corporeal product. The body is the intimate and internal condition of all knowledges … (p. 125)

Grosz shows that, in turning a reflexive gaze back upon knowledge itself, Nietzsche acknowledges the bodily origins of knowledge. Although Foucault does not explicitly take up lived experience as fundamental to the generation of knowledge, Foucauldian analytics still facilitate the sort of reflexive analyses that create space for the consideration of alternatives to dominant modes of knowledge generation. Furthermore, Foucault’s work on the body, as well as Foucauldian analyses applied to theories of the body, offer important contributions to work on bodily experience in relation to the production of knowledge. Foucault’s (1998) assertion that domination “establishes marks of its power and engraves memories on things and even within bodies” (p. 377, as cited in Scheurich & Bell McKenzie, 2005, p. 852) suggests that lived experiences of oppression alter bodies or generate bodily difference. This is significant in relation to Harding’s (1991) suggestion that different bodies have the capacity to generate different knowledges. It has also been suggested that the body as theorized by Foucault does in fact presuppose “an experiential understanding of the body” (Oksala, 2004, p. 99), and
that this body itself represents a site of potential resistance to normalizing power; and a
space for the creation of new possibility (Butler, 1993; Oksala, 2004).

The generation and application of embodied knowledge has also been taken up in
a more practical sense in the work of miners and what has been described as ‘pit sense’
(Sauer, 1998; Somerville, 2006). “In pit sense all the senses are employed in a complex
interconnected way … This includes sound, smell, touch, and kinaesthetic sense as well
as other senses that have no name” (Somerville, 2006, p. 43). Sauer (1998) explains pit
sense as a form of ‘embodied sensory knowledge’ which miners describe as essential to
protecting their safety in a practice context characterized by rapidly changing sensory
information. Pit sense is described as a unique form of embodied knowledge that is felt in
the body and revealed in action, but which cannot be articulated in language (Sauer,
1998). Sauer suggests that miners gain embodied sensory information about their work
environment on the job and in an embodied way; it is a form of knowledge that cannot be
articulated in written reports and procedures, and that thus cannot be acquired apart from
embodied experience inside the mine. Sauer’s work provides a useful case through which
to critically consider conventions of knowledge generation and transfer. Building upon
Sauer’s work and extending consideration to embodied experience as an important source
of knowledge amongst caregivers, Somerville (2006) is more explicitly reflexive, noting
that “the highest status is reserved for the most abstract and immaterial learning … and
the lowest status is accorded to concrete, material learning, much of which we learn in
daily embodied actions” (p. 39).

2.4 Embodied reflexivity

Reflexivity has only minimally been written about as an embodied phenomenon.
Bleakley (1999) discusses a ‘holistic reflexivity’, which he characterizes as an “aesthetic
and ethical act of participation in the world” (p. 328). Cunliffe (2002) suggests an
embodied sort of reflexivity that surpasses “reflexive intellectual critique” in the interest
of “acting reflexively” (p. 39). Calling for an embodied reflexivity in qualitative research,
Finlay (2005) suggests ‘reflexive embodied empathy’ as a way of relating to another’s
embodied way of being, in the service of understanding the intertwined nature of
individual subjectivities. Also writing about qualitative research, Burns (2006)
demonstrates the potentially cyclical and interactive nature of embodied reflective and reflexive processes. Pagis (2009) distinguishes between embodied and discursive modes of reflexivity, focusing on the “reflexive capacity of bodily sensations” (p. 265) to inform an embodied consciousness, and arguing that embodied self-reflexivity occurs at a subconscious level before bodily sensations are translated into discourse.

Offering significant depth in structuring his view of reflexivity (which he suggests can be conceived of in terms of incarnation or embodiment), Sandywell (1996) considers the intellectualism inherent in conventional constructions of thought and consciousness. Citing a broad range of philosophers (Heidegger, Merleau-Ponty, Wittgenstein, James, Dewey and Mead), Sandywell (1996,) contends “that our taken-for-granted ideas about the essence of thinking are profoundly one-sided, intellectualistic and disabling in their emphasis upon abstract cognition and pure theory” (p. 272). He notes the presence of the Cartesian separation and prioritization of mind over body in traditional conceptions of reflection that imagine the mind as a separate self, detached from and capable of reflecting back upon the body. In contrast to reflective thought, Sandywell contends, reflexive thought conceives of mind and body in a more unified sense, enabling in reflexivity the bending back of self upon self. For him, reflexivity is a cognitive and embodied process of reflection upon thought (as a process of knowledge generation), which is itself a cognitive and embodied process. Sandywell is reflexive about reflexivity, arguing that ‘to “think about thinking” means to abandon mechanistic and reductive models of “thought” and return to the realm of everyday activities which, in their engaged complexity, forces us to question the cognitive model of “thinking”’ (p. 272). Following this line of argumentation, Sandywell conceives of an ‘incarnate’ or ‘embodied’ reflexivity.

It is important to note that Sandywell (1996) argues for an embodied conception of reflexivity in addition to, rather than instead of, cognitive models. Sandywell exemplifies reflexivity as both intentional and embodied, as paralleling the postmodern project of deconstruction, and as implicated in particular in the generation of knowledge. The aim of reflexivity, in Sandywell’s conception, is to recognize alternative knowledges and ways of knowing or of generating knowledge. Indeed, for Sandywell (1996),
consciousness is not a disembodied faculty or stream of ideas; but neither is existence an unformed mass of sensory impressions or unmediated matter; both moments are imbricated in the knowledgeable process of social existence—an interpenetration exemplified by the diverse ways in which human agents find themselves creatively orchestrating the practices and organizations of material existence. (p. 282)

What Sandywell highlights is “the dialectical relation between embodied reasonableness and formal rationality” (p. 289); the ‘interpenetration’ of sensory experience and the sense made of that experience. In short, within his conception of reflexivity, Sandywell acknowledges the coexistence of and interaction between cognitive and embodied processes of thought.

2.5 Excavating embodied reflexivity: storytelling as a path of access to embodied knowledge

To this point I have relied upon a heavily cognitive approach to examine conceptions of reflexivity, embodiment, and the possibility of an embodied reflexivity. My aim in the next section is to show reflexivity, as a process of knowledge generation, in both cognitive and embodied forms. I propose to show reflexivity by way of reflexive writing about my own practice experience as an attendant service worker. I present this story as a case through which to observe and demonstrate reflexivity, and to consider how attending to embodied reflexivity might contribute to the generation of knowledge, in particular by illuminating tacit or invisible embodied knowledges. This writing demonstrates reflexivity as cognitive thought about different (alternative, non-dominant, competing) ways and domains in which knowledge can be generated. This writing also seeks to show that reflexive processes can occur in an embodied manner, such that reflexivity can also take place in the body.

It is perhaps worthwhile to note that this narrative was not produced with reflexivity in mind. I sat down to write about my experience, and the story that follows came out in the form of a stream-of-consciousness narrative. In *The wounded storyteller*, Frank (1995) explores the body’s need for voice in relation to experiences of illness:
“The ill body … speaks eloquently in pains and symptoms—but it is inarticulate” (p. 2). Stories, Frank contends, are embodied; beyond simply being about illness, illness narratives are stories told through a wounded body. “The body sets in motion the need for new stories when its disease disrupts the old stories” (p. 2); the need for illness narratives thus arises when lived bodily experience diverges from dominant narratives.

Frank explains illness narratives as symptomatic of and arising as a form of resistance to the oppressive dominance of medico-discursive constructions of illness. In modern times, characterized by the Cartesian reification of rationalism, “popular experience is overtaken by technical expertise” (p. 5). Frank calls this scenario, in which individual voices are silenced by a dominant medical discourse and denied the opportunity to speak for or represent themselves, “medical colonization” (p. 10). In postmodern times, however, people struggle to identify with dominant medico-discursive representations of their experience, “feeling a need for a voice they can recognize as their own” (p. 7). “Telling stories of illness is the attempt, instigated by the body’s disease, to give a voice to an experience that medicine cannot describe” (p. 18); as embodied stories of local ‘truths’, illness narratives represent an important site of resistance to the dominant voice of modern science.

Inasmuch as they stand to challenge the stability of concretized dominant knowledges, illness narratives might be thought of as forms of reflexivity. Frank (1995) describes the voice that storytelling gives to bodies as offering an important contribution to the generation of knowledge. At a personal level, Frank contends, embodied stories validate and attest to the uniqueness of individual experience. At a social level, stories at once reproduce old truths and create new possibilities, drawing on and contributing to the social vocabulary of experience, what Geertz (1973) refers to as “the consultable record of what man [woman] has said” (p. 30). Storytelling, in Frank’s (1995) account, contributes meaningfully to the generation of knowledge in postmodern times. “The social scientific notion of reliability—getting the same answer to the same question at different times—does not fit here” (p. 22). From a postmodern stance, realities are too complex to ever be completely represented; the best we can do is produce and legitimate more and more accounts, each necessarily local and partial, in order to approximate more
comprehensive representations of ‘truths’. Embodied stories offer a path of access to diverse accounts of experience, which may diverge from, contest, destabilize and/or expand the scope of dominant narratives that are grounded in, uphold and reproduce objective ‘truths’; ‘truths’ that may be inconsistent with, and which may serve to obscure the reality of, individuals’ lived experiences.

Illness narratives in Frank’s (1995) account are embodied stories that serve as a medium through which the sensations of a body’s ‘disease’ might be conveyed and validated. The following narrative demonstrates reflexive writing about my practice experience attending to a wound(ed body). Although it is not an illness narrative in the strict sense of a story told through the ‘diseased’ body itself, it is nonetheless an embodied story that tells of embodied interaction with and embodied knowledge of a wounded body. And although it is not a story instigated by and told through a body afflicted by ‘disease’ in a medical sense, it is a story told through and at the insistence of a body deeply afflicted by the ‘dis-ease’ of an encounter with the medical world. Embodied reflexivity, like ‘disease’, is felt in the body. Like the ‘diseased’ body, the reflexive body is inarticulate, challenged to communicate its ‘dis-ease’. The following narrative demonstrates reflexive engagement with an experience of embodied reflexivity. It tells of a lived experience of the sensations of critical thought processes occurring and felt within the body, and is told through the ‘dis-eased’ reflexive body. This story illuminates the local and partial ‘truths’ of (my) embodied knowledge.

2.6 The pressure sore

Six years ago, one of the last things I ever could have imagined myself doing, in life and even in my job as an attendant, was caring for a wound. When I was first trained as an attendant I learned about preventative skin care, and about how to treat minor skin breakdowns to prevent them from worsening. I learned about important medical technologies, and with no prior knowledge of skin outside of my own personal experience, was fascinated to see how quickly the right medical supplies can facilitate the healing of some minor skin degradation. Through daily embodied experience with skin and basic medical supplies I gained a fairly thorough understanding of skin; enough to know, one September about a year after I started the job, that the usual measures for
clearing up a minor blemish were not working: the hydrocolloid dressing wasn’t
disappearing the little red spot in the skinfold as it usually did. In my opinion, the red
spot was growing, deepening. Its characteristics were changing. The red was joined by
some streaks of yellowish-white. It began to look moister than it had. It frightened me to
watch the skin change in this way. I soon began to realize that this wasn’t even skin I was
dealing with anymore, but flesh. This is where my experience with wound care began.

To understand this story fully, it is important to understand my professional
position, in particular, my position of power relative to the situation. As a personal
attendant, my job description (as it was explained to me when I was hired by the woman
to whom I would be serving as an attendant) was to perform the various tasks that her
paralyzed body could not perform without assistance. In essence, I was hired to provide
substitute hands and legs, to act as her body might. Given this job description, I did my
best, as I had been instructed, to check myself at the door; to bring to work my hands,
arms and legs, and leave my ‘self’ at home. On one hand, this task makes a great deal of
sense. My employer was looking to hire a competent and cooperative body, not an
opinionated or argumentative personality. On the other hand, however, the task of leaving
my intellect aside is both impossible and probably, realistically, undesirable. Looking
past the impossibility of the task of bringing nothing to work but my physical abilities, I
was hired, at least to some extent, on the grounds of my mental—and not solely
physical—abilities. Ultimately, the point was not to leave my intellect on the doorstep,
but rather to leave whatever beliefs or opinions I may hold about anything I am asked to
do on the job—in particular, anything relating to my employer, her body or her
disability—at home. The reason for this, as I understand it, has to do with power. In
hiring me, an arts and humanities undergraduate student, instead of a trained health
professional, my employer was able to assert, and maintain without challenge, her
conviction that she is the expert of her own body.

In the year prior to the development of the pressure sore, I had never had reason
to question or challenge my employer’s chosen course of action as regarded care for her
skin or her body. As far as I was concerned, after all, she was the expert. And so each day
I did my job as I had been trained. I carefully observed and described the red spot.
Indicating my concern was the best I could do within my role. As the days and weeks passed, I observed and described as the spot became deeper, and redder, and scared me more and more.

I don’t remember when exactly the breaking point was reached. My employer was very busy that September, as too, I’m sure, were the clinics she would need to make appointments with. What I do remember clearly are the ensuing four years of appointments at three different wound care clinics; the interactions with what seemed an endlessly revolving door of health practitioners; the way my job (and life) changed dramatically when my employer was sentenced to bed rest, a course of action whose pernicious and extensive implications the prescribing medic could not have possibly even begun to comprehend. Nor, I suspect, did they have any real sense of the totalizing nature of that pressure sore in my employer’s life; for it became a guiding force, a primary consideration impacting the planning of every activity, every day.

Many times over the years since that fateful September I have reflected upon the circumstances under which that wound developed, initially, and as it continually worsened, even after it began to receive the ‘proper’ medical attention. It is a strange thing to consider, ‘possession’ of a wound. Of course, it is my employer’s wound; it is located on her body. But she never saw it, hardly acknowledged it for the first month of its existence. During that time I was deeply concerned about it and intimately involved with it. I cleaned and dressed it, observed, measured and described it every single day. In a sense, that wound was also mine. A constant presence playing a significant role in my daily experience, I had come to know that wound in an embodied way.

Until we took it to the hospital, care for the pressure sore was informed by the embodied knowledges of my employer and myself. In the hospital wound clinic, my experience was surreal. Although I knew that wound better than anyone else, within the realm of the hospital my experiential knowledge simply did not count. In the view of the staff at the hospital wound clinic, I was, at best, a mere bystander. At worst, I am certain there was speculation that this wound was my fault; that my lack of proper training was to blame for the extreme breakdown of this tiny (1 cm²) patch of skin and flesh. In either
case, each time a professional entered the room it was as though I had disappeared. Feeling like a useless third wheel, it was then that I retreated and took up residence as a ‘disembodied’ fly on the wall of the hospital wound clinic.

It’s an interesting vantage, the fly on the wall; a silent observer of interactions that typically tend to go unobserved. At times it was difficult to remain silent, in particular when, based on my experience with the wound, I strongly disagreed with a prescribed course of action. I knew the nuances of that wound. I saw how it responded to different treatments, how it changed based on various factors. But doctors didn’t want to hear from me, or my employer. It was clear to me that our embodied knowledges about my employer’s body in general, and the wound in particular, carried very little weight in that environment.

As I sat quietly and observed, I often thought about power; about the constant struggle for legitimacy in which myself, my employer and the clinic staff were engaged; and, ultimately, about the conditions which led my employer to hire me instead of someone well trained in wound care, perhaps someone whose authority or ‘expertise’ might have more forcibly insisted she seek medical attention for the skin blemish before it developed into a chronic wound. With time it became clear to me that my employer recognized that I had become the expert of her (specific and context-bound) wound. I could see that she took my knowledge of it very seriously. But still the medical professionals showed little (if any) regard for my knowledge (or hers, for that matter).

One wound clinic insisted that nurses, trained in the generalities of wound care, rather than the particularities of the context, come to my employer’s house to attend to the wound. This assertion on the part of the medical institution was particularly interesting: sending professionals trained by recognized educational standards into my employer’s home to do the job of the practitioner she had trained herself (i.e. me). My employer had, after all, purposefully elected a model of attendant services that allowed her to customize her attendant services by training and managing her own attendants, rather than accepting a pre-packaged support service provided by an agency. I have reflected a lot on the contested/contestable nature of this scenario, questioning what
precisely falls under the jurisdiction of individuals with regard to their own health care and at what point we should reasonably be expected to concede control and management to ‘professionals’. Of course, my employer does not require someone trained in a standardized way to assist her in the completion of various activities of daily living, but would it be to her advantage, to the benefit of the collective, to have someone professionally trained interacting with her body? Or would therein lay an assumption about her disabled body, as sick and therefore necessarily requiring constant medical supervision? Surely the same advantages would stand true were my ‘able’ body constantly subjected to a medical gaze (which, of course, it is not). Why, then, should that gaze be imposed upon someone with a disability?

In my view, it is not a far stretch to shift from questions of this nature to questions about the legitimacy of different forms of knowledge. It is certainly true that when the pressure sore first developed, I had no knowledge of pressure sores, wounds or wound care. Even now, my knowledge of pressure sores, wounds and wound care generally remains limited. My knowledge of that one particular pressure sore, however, is extensive. I knew that wound in an embodied way, well enough that on multiple occasions I predicted the negative effect that a newly prescribed treatment would have on it. More than once I made a suggestion that was dismissed by my employer, the clinic staff, homecare nurses, or some combination of the above, suggestions based on my very specific knowledge of the wound’s behavior, and which I believe may have had a positive impact on the wound. To this day it is difficult for me to accept the possibility that my knowledge of that wound is a legitimate form of expertise, which may offer a unique contribution (however minor) to existing understandings of wounds and wound care. But I am beginning to understand this self-doubt in relation to the dominance of medical discourse, and to see how attending to knowledge that is generated experientially through the body, such as my embodied knowledge of my employer’s wound, has the potential to expand concretized ‘truths’.
2.7 Embodied reflexivity and knowledge generation in the context of professional practice

I have presented this narrative in an attempt to show embodied reflexivity in the context of professional practice, as a process that offers an important avenue for knowledge generation in professional practice and invites critical consideration of how we think about what counts as legitimate knowledge. Embodiment and reflexivity both are concepts familiar to contemporary professional practice and education scholarship, where an emergent literature on phronesis advocates for recognition and legitimation of practical wisdom alongside conventional forms of scientific knowledge and technical rationality (Kinsella & Pittman, 2012; Polkinghorne, 2004). In this literature, reflexive consideration of the generation of knowledge calls for attention to intelligent action, actively demonstrated in practice contexts, through which embodied or tacit knowledges are revealed. Kinsella (2012) situates embodied reflection and critical reflexivity along a ‘continuum of reflection’ that she suggests is “implicated in the development of professional knowledge characterised as phronesis” (p. 35). The fusion of embodiment and reflexivity is foreshadowed in Kinsella’s work by Bill Green’s conception of Kinsella’s continuum as “a pulsating quadrant in which any piece might overlap with another at anytime” (Kinsella, 2012, p. 38). The narrative I have presented here makes explicit this suggested connection between embodied reflection and critical reflexivity, demonstrating reflexivity as an embodied process of critical thought that is felt within the body.

One concrete example of the embodied reflexive sensations I felt in a practice context is the fear I experienced while attending to the wound. Within the context of my employer’s home, my embodied knowledge and hers were all we had to work with. As I watched the skin degrade into flesh, I began to sense that the demands of my practice context were surpassing the embodied knowledge I had gained, first through training on the job and then through my own daily experience interacting with my employer’s skin. I became conscious of my lack of formal technical education, and the process of questioning the validity of our combined experiential knowledges manifested in me as fear. I was not yet in a position to comprehend why my employer preferred to manage the
deepening wound at home, herself (with my assistance), instead of surrendering care of it to someone more knowledgeable about the generalities of skin or wound care than she or myself.

A second example of the embodied reflexive sensations I experienced in the practice context is the overwhelming feeling of disembodiment I experienced each time we visited the hospital wound clinic. Whereas within the context of her home my employer looked to me as the expert of her wound, in the hospital wound clinic both my voice and hers were silenced. It was then that I began to understand my employer’s hesitance to surrender her body to the medical gaze. For while the hospital’s technical expertise offered a new perspective on the wound, our practical, experiential and embodied knowledges were not included.

In the hospital wound clinic. I found myself caught up in an epistemological clash. The technical-rational approach to knowledge, the modern scientific approach espoused by the medical institution, asserting its authority so strongly, overpowered my embodied experiential knowledge. I felt so certain of the observations I had made. Yet, unable (not to mention lacking the opportunity) to translate those insights, to express them in the very specific language required of modern science to obtain legitimation, I was silenced, to such a degree as to feel I had been made invisible, at times as though I was not even there. In a different environment, however, at a distance from the oppressive gaze of the medical establishment, my embodied experiential knowledge was recognized, legitimized, and valued very much.

During my experience with the wound, the language of reflexivity was not yet part of my vocabulary. In the years that followed, I was so profoundly struck by that experience that I was driven to pursue academic investigation of it; in the words of hooks (1994), “I came to theory because I was hurting … desperate, wanting to comprehend—to grasp what was happening around and within me” (p. 59). Reflecting now, through a reflexive lens, I am able to describe my experience of attending to my employer’s wound in terms of reflexivity; to frame the simultaneously and interpenetratively cognitive and embodied processes of knowledge generation in terms of reflexivity; and to characterize
the ‘dis-ease’ I felt within my body in terms of embodied reflexivity, demanding
reflexive thought about what counts as legitimate knowledge, when, where, and for
whom.

The writing of this narrative, too, the translation of embodied reflexive
engagement with experience into discourse, represents a reflexive act of knowledge
generation. Until I was able to tell it, the story weighed heavily within me. And while it
still constitutes part of my embodiment, inasmuch as it will always be part of the
experience through which my body has lived, it has now also become part of “the
consultable record of what man [woman] has said” (Geertz, 1973, p. 30). Translated into
discourse via the medium of a story, this narrative is a testament to the experience of
embodied reflexivity. As a concrete representation of the local and partial ‘truth’ of my
experience, a perspective that diverges from and contests the at times oppressive
dominant voice of modern medicine, this embodied story about my embodied experience
of attending to a wound may serve to destabilize and/or expand the scope of some
dominant narratives. It is reflexive in its critical questioning of a legitimised form of
knowledge, and significant for its contribution to the creation of new possibilities for the
-generation of knowledge.

2.8 Conclusion

A central objective of this chapter has been to explore embodied reflexivity as an
approach to knowledge generation in the context of professional practice. Writing about
nursing and health care practice, Cheek (2000) notes that “postmodern and poststructural
approaches enable the development of a reflexivity that can challenge and open up to
scrutiny otherwise closed and taken-for-granted aspects” (p. 126). Cheek’s words echo a
common thread in emergent conversations surrounding reflexivity in professional
practice, which calls for reflexive consideration of the types of knowledge that are
allowed to inform professional practice, as well as acknowledgement of the values which
permit legitimation of certain knowledges, potentially at the expense of certain others
(Kinsella & Whiteford, 2009; Phelan, 2011; Taylor & White, 2003). The particular
example taken up in this chapter is the legitimation of technical-rational knowledge at the
expense of acknowledging or considering often more tacit or embodied experiential knowledges.

In much the same way that Frank describes illness narratives as symptomatic of and arising as a form of resistance to the oppressive dominance of medico-discursive constructions of illness, I suggest it is possible to think about the emergence of considerations of reflexivity and embodiment in discussions surrounding professional practice in a similar way. “Historically, emotional responses of practitioners to the situations they face have been cast as problematic and requiring control” (D’Cruz, Gilingham, & Melendez, 2007, p. 80), a position which reflects values of cognitivism and objectivity. As I have attempted to demonstrate by way of reflexive writing about my own practice experience, reflexivity, as “critical awareness of the factors that influence knowledge creation”, demands “acknowledgement of the dynamic relationship between thoughts and feelings: how thoughts can influence feelings and vice versa” (D’Cruz et al., 2007, p. 80). Where affect has conventionally been intentionally suppressed in practice settings, attending to embodied experience demands acknowledgement, as well as critical consideration, of the role of affect in professional practice (for more on the relevance of embodied understanding for professional practice, see Polkinghorne, 2004; Todres, 2008).

As the notion of reflexivity has attracted increased attention in discussions surrounding professional practice, one facet of the concept that has largely been overlooked is its potentially embodied character. My aim in this chapter has been to demonstrate the value of attending to embodied reflexivity. In particular, I have aimed to show how attending to embodied reflexivity can help to illuminate (embodied) knowledges which, obscured by structures of dominance, might otherwise remain tacit or invisible. If reflexive analysis exposes the insufficiency of models of knowledge generation that are limited to its recognition as a cognitive-intellectual process, then reflexive analysis can also expose the partiality of models of reflexivity that fail to account for its embodied character. A reflexive exercise in and of itself, acknowledging and attending to embodied reflexivity offers a unique contribution to how we think about what counts as knowledge; creating space for the legitimation of new kinds of ‘truths’.
2.9 References


3  Self-management and the government of disability: reinforcing normalcy through the construction of able-disabled subjectivities

Once my father told me that in ancient China the very rich or powerful families would bind the feet of young girls. As these girls grew up they became unable to walk more than a few hobbled steps. If a woman were truly rich and powerful she would give up walking altogether and she would also grow her finger nails until her hands were heavy and functionless. She would be carried about all day by slaves who bore her chair and her cushions to support her hands. They would feed her and look after her every need.

Now what is interesting to me about this story ... is that my body works as if I were one of those ancient Chinese ladies. I get around in a fancy motorized wheelchair and a van adapted with a wheelchair lift. I type on a computer with a breath control that reads my puffs and sips as Morse Code and translates the code into letters and computer controls. Otherwise my every physical need from eating to driving the van must be met by a team of attendants. These attendants cover a 24-hour shift and their wages are funded with government dollars.

One critical difference between my life and that of an ancient Chinese lady is that she was considered to be of value in her society just because she was there. Her mere presence as a symbol was of more value than any other potential contribution she could make and she was supported and shaped through great suffering to become that symbol ... In my world, people are valued according to their conspicuous function and activity. Few things are viewed more negatively than disability in my society.

--Judith Snow, “Creating What I Know About Community”

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3.1 Introduction

In *From behind the piano*, Jack Pearpoint (1990) chronicles one segment of the manifold barriers and challenges his friend and colleague Judith Snow faced as she waged war against bureaucracy, in a fight to be recognized by the province of Ontario “as a citizen, not as a body awaiting rigor mortus in a decorated mortuary” (p. 32). Judith was born in Toronto, Ontario, in 1949, a place and time where segregating disabled individuals from the community and moving them to medicalized institutions represented a generally uncontested norm. Defying all medical advice, Judith’s parents chose not to have her institutionalized. Due to the absence of infrastructure for facilitating alternative arrangements for providing support, Judith’s parents fulfilled her attendant needs, from infancy until she was nearly twenty years old. As a student at York University in the early 1970s, Judith was able to manage her attendant needs with the support of a student grant. However, upon graduating, Judith was again confronted with the lack of infrastructure for organizing and funding attendant supports outside of an institutional environment. To the bureaucratic institutions responsible for dealing with disabled people, Judith was practically incomprehensible. A person with a disability, and a master’s degree, and a professional life, Judith defied all bureaucratic logic.

In March of 1980, following eleven years of futile struggle for legislative recognition, Judith was on “the brink of suicidal stress” (Pearpoint, 1990, p. 22). As friends and colleagues coalesced around Judith, the decision was made to go public with her “case history of frustration” (p. 25), in one last-ditch effort to demand legislative change. Ten years later, to the day – ten more years of dedication to a cause, at once private and public – the Government of Ontario, at long last, announced that “funding would be made available to individuals to allow them to live their own lives” (p. 95). The inconceivably great lengths Judith and her networks had gone to finally culminated (another four years later, in 1994) in the introduction of a self-managed model of attendant supports in Ontario.

I introduce Judith here and integrate her story (as told by Jack Pearpoint) for several reasons. The first is on account of the striking parallels between Judith’s life and
the modern history of disability. The second is for the important role Judith has played in Ontario’s local history of disability. The third is that Judith’s life tells a tale of triumph. However, as is a reality for many disabled people, it also tells of constant struggle, beset by an imminent shadow of potential crisis. For this reason, Judith’s story lends itself particularly well to the critique of self-management I present in this chapter. Finally, the perils of living with disability are often not well understood. Illustration of this discussion through one individual’s “case history of frustration” (Pearpoint, 1990, p. 25) helps to bring the analysis to life, underscoring not just the reality of the problem at hand, but also the urgency with which it needs to be pursued. Judith’s story reminds us that valuable human lives are at stake.

This chapter begins with a brief introduction to the modern history of disability in North America to contextualize the following analysis of the self-managed model for organizing attendant supports. I then introduce biopower as a conceptual framework to demonstrate the centrality of neoliberal governmentality to both the modern history of disability and the contemporary politics of disability in modern Western societies. My primary contention is that, while self-management facilitates the construction of a new genre of disabled subjectivities, it simultaneously serves to reinforce contemporary networks of normalizing power. I argue that, insofar as they are constructed in terms of neoliberal political rationalities – which are foundational to discourses surrounding self-management – new ‘able-disabled’ (Titchkosky, 2003) subjectivities work within, and serve to reinforce, not only traditional conceptions of disability but also accepted norms of neoliberal citizenship. Certainly, the right to self-manage attendant services represents a form of resistance that is a significant and important achievement of the disability rights movement. However, insofar as that resistance becomes co-opted as a mechanism of constraint, it is susceptible to critique by contemporary critical disability studies and radical disability activism. A secondary aim of this chapter is thus to exhibit the value of approaching contemporary disability theory from the perspective of governmentality.

This work is situated within an emergent body of disability theory that is often called critical disability studies. Margrit Shildrick (2009) describes one central focus of the field as “an investigation of what it is that continues to impede the evolution of
equitable conditions of possibility” (p. 2). The aim of this critical approach is not to discredit the initiatives undertaken by previous waves of disability studies and activism – initiatives such as inclusion and disability rights, which developed in light of the social model of disability – but to interrogate their shortcomings and build upon their successes. In congruence with this “postconventional” (Shildrick, 2009, p. 2) approach, I have taken a deliberate choice in this chapter to use the term ‘disabled people’ rather than ‘people with disabilities’. This is consistent with Shildrick, who explains,

The current preference within both critical disability studies, and some but no means all activist circles, is for ‘disabled people’ rather than ‘people with disabilities’. After a recent history in which the latter was promoted as a reaction to older and more evidently stigmatizing terms such as handicapped, retarded, cripples and so on, or to supposedly more positive alternatives such as differently abled, physically challenged or special needs, the use of so-called people-first language form is now seen as a confirmation of the person that fails to encompass the significance of disability .... It is as though disability were a contingent add-on rather than a fundamental element of identity. (p. 178, emphasis in original)

A.J. Withers (2012) expresses similar concern about the separation of disability from personhood implied in people-first language, noting that “the language ... implies that disability is something separate and apart from personhood or humanity, unfortunate conditions attached to otherwise normal people” (p. 6–7).

Withers (2012) identifies as an additional problem with the lexicon “the ease of interchangeability of the word disability with medical diagnoses: people with autism, people with spinal muscular atrophy, people with schizophrenia, people with epilepsy, people with disabilities and so on” (p. 7). Conflation of disability with medical diagnoses reflects the antiquated medical model of disability, a conception of disability as tantamount to a medical condition. A more contemporary conception of disability, represented by the social model of disability, recognizes disability not as a direct effect of an individual’s ‘impairment’, but rather of a disabling physical and social environment. Withers thus advocates for the reclamation of the term disabled people, emphasizing that “disability exists as a consequence of an active process of marginalization – people are
disabled” (p. 7). Withers contends that “while the phrase has a negative connotation ... disabled people have largely reclaimed it” (p. 7).

This debate concerning language parallels a broader tension that stands between disability activists and the academic field of critical disability studies. To reiterate, the contemporary critical turn in disability academics is not concerned with discrediting or disproving the social model of disability. Yet, because the social model has figured so prominently as a driving force behind contemporary disability politics, such poststructuralist and postmodern approaches have themselves met with much skepticism and critique, in particular for being overly complex, and insufficiently accessible (Corker & Shakespeare, 2002). Mairian Corker and Tom Shakespeare agree that critical analyses must remain pertinent and accessible, but simultaneously stress the importance of developing a “theoretical base” to support the “conceptual power” of the social model (p. 13). In their esteem, “people’s lives are far more complex than modernism likes to believe” (p. 14), and “disability studies has little choice but to engage with these ideas” (p. 13). In response to ethical concerns about the purpose and usefulness of critical disability studies, Corker and Shakespeare caution that “theory has to be conceived as a means to an end, rather than an end in itself” (p. 15), and remind us that in the previous wave of disability studies and in the current wave alike, “the goal remains the same: to contribute to the emancipation of disabled people, whoever they are, and whatever they decide that emancipation means, and to the development of inclusive societies” (p. 15). In this sense, critical disability studies offers the social model an expanded theoretical toolbox through which to further the disability movement.

3.2 A brief introduction to the modern history of disability in North America

What is disability? To this seemingly simple question there really is no singular answer. Disability is a fluid concept, whose definition “depends not only on the context in which it is defined, but also who defines it” (Withers, 2012, p. 3). Governments who provide financial support for disabled individuals, for example, lean towards a narrow biomedical definition of disability. Some activists and academics, by contrast, tend to draw on
broader definitions of the concept; from a radical perspective, it is possible to imagine that we are all disabled in some sense of the term (Shildrick, 2009; Titchkosky, 2003; Withers, 2012).

For as long as some humans with diverse embodiments and abilities have been labelled ‘disabled’, normalizing societies have enforced their exclusion. Concurrent with the increase in industrialization of western Europe and North America in the late eighteenth and nineteenth centuries, there was a shift in popular understandings of disabled people who came to be viewed as passive, needy, vulnerable, and dependent. This same period was characterized by the increasing scientific pathologization and classification of various ‘abnormal’ embodiments, as well as the rise of hospital-based medicine and the creation of asylums (Thomas, 2007). Indeed, for much of the modern era, segregation and institutionalized ways of living have represented a norm for disabled people. Governments have most often dealt with biologically (physically, psychologically) diverse humans by medicalizing their differences and relegating them to institutions.

During the 1960s and 1970s, however, the social climate surrounding disability began to change. Some disabled people living in institutions began to demand recognition of their rights – the right, for example, to live a ‘normal’ life, free from the confines of a medical institution. Alongside and informed by contemporary social movements such as deinstitutionalization, community integration, consumerism, and civil rights (Yoshida, Willi, Parker, & Locker, 2004), as well as women’s rights and feminist movements, a disability rights movement emerged. Traditional understandings of disability began to be taken up and challenged by activists and academics, both in North America and abroad.

In North America, this set the groundwork for a burgeoning independent living (IL) movement. The IL philosophy builds on deinstitutionalization with two added fundamental principles: first, “that people with disabilities know best their needs and ... second, that living in the community requires appropriate supports and services to meet those needs” (Yoshida et al., 2004, p. 180). These principles helped to define the IL
platform, and contributed to the demedicalization of disability and to the articulation of disability in relation to individual rights and freedoms.

The IL movement aimed to overturn traditional conceptions of disability, typically referred to as medical or rehabilitation models. Such dominant medicalized perspectives conceived of disability as akin to an illness or a disease and consequently sought “to cure” disabled people or to “educate them out of their differences” (Snow, 2012, para. 27). The IL movement, by contrast, taken up by academics and advocates alike, was framed in terms of the neoliberal principles of independence and self-sufficiency. The political strategy was to demonstrate that, given the proper supports, disabled people could participate more fully in consumer capitalist society. Reflective of this strategy, the IL platform adopted a neoliberal lexicon, re-naming disabled individuals consumers and appealing to their rights as citizens.

3.3 “Illegal or just annoying?”: The origins of Ontario’s self-managed model

Around the same time that the IL movement was forming in the United States, Judith Snow was actively living a parallel struggle in Toronto, Ontario. Upon graduating from York University in 1975, Judith faced yet another unique challenge. She was no longer eligible for the student grant that had previously supported her, and in 1975 there was no attendant services program in Ontario that was equipped to provide support to an individual who had both a disability and a professional life. Pearpoint (1990) writes,

She insisted on going to work every day. No one could quite decide if this was illegal or just annoying. The legal question arose because under Ontario law, if you are disabled, you are by definition unemployable. Ergo, if you are employable, you are not disabled. As ever, Judith didn’t fit. (p. 17)

Judith’s seemingly contradictory embodiment and ambivalent legal status exemplified not only the human potentiality that is stifled by the practice of institutionalization, but also the impending necessity of a proper legislative response to disabled persons who are both employable and require support services.
But bureaucracies move slowly, and Judith’s need for both a place to stay and the physical supports to live were immediate. She was deemed “too needy” for contemporary attendant support alternatives (which, ironically, she had helped to create) (Pearpoint, 1990, p. 16). The bureaucratic response was to offer Judith residence in a geriatric ward at a long-term care facility, “where she could be ‘attended to’ while waiting for death” (Pearpoint, 1990, p. 16). After all, Judith was due to expire any day. “She was told from birth that ‘people like that’ don’t live past 30” (p. 18). Institutionalized, as an adult and for the first time in her life, Judith’s health deteriorated. When her work schedule conflicted with the schedule imposed by the hospital, Judith was forced to choose between eating and going to work. When Judith chose work, she became severely malnourished. It was weeks before anyone realized the ensuing illness was in large part due to a severe reaction to the vitamin supplements she was given to compensate for missed meals. Judith was expected to die before her thirtieth birthday. She almost did; not because of her disability, but because of the way it was (mis)understood and (mis)managed by the bureaucratic institutions in charge of dealing with her.

As Judith’s private life plummeted towards rock bottom, her friends and colleagues were oblivious:

None of us really understood the intensity of Judith’s survival workload, because we knew her in the context of her job. She wanted to keep us thinking that way. She loved that. We didn’t see ‘the handicap called Judith who also works,’ but rather a very talented colleague who happens to use a wheelchair and needs someone else’s hands to eat, go to the bathroom, get dressed and go to bed. (Pearpoint, 1990, p. 20)

Judith’s situation deteriorated to such a point that she decided she would rather die than continue to live in an institution: “We all had to decide if we wanted Judith in the world – and if so, how we were going to make it happen” (p. 21). Judith’s friends and colleagues pooled their collective resources – first to fabricate a makeshift system for attendant supports, then to take a political stand.
To make a long (fascinating, infuriating, and awe-inspiring) story short, in the years that followed, Judith became a living prototype for what would eventually come to be known, much to the credit of Judith and her ‘unique circle of friends’ (Pearpoint, 1990; Snow, 2012), as self-managed attendant services (SMAS). In response to demands for a model of service delivery “which had as its foundation the independent living principles of choice, flexibility and control on the part of the consumer” (Yoshida et al., 2004, p. 189), SMAS offers some physically disabled individuals the opportunity to receive funding (more-or-less) directly from the government, to independently recruit, hire, train, and manage support staff. As a result of the IL movement, programs of this sort now exist across Canada and internationally.

The SMAS program in Ontario has received much praise and appears to provide great consumer satisfaction (The Roeher Institute, 1997; Yoshida et al., 2004). Yoshida et al. (2004) conclude their descriptive evaluation by stating that the “challenge now in Ontario will be for the self-managed attendant service user community to transform the concept ... into workable service models for the benefits of all people living with disabilities” (p. 202), which implies that the model is just some finetuning away from a universally workable program. However, Yoshida et al.’s focus is on identifying the social and political factors that led to the creation of SMAS, as well as some of the program’s major achievements in its first ten years. Representing only the perspectives of program participants, the existing literature on SMAS is limited in scope, and critical perspectives are lacking. Failure to include the voices of those individuals excluded from participation in the program, whether willingly or not, actively silences the experiences and discourses that may counter the dominant narrative of praise for the program.

I feel particularly strongly about the importance of critically appraising the self-managed model for organizing attendant supports, in large part because Judith’s story affirms what I observed during my experience working as an attendant to individuals who organize their attendant supports through the self-managed model, which is that the self-managed model, although it represents a better option for many physically disabled individuals, is not without its shortcomings. As I explore in this chapter, the self-managed model devolves responsibility for organizing and managing attendant supports – an
endless(ly taxing) occupation – onto disabled persons themselves. The program is
discursively framed as a privilege, an opportunity for some disabled individuals to obtain
full(er) citizenship by becoming more fully participating workers and consumers; in
particular through the realization of increased financial independence, achieved through
the absorption of increased personal risk and responsibility. I certainly do not mean to
suggest that self-managers or disabled people should not pursue these goals. However, it
is important to draw attention to the ‘invisible work’ (Church, Frazee, Panitch, Luciana,
& Bowman, 2007)—that is, the unpaid and most often unrecognized labour—that goes
into the task of self-management. Such critique is necessary to evaluate the purported
goals of the SMAS program, including the promise that IL-inspired models contribute to
the transformation of disempowering attitudes towards disabled people and to
overcoming their social oppression. Shildrick (2009), for example, notes that legislative
changes inspired by the IL movement have “undoubtedly promulgated a more inclusive
organization of social life” (p. 5). But the transformative success many had optimistically
hoped for has yet to be seen. As I will demonstrate in the following analysis, it is outside
the scope of IL-inspired models to achieve such transformation. I contend that this is
because the legislative alterations and spaces for resistance incited by the IL movement
are founded on neoliberal models of citizenship that foster particular ideals of normalcy,
and ultimately perpetuate many of the attitudes and oppressions disabled people face.

3.4 Disability: an effect of biopower as a form of
neoliberal governmentality

As a preface to the following critique of the self-managed model for organizing attendant
supports, I begin by introducing bio-power as a conceptual frame to demonstrate the
centrality of neoliberal governmentality to both the modern history of disability, and the
contemporary politics of disability in modern Western societies. According to Foucault
(1978), political power in the modern era operates differently than in pre-modern times.
Power has historically been conceptualized as the domain of the sovereign, who
possessed the power to allow life or enforce death. Power in this sense has traditionally
been understood as a repressive, constraining force administered in a juridical manner. In
the modern age, by contrast, Foucault theorizes the emergence of a different type of
power; a power that is multi-local, and which, operating at a distance from the state, is a power “to foster life or disallow it to the point of death” (Foucault, 1978, p. 138). This power over life operates at two poles, both of which are concerned with the optimization of life. The first pole—anatamo-politics—is focused on the discipline of individual bodies, with the second pole – bio-politics – focused on the regulation of the population. Concerned with the optimization of life at both of these levels, biopower is productive rather than repressive; it produces people with certain kinds of subjectivities, and demarcates the parameters of their possible and acceptable conduct (Tremain, 2006).

Biopower informs the particular form of governmentality exercised by liberal governments, and is characterized by “liberalism’s insistence that political authority had necessary limits, bounded by individual freedom and the self-regulatory properties of social domains such as the market” (Power, 2005, p. 644). Whereas political strategy in the pre-modern era could be enforced through the repressive rule of law, in the modern age a discourse of rights and freedoms displaces traditional, repressive strategies of government. Elaine Power notes that in the modern era, “liberal governments had to learn to govern through the freedom of individual citizens” (p. 644, original emphasis). This characteristic ability of liberal government to govern through the exercise of freedom has been described as a ‘polymorphous’ form of domination (Shildrick, 1997).

Foucault (1978) explains that “another consequence of this development of biopower was the growing importance assumed by the action of the norm, at the expense of the juridical system of the law”; bio- power “effects distributions around the norm” by constructing and hierarchizing bodies based on their (economic) “value and utility” (p. 144). Economically productive bodies, assigned greater value, correspond to subjectivities constructed as ‘normal’, whereas those deemed to be unproductive, or counterproductive, are constructed as ‘abnormal’. Thus, while biopower is a disciplining and regulating force, it is also normalizing. Neoliberal governmentality, inasmuch as it operates through the exercise of biopower, is dependent upon this deeply entrenched valuation of normalcy. As the crux of contemporary neoliberal governmentality, biopower operates by constructing “subjects whose actions are governed through the exercise of their own capacity to choose in accordance with the norm(al)” (Tremain,
Thus, for neoliberal governmentality to operate, it is essential to foster the desire for such normalcy and to educate the population about how to achieve it.

Foucault (1978) locates the origins of biopower at roughly the same historical moment as Carol Thomas (2007) observes the emergence of the concept of disability. This, I contend, is not coincidental, but rather suggests that the concept of disability emerged as an effect of biopower. As a normalizing force, biopower fosters and perpetuates many of the attitudes and oppressions that inform the way that disabled people have historically been treated and managed, and that disabled people continue to face. Disabled subjectivities have historically been constructed in terms of vulnerability and interdependence. Construction of disability in this way stands in marked contrast to requirements of neoliberal citizenship, which are most often defined in terms of (economic) independence and self-sufficiency. Inasmuch as it “effects distributions around the norm” (Foucault, 1978, p. 144), biopower also effects the construction of disabled subjectivities as abnormal, un-productive, and thus without value, thereby excluding them from the possibility of achieving full citizenship.

This overview of biopower sets out the conceptual framework from which I approach the following analysis of the SMAS program in Ontario. In the analysis that follows, I show how neoliberal governmentality produces disabled bodies and subjectivities through programs such as SMAS, “by guiding, influencing, and limiting their actions in ways that accord with the exercise of their freedom” (Tremain, 2006, p. 46). Discourses of self-management facilitate the construction of an able-disabled subjectivity that is constructed in terms of neoliberal citizenship, and that reinforces contemporary networks of normalizing power. Insofar as it supports norms of neoliberal citizenship, the able-disabled subjectivity that is promoted through discourses of self-management at once reproduces traditional conceptions of disability, and contributes to the perpetuation of negative attitudes and oppressions towards disabled people.

3.5 Self-management and the government of disability

In 1994, the Government of Ontario launched self-managed attendant services (SMAS) as a pilot project, offering one hundred physically disabled individuals the opportunity to
self-manage their attendant supports (Yoshida et al., 2004). After receiving an overwhelmingly positive review by The Roeher Institute in 1997, it was decided that a full program would be launched in 1998. By 2004, the program had 691 participants, with 300 applications pending (Yoshida et al., 2004). Ten years later, in 2014, the program was full with 750 participants. That same year, the province announced plans to expand the program to support an additional 250 participants by 2016. New applications are accepted on an ongoing basis, but are only considered “when spots open up (due to people departing the program) or when new funding becomes available” (Direct Funding Program, 2016, para. 1).

Programs like SMAS have made it possible for some people with certain disabilities to conduct their lives at a far greater distance from the supervision and guidance of medical institutions than has ever before been possible. However, this model of self-management mimics the rehabilitation model of disability; while rehabilitation in the medical sense is concerned with restoring the physical functioning of the disabled body, the self-managed model is concerned with restoring the societal functioning of the disabled subjectivity. In other words, the self-managed model promotes ideal disabled subjects whose desires and capacities for self-management align with the requirements of neoliberal citizenship: full participation in consumer society, financial independence, and self-sufficiency. In this way, through the construction and promotion of an able-disabled subjectivity, the SMAS program reinforces the very networks of normalizing power that are responsible for the ongoing oppression of disabled people.

SMAS, and other IL-inspired models like it, respond to the desire of disabled people to conduct their lives at a distance from supervision and guidance by the institution of medicine. Disabled people have justified this demand by asserting that their disability is not a medical condition; provided the appropriate supports are made available to them, disabled people are capable of meeting their own needs, governing themselves appropriately, and thus living independently in the community (Stienstra, 2012; Yoshida et al., 2004). On one hand, SMAS responds to this demand, insofar as it allows self-managers to inhabit accommodations of their choosing, and receive support from attend- ants not necessarily associated with the formal health or caring professions.
On the other hand, while self-managers are freed from the direct surveillance and control of the medical institution, they are still subject to the “continuum of apparatuses (medical, administrative, and so on) whose functions are for the most part regulatory” (Foucault, 1978, p. 144), because the direct funding self-managers receive is distributed as a form of social assistance (Yoshida et al., 2004).

As receivers of social assistance, SMAS program participants are subject to intensive surveillance by the Government of Ontario. The operation of biopower is evident here in the ways that the program aims to “qualify, measure, appraise, and hierarchize” (Foucault, 1978, p. 144) all interested applicants. Pearpoint (1990) describes the tedious and superfluous administrative processes Judith was repeatedly subjected to when the province was deciding (whether) to provide her funds:

The waiting process was long. Governments need time to work out procedures. We had no choice but to be patient. During this phase, Judith was measured, weighed, examined, scrutinized, and assessed on every known government form, and by almost every known assessment expert. After the tenth set of enormously complex forms that required staff visits and detailed information of the most intimate, personal and irrelevant nature, we rebelled. We said, “No more”. It was redundant to document once again that in fact Judith was disabled and needed assistance to brush her teeth, etc. No. She would not get better. Yes, she would need attendant care services for the rest of her life. (p. 29)

This same type of procedure is echoed in the SMAS application process (CILT, 2015a, 2015b), which requires the potential self-manager to surrender excessively detailed information about their personal care regimes. The application guidebook stresses that applicants should be prepared to “answer questions of a personal nature” (CILT, 2015b, p. 11), in person, at their interview with the selection panel. Applicants are further required to sign a form authorizing “any provincial, federal, or municipal government ministry, agency or body; any financial institution; any attendant service provider or any health care provider who has knowledge, information, or documentation pertaining to [their] disability” (CILT, 2015a, p. 6) to share information with representatives of the
program; thereby waiving the applicant’s right to confidentiality of health information as protected under provincial and federal legislation.

The SMAS application process is rigorous and space in the program is limited. It is essential that potential self-managers present themselves to the selection committee in such a way as to demonstrate their capacity to self-manage in accordance with a predetermined set of norms (CILT, 2000). Writing about social assistance in Canada, Power (2005) has observed that:

those who are not, or not yet, ready for freedom must be governed through older disciplinary methods, with the goal of instilling enough self-discipline and self-responsibility that they will one day be able to properly exercise their freedom and be governed accordingly. (p. 644, original emphasis)

The application process thus serves not only to “qualify, measure, appraise, and hierarchize” (Foucault, 1978, p. 144), but also to present interested applicants with a clear picture of the requisite self-discipline and self-responsibility expected of responsible self-managers. The program literature explicitly lists prerequisites for eligibility. Details of the program’s features also provide a tacit set of requirements for eligibility. For example, the program provides a maximum average of seven hours of support per day, and is thus only suitable for individuals who are not overly ‘needy’, or those who have either adequate support networks or supplemental income to purchase additional support. For individuals who do not currently qualify for the program, the program literature indicates the level of self-discipline and self-responsibility they would need to achieve in order access the ‘freedom’ promised by the program.

3.6 The able-disabled and neoliberal citizenship

By setting certain standards of self-discipline and self-regulation, the SMAS literature conveys a message that it is possible for disabled people to access rights and freedoms. However, it is abundantly clear that access to these rights and freedoms is conditioned. The above example suggests that disabled people worthy of government support possess a certain requisite social status or social situation, which may be expressed in terms of
economic stability, family supports, social networks, employability, and so on. Regardless of the means through which they achieve it, it is essential that disabled self-managers demonstrate their capacity for (economic) independence and self-sufficiency. Access to the ‘freedom’ the program promises is thus conditional upon adherence to the norms of neoliberal citizenship: increased “choice, flexibility and control” is made available, but only to those willing and able to take on increased personal “risk and responsibility” (CILT, 2012, p. 10, emphasis added). Self-managers are required to accept full responsibility for all administrative and human resources tasks associated with organizing their own attendant supports. Examples of these tasks include registering as a business with Canada Revenue Agency; managing accounts and keeping records; filing accountability reports; recruiting, hiring, training, managing, and scheduling a support team. The program thus promotes “neo-liberalism’s promise of government through market freedom” (Power, 2005, p. 655); however, it does so in such a way as to devalue and/or delegitimize potential alternative forms of occupation and support provision. It is worthwhile to note that self-managers are in no way compensated for the administrative and human resources responsibilities they absorb as self-managers, work that would elsewhere merit financial compensation.

As the above examples have shown, SMAS promotes disabled individuals’ use of self-management as a means to citizenship, as defined, for the most part, in terms of economic participation, independence and self-sufficiency. In this way, the program reproduces a specific standard of normalcy, expressed in terms of citizenship, that promotes adherence to certain idealized norms of embodiment. The able-disabled, also called ‘super-crips’ (Shildrick, 2009; Titchkosky, 2003; Withers, 2012), are an increasingly common image of disablement, representing those disabled people who have successfully distanced themselves from traditionally constructed disabled subjectivities. The able-disabled achieve such ends by adhering to able-bodied norms, such as maintaining economic independence through paid employment. Images of the able-disabled convey a message that disability is an individual problem, a personal tragedy that, if one works hard enough, can be overcome. This construction is problematic for several reasons. First, it reinforces a traditional construction of disability as the problem of the disabled person, one they can and should overcome. Second, it obscures the
countless hours of invisible work, not to mention the personal (including financial) resources that go into crafting such an image. Finally, the image of the able-disabled serves not only to mark what is the ‘proper’ way for disabled people to conduct themselves in the face of disability; it extends much further, to the population at large:

Statistics and stories of “citizens with disabilities” can best be understood as the new morality tale told to all Canadians: If people with disabilities can, then anyone can, govern their conduct so as to actualize their participation in the normative order, all of us can crystalize our identities as the “able-disabled”. After all, today, almost any difference from the demands of normative social order can be reified as a disability (or illness), and still we all can seek to overcome the challenge of difference and become able to function within society, such as it is. (Titchkosky, 2003, p. 538)

What Tanya Titchkosky outlines here is the way in which promoting the able-disabled as a newly possible (and preferable) disabled subjectivity reinforces norms of neoliberal citizenship, assimilates the able-disabled into these norms, and reminds able-bodied citizens that they, too, can and should conduct themselves in accordance with these norms.

3.7 Discussion

The SMAS program is founded on the assertion that disability is not inherently medical in nature; that disability does not require constant medical attention; and that it is within both the rights and the capabilities of many disabled people to be primary, if not sole, decision makers regarding the organization and management of their own attendant services. A key element of the argument for SMAS is that disabled people should be free to choose who will provide their attendant supports; since the attendant support needs of physically disabled people are not necessarily medical in nature, attendant supports need not necessarily be provided by trained professionals. The appeal to self-managed care is informed by, and maps easily onto, a neoliberal framework that values individual responsibility to take control over one’s own life, and the personal exercise of one’s freedom to choose. However, framing the program as an opportunity to access neoliberal
citizenship, via (economic) independence and self-responsibility, shrouds the underpinning claims that purport to demedicalize attendant services specifically, and disability in general. The dynamic is similar to that observed by Polzer (2016), wherein the feminist language of ‘choice’ is mobilized to market pharmaceutical and biotechnology products oriented to promoting ‘women’s health’. In both cases, language that was initially and intentionally employed as a means of resistance to medicalization is co-opted and deployed in a political strategy that capitalizes on individuals’ desires for autonomy. Like women ‘empowered’ to make ‘informed decisions’ in the context of genetic testing, disabled people are ‘empowered’ to exercise their freedom to choose in accordance with a predetermined set of options and norms, in ways that may ultimately subject them to a more intense network of medicalizing gazes. In the case of SMAS, this co-optation of resistance may thus have a counterintuitive effect.

A second element of SMAS that is obscured when the privileges associated with SMAS are emphasized is the aforementioned ‘invisible work’ of self-managing attendant services. It was previously suggested that this work includes the countless hours of labour that organizing and managing attendant services entails, but disabled self-managers do not shoulder this workload alone. Although attendants are not the focus of this particular analysis, the self-managed model for organizing attendant supports fundamentally revolves around a dyad, a relationship between members from not one but two marginalized populations: disabled employers who are charged with the responsibility and freedom of organizing their own attendant services, and attendants who are often women, and, more specifically, women of colour and/ or immigrant women (Church, Diamond, & Voronka, 2004; Cranford 2005). Lacking any protection in the form of organized labour, the precarious nature of informal attendant work endangers the protection of attendants in their workplace (Church et al., 2004; Cranford 2005). As a particular form of precarious work in neoliberal societies (see also Facey, 2016; MacEachen, Polzer, & Clarke, 2016), the health-related aspects of informal attendant work is an area of research that is deserving of further critical inquiry. Of particular interest is the apparent conflict that is constructed by programs such as SMAS between the rights of (often female or otherwise marginalized) attendants and those of individuals living with disabilities. Insofar as programs such as SMAS are dependent on these forms
of labour, critical analysis is necessary to explore how they affect, and perhaps further entrench, socioeconomic and other intersecting inequalities (gender, race) that are central to practices of neoliberal governance.

An example of such inequality, also related to the work of managing SMAS, is the social stratification that the program effects. The work involved in organizing and managing attendant services, so subtly downplayed in the program literature, ultimately acts as the crux of eligibility for the program. Those disabled people who demonstrate the desire and ability to act in accordance with a certain set of neoliberal norms, and to take on the associated workload, gain access to that newly possible able-disabled subjectivity. Those deemed incapable or unwilling to take on this work are constructed as undeserving Others (Orchard, 2016; Power 2005). Similar to Polzer’s (2016) observation regarding participation in genetic testing as a form of biological citizenship, one effect of this stratification is to emphasize the role of personal rather than social factors that impact an individual’s capacity to act in accordance with that socially sanctioned set of neoliberal norms. A second effect is that those disabled people who are, even temporarily, denied access to the ‘freedom’ to self-manage stand to remind other citizens of the potential consequences should they fail to abide by neoliberal societal norms (e.g., subjection to a more repressive form of government). As Power (2005) notes, liberalism “depends on the ‘unfreedom’ of some to ensure that the rest will consent to be governed in and through freedom” (Power, 2005, p. 644). Albeit in a slightly different way than the able-disabled encourage adherence to neoliberal norms, so too do traditionally disabled subjectivities. In these ways, the normalizing power exercised through neoliberal forms of government maintains, and actively works against the possibility of overcoming, the negative attitudes and oppressions that continue to shape the lived experiences of people with all kinds of disabilities.

My primary aim in this chapter has been to demonstrate how the neoliberal construction of disabled subjectivities contributes to the government, not just of disabled people, but of all citizens. As I have illustrated, the discourse of self-management promoted by SMAS appeals strongly to disabled persons’ desires for independence and self-sufficiency, and reinforces norms associated with able-bodiedness and neoliberal
citizenship more generally. Thus, while self-management facilitates the construction of a new genre of disabled subjectivities, it simultaneously serves to reinforce contemporary networks of normalizing power. Consequently, while self-management contributes to the very important project of creating new possibilities for the lives of disabled people, it is an incomplete means, and by no means an end to the reconceptualization of disability as a means of gaining broader social acceptance for, and thereby improving the lives of, all people who are labelled ‘disabled’.

SMAS and other programs like it represent a significant and important achievement of the disability rights and independent living movements. However, inasmuch as they promote adherence to norms of neoliberal citizenship, their conceptual underpinnings are at odds with the contemporary critical turn in disability studies and radical turn in disability activism. Disability academics and activists alike are beginning to pay more attention to the hidden operations of power that impact the lives of disabled people; both are similarly concerned to problematize neoliberal modes of governance and their tendency to perpetuate the marginalization of disabled people, despite their claim of increased inclusion in consumer capitalist society (Graham & Slee, 2008; Titchkosky, 2003; Withers, 2012).

Given these aims of contemporary disability theory and activism, there is great value in approaching contemporary disability studies from the perspective of governmentality. This chapter contributes to a growing body of Foucauldian analyses of power in the field of disability studies (Corker & Shakespeare, 2002; Shildrick, 2009; Titchkosky 2003; Tremain, 2006; 2005). However, Foucauldian approaches to disability studies are relatively new, and their full potential remains, as yet, unexplored (Thomas, 2007). I do not intend to imply that Foucauldian analyses represent the only way forward for critical disability studies; rather, they represent an important resource, especially given the current critical turn in disability academics and radical turn in disability activism. Inasmuch as they are concerned to redefine disability by deconstructing traditional conceptions of normalcy, a Foucauldian lens represents an invaluable resource for critique and social change.
Judith and others who have allowed their stories to become a platform for such change have enabled incredible strides in the direction of changing attitudes towards, and ending the oppression of, disabled people. Had Judith accepted her prescribed role as a passive and needy disabled person, destined for a brief life of institutionalization, she may well have died as “the handicap called Judith” (Pearpoint, 1990, p. 20) on that geriatric ward (or another one like it) before reaching the age of thirty. She certainly would never have had the opportunity to explore the possibility of becoming a student, an artist, an activist. Given the opportunity, Judith demonstrated many possible facets of life for a disabled person, living outside of the oppressive walls of a medical institution. However, in celebrating the many triumphs Judith achieved in her lifetime, it is important not to overlook the abundance of unnecessary hardship she faced, which she, like many (most? all?) disabled people continue to confront. For, while government funds provided for Judith’s attendant needs, it is still the case that “few things are viewed more negatively than disability in [our] society” (Snow, 2012, para. 27).

3.8 References


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Power (Eds.), *Neoliberal governance and health: duties, risks and vulnerabilities* (pp. 225-246). Montreal, PQ: McGill-Queen’s University Press.


4 Methodology

Aspects of the methodological approach to this dissertation are discussed in each of the four integrated manuscripts. This section provides an overview of the study methodology, including: the overarching theoretical framework, the design and execution of the reflexive ethnographic study, and suggested criteria for evaluating this research.

4.1 Theoretical framework

4.1.1 Critical disability studies

The burgeoning field of critical disability studies (CDS) applies a diversity of critical social and cultural perspectives to the analysis of disability. In the words of Margrit Shildrick (2009), CDS entails “an investigation of what it is that continues to impede the evolution of equitable conditions of possibility” (p. 2). The development of disability studies as an academic discipline is generally associated with “a paradigm shift; from disability as personal predicament to disability as social pathology” (Goodley, 2011, p. xi). This shift was ushered in with the development of the disability social model—“a groundbreaking conceptualization of disability that broke from all of the models before it” by considering the social conditions that contribute to disablement (Withers, 2012, p. 97). CDS builds upon the theoretical developments of the social model, challenging its theoretical sufficiency, nuancing its claims (Shakespeare, 2014) and expanding the scope of CDS to include intersections “with other important agendas of class, feminist, queer and postcolonial studies” (Goodley, 2011, p. 157). Such disciplinary alliances facilitate the reconceptualization of disability in a multitude of unconventional ways, “remaining ever vigilant of political, ontological and theoretical complexity” (p. 157).

While proponents (Oliver & Barnes, 2012) and critics (Shakespeare, 2014) of the social model remain engaged in debate over its scope and usefulness, CDS has emerged as a new way forward. The aim of CDS is not to discredit the initiatives undertaken by previous waves of disability studies and activism—initiatives such as inclusion and disability rights, which developed in tandem with the social model of disability—but rather to interrogate potential shortcomings and build upon their successes. Like disability studies, CDS is about thinking disability differently. The unique focus of CDS
is on the interrogation of the complexity of disability as a social problem, which intersects in complex ways with the lives of individuals, families and communities. Distinguishing CDS from other strands of disability studies, Goodley (2011) notes that, “while critical disability studies might start with disability, they never end with it” (p. 157); CDS requires looking beyond disability in order to answer critical questions about the persistence of disability experienced as oppression, exclusion and inequality.

Drawing on CDS as a theoretical framework, this dissertation is informed by and contributes to a developing conversation among disability scholars and activists whose work attends to hidden operations of power which impact the lives of people who live with disability. The first manuscript of this dissertation (Chapter 2) outlines a conception of reflexivity that is fundamentally concerned to uncover diverse perspectives and to understand the relationship between dominant and marginalized perspectives. The second manuscript (Chapter 3) elaborates and applies a Foucauldian analysis of disability to deconstruct ‘independent living’ as a reified discourse that may be seen as emblematic of neoliberal citizenship and based on able-bodied norms. The analyses of knowledge and power outlined in these manuscripts set the backdrop against which the reflexive ethnographic methodology was developed.

The results of the reflexive ethnographic study, discussed in the third and fourth manuscripts, explore dominant and marginalized perspectives on the work of self-managing attendant services. The third manuscript (Chapter 5) considers the work of self-managing attendant services in light of critical disability studies perspectives on work. With a focus on relational work, the fourth manuscript (Chapter 6) considers the work of self-managing attendant services in light of critical disability studies perspectives on temporality and relationality. These studies draw on and contribute to CDS literature that works to redefine disability by deconstructing traditional conceptions of ‘normalcy’ (see for example, Corker & Shakespeare, 2002; Shildrick, 2009; Titchkosky, 2003; Tremain, 2006; 2005) and by problematizing the tendency for neoliberal modes of governance to perpetuate the marginalization of disabled people, despite claims to increase inclusion in consumer capitalist society (Graham & Slee, 2008; Titchkosky, 2003; Withers 2012).
4.1.2 Critical feminist perspectives

A critical feminist epistemological lens also permeates the overarching theoretical framework of this dissertation. Feminist epistemological insights emphasizing the situatedness of knowledge generation (Grosz, 1994; Harding, 1991) inform the study design (i.e. the recognition of a variety of situated perspectives), and the processes of representing the research (i.e. reflexive discussion of my positionality relative to the research). In line with critical disability studies theory, a critical feminist perspective acknowledges the centrality of disabled people (service users, or ‘self-managers’ in this context) as stakeholders in attendant services. The critical feminist approach also draws attention to the shared and situated knowledges of a range of people who participate in the feminized labour of disability care work (Hughes, McKie, Hopkins, & Watson, 2005). In keeping with critical feminist epistemological insights, the perspectives of a range of stakeholders who have everyday lived experience with the work of self-managing attendant services were considered, including service users, attendants, family members, and program administrators.

Importantly, critical feminist perspectives shape the conception of work adopted in this dissertation. Feminist theories of work take as their starting point feminized forms of labour that are conventionally performed by women and are often not acknowledged to constitute work. These perspectives on work also consider how the performance of feminized labour contributes to the marginalization of women and others who perform labour that is not typically thought of as work. Distinct from critical feminist perspectives on work, feminist disability studies perspectives also centre lived experiences of disablement amidst the development of social theories that emphasize the social construction of disability (Crow, 1992; French, 1993; Morris, 1991). Following critical feminist disability studies scholars (Garland-Thomson, 2011; Price, 2015), I have attempted to balance examination of the discursive dimensions of the work of self-managing attendant services (such as those represented in policy and program documents) with consideration of embodied and relational experience (discerned through rich description and in-depth participant accounts).


4.2 A reflexive paradigm

This research is located within a critical theoretical paradigm that emphasizes the historical situatedness of power as it circulates through societal structures and social practices (Lincoln, Lynham, & Guba, 2018). Through a reflexive lens, the research process itself may be seen to represent a social relationship imbued with power (Kinsella & Whiteford, 2009). In efforts to balance the distribution of power within the research process, some feminist and disability studies scholars advocate a shift towards an emancipatory paradigm (Barnes, 2009; Morris, 1992). In light of critiques, including the contribution of personal resources required of participants and questions about the capacity for emancipatory approaches to truly transform the social relations of research production (Barnes, 2009; Lennie, Hatcher, & Morgan, 2003; Oliver, 1997; Shakespeare, 2014), a reflexive methodological approach was adopted to prioritize ongoing reflexive interrogation of operations of power in the research process.

McCabe and Holmes (2009) suggest reflexivity as a route “to achieve the goals of emancipation that are intrinsic to qualitative research conducted within a critical paradigm” (p. 1518). Their theorization of reflexivity as an emancipatory approach draws on a Foucauldian conception of power and interrogates the ways in which knowledge generation practices may uphold the status quo. Emancipation, in their view, involves the “illumination” of “dominating truths” and requires individuals and groups “to negotiate new ways of acting” (p. 1522). McCabe and Holmes suggest reflexive engagement in the research process offers an opportunity for emancipation of both researchers and participants, as each offers the other a window into a new way of knowing. They argue that this approach fosters a “deeper, more organic change over time” (p. 1525) than the situational empowerment described in some versions of emancipatory research. A reflexive paradigmatic approach that “prioritizes disabled people’s knowledge and experience” (Barnes, 2009, p. 463) informed the design of the study, as well as interpretation and representation of the data. Following Lather’s (1991) critical emancipatory approach, “reflexive practice [was] privileged as the site where we can learn how to turn critical thought into emancipatory action” (p. 13).
4.3 Reflexive ethnography

The reflexive methodological approach that guides this research draws on conceptions of reflexive methodology from two distinct subfields: autoethnography and critical ethnography. In both subfields, the researcher’s situatedness with respect to the research and interpretations offered is acknowledged; self-reflexivity aims to make transparent and to subject to interrogation the researcher’s positionality relative to the research. Reflexive ethnographic approaches gained legitimacy at a particular moment in disciplinary history, when “orthodox, social science methodology was shaken by the critiques of poststructuralist, postmodernist, and feminist writers” (Ellis & Bochner, 2003, p. 216-217). Such critiques questioned ethnography’s claim to the “privileged status of science” (Ferraro, 2004, p. 78), challenging conventional disciplinary claims to objectivity and truth, which upheld a disciplinary objective to “construct a grand theory of human behavior” (p. 78). Influenced by feminist science and social movements from the 1960’s onward (Foley, 2002; Foley & Valenzuela, 2005), reflexive ethnographers “have replaced the grand positivist vision of speaking from a universalistic, objective standpoint with a more modest notion of speaking from a historically and culturally situated standpoint” (Foley & Valenzuela, 2005, p. 218).

A reflexive methodological approach thus foregrounds a conception of research as a situated process of knowledge generation and attempts to increase transparency with regard to individual and social factors that shape the research process. Ellis and Bochner (2003) suggest “reflexive ethnographers … use the ‘self’ to learn about the other” (p. 212).

Although reflexive ethnographies primarily focus on a culture or subculture ... the researcher’s personal experience becomes important primarily in how it illustrates the culture under study. Reflexive ethnographies range along a continuum from starting research from one’s own experience to ethnographies where the researcher’s experience is actually studied along with other participants, to confessional tales where the researcher’s experiences of doing the study become the focus of investigation. (p. 211)
This research began with questions generated during my personal and professional experiences working as an attendant. My experiences are acknowledged insofar as they inevitably shape my interpretive lens. In the first manuscript (Chapter 2), a reflexive account of my experience working as an attendant informs a theoretical exploration of ‘embodied reflexivity’—a form of reflexivity that informs the methodological approach taken in this dissertation. My embodied experiences of working as an attendant are further acknowledged to have informed the study design (i.e. the questions I asked participants). Although I did not plan to discuss my experiences with participants, they did at times surface spontaneously during conversations and/or interviews with participants throughout the research project.

The reflexive approach “is understood as a political tool and not as a quest for truth … a scientific approach that challenges the status quo”; “a political process that promote[s] discussion and dialogue in the face of strong social resistance” (O’Byrne, 2007, p. 1387). Reflexive ethnography was adopted as a means to name, describe, and better understand the work of self-managing attendant services; to incite and promote discussion about a phenomenon—the work of self-managing attendant services—that has, to this point, been largely unrecognized. This approach facilitated the collection and recording of diverse, situated perspectives. The task was “not to unmask and demystify but, rather, to multiply perspectives toward an affirmation of life as a means to knowledge without guarantee” (Lather, 2007, p. 17).

4.4 The study of ‘culture’

Cultural anthropologists have historically used ethnography to document “the exotic customs of people in far-off places” (Ferraro, 2004, p. 15), however critiques have led to a broadened definition of culture and an expanding scope of ethnographic practice. In recognition of the dynamic nature of cultures, and in rejection of the “liberal, humanist doctrines of ameliorism, orientalism, colonialism, and racism” (Foley, 2002, p. 470) upon which the discipline was founded, many contemporary ethnographers conduct research much closer to home, focusing on mainstream culture or subcultures. From a contemporary perspective, culture is “everything that people have, think, and do as members of a society”; “cultures comprise material objects; ideas, values and attitudes;
and patterned ways of behaving” (Ferraro, 2004, p. 24). This way of thinking highlights that the collection of people who participate in self-managed attendant services are part of a culture. They share in common material objects (such as program literature and documentation); share some common values (pertaining to their election of the self-managed model); and engage in at least some common practices and behaviour patterns (such as the practices of recruiting, hiring, training and managing attendants).

Self-managed attendant services are perhaps more aptly framed as a subculture, in that self-managers and others involved in the organization and management of self-managed attendant services “share a number of cultural features with the mainstream, but they retain a certain level of cultural uniqueness that sets them apart” (Ferraro, 2004, p. 26). Framing self-managed attendant services as a subculture may be particularly useful as a means of investigating power relations that shape the program. As Ferraro (2004) notes, “subcultural groups within a society are not afforded all of the benefits enjoyed by the mainstream. The mainstream both outnumber the various subcultural groups and also control the society’s major institutional structures” (p. 26). Framing self-managed attendant services as a subculture recognizes both the legitimacy of the way that self-managers “have, think, and do as members of a society” (p. 24), and the dynamic nature of that subculture as it exists in tension with mainstream culture.

To frame self-managed attendant services as ‘culture’ challenges the conventional notion of a contained and stable field ‘site’ upon which much traditional ethnographic research was built. Describing a ‘spatial turn’ in social theory, and evoking a spatial politics of ethnography, Tsolidis (2008) challenges the methodology’s conventional reliance upon the construct of the site and argues for a conception of space not “as a container that captures or holds”, but instead “as a dynamic between social and material relations, which are characterized by power” (p. 273). Tsolidis’s reconceptualization of space in this way facilitates recognition of the sociohistorical complexity of influences upon the spaces within which cultures exist. A distinctive feature of the self-managed model, for instance, is that it occurs in individuals’ homes, rather than the communal spaces conventionally associated with institutionalized care. With implications for ethnographic methodological practices, Tsolidis suggests indiscriminate adherence to
methodological convention may “reinscribe culturally privileged ways of seeing” (p. 279). Tsolidis therefore suggests that “as researchers we need to be mindful of the potential of our work to redefine minorities as peripheral through research in such spaces” (p. 279), and to “develop creative methods that align to spatiality rather than remain restricted by site” (p. 280).

4.5 Methods

This research employed several methods in pursuit of the objectives: 1) to broadly understand the work that self-managers and potential others contribute to the organization and management of attendant services; 2) to produce a representative account of the work of self-managing attendant services that is relevant to the people who perform such work; and 3) to consider participant accounts in the light of existing ‘official’ accounts of self-managed attendant services. Program administrators, self-managers and attendants were recruited for formal interviews. Data collection methods included interviews, reflexive journaling, and field materials.

4.5.1 Recruitment and sampling

Materials to recruit participants to the study (see Appendix A) were posted in public places (several grocery stores and libraries) in the community and online (via an add on Kijiji.com). Additionally, I contacted local and provincial independent living centres affiliated with the Ontario program. The local independent living centre reviewed the recruitment materials and forwarded these to an undisclosed group of prospective participants. The provincial independent living centre sought approval of their board of directors before circulating recruitment materials to an undisclosed group of prospective participants. As prospective participants contacted me to discuss participation in the study and mentioned how they had come to acquire information about the study, it became apparent that some snowballing was taking place. For example, one administrator said they had received notice of the study via another local independent living centre that I had not been in contact with. In another example, a self-manager said they had become aware of the study through word of mouth.
A purposeful approach to sampling was used to “discover, understand, and gain insight” through the pursuit of “information-rich cases ... from which the most can be learned” (Merriam, 2009, p. 77). Participation was open to male, female and non-binary individuals. Initially, I proposed to include participants who had extensive (at least 3 years) and varied (i.e. positive, neutral and negative, successful and unsuccessful) experience with self-managed attendant services. During the recruitment process, communication with prospective participants highlighted a potential conflict between the recruitment objectives to find participants with extensive and varied experiences. An independent living centre administrator suggested that participants with less experience might offer valuable perspectives since the transition to the self-managed model would be more recent. With this in mind, I welcomed the participation of self-managers with more diverse profiles of experience including: one self-manager who had used attendant services for many years but was new to the self-managed model; and one former self-manager who had many years of experience with the self-managed model but was no longer a participant of the Ontario Direct Funding program. Additionally, two participants indicated their involvement began with advocacy, predating the inception of the ODF program. The following table provides a breakdown of participant pseudonyms and roles in relation to self-managed attendant services (Table 1). To protect confidentiality, participant demographic data is presented in a separate table (Table 2).

Table 1: Participant pseudonyms and roles

<table>
<thead>
<tr>
<th>Self-Managers (SM)</th>
<th>Primary Support Personnel (PSP)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pseudonym</strong></td>
<td><strong>Pseudonym</strong></td>
</tr>
<tr>
<td>Lydia</td>
<td>Brenda</td>
</tr>
<tr>
<td>Denise</td>
<td>Marleigh</td>
</tr>
<tr>
<td>Karen</td>
<td>Paul</td>
</tr>
<tr>
<td>Mason</td>
<td>Geraldine</td>
</tr>
</tbody>
</table>


<table>
<thead>
<tr>
<th></th>
<th>Name</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>Kimberly</td>
<td>5 Mark</td>
</tr>
<tr>
<td>6</td>
<td>Mary</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Ed</td>
<td>Administrators (A)</td>
</tr>
<tr>
<td>8</td>
<td>Joan</td>
<td>Pseudonym</td>
</tr>
<tr>
<td>9</td>
<td>Gary</td>
<td>1 Judy</td>
</tr>
<tr>
<td>10</td>
<td>Alan</td>
<td>2 Anita</td>
</tr>
<tr>
<td>11</td>
<td>Marcie</td>
<td>3 Peter</td>
</tr>
</tbody>
</table>

Table 2: Participant demographic data

<table>
<thead>
<tr>
<th>Age</th>
<th>SM</th>
<th>PSP</th>
<th>A</th>
<th>Years of involvement with ODF</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>SM</td>
<td>PSP</td>
<td>A</td>
<td>&lt; 2</td>
</tr>
<tr>
<td>20-25</td>
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<td>-</td>
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<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Full-time</td>
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<tr>
<td>Retired</td>
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### 4.5.2 Interviews

Semi-structured interviews were conducted with eleven self-managers, five primary support personnel and three program administrators. Interviews lasted between 36 and 142 minutes (average = 81 minutes), and were audio recorded and transcribed verbatim. Interviews were conducted in negotiated locations of the participants’ choice. Twelve interviews were conducted in private residences, four took place in the participant’s workplace, and two took place in public locations. The purpose of the interviews was to elicit thick description (Geertz, 1973) of participants’ thoughts and interpretations about the work involved in self-managing attendant services. All interviews followed a semi-
structured interview format based on an interview guide (see Appendix B). Separate interview guides were developed for each of the three participant categories: self-managers, primary support personnel, and administrators. While the interview guide served to shape the conversation, participants were invited to contribute to the direction and flow of the interview. I began each interview by letting participants know that I had a set of questions I would like to ask and offering participants the opportunity to have the first word. I closed each interview by asking again if there was anything else participants would like to share.

The interview guides were developed with awareness of “the role of interviewing as a knowledge-producing social practice” (Brinkmann, 2013, p. 4). Dr. Kinsella and I engaged in extensive dialogue concerning the questions that would be posed, the range of possible answers questions might generate, and the potential consequences of generating particular forms of knowledge. For example, the interview guides were developed with awareness of the status of self-managed attendant services as a publicly funded program on which many people depend; a program whose existence is always vulnerable to changes in public spending, and that could stand to be influenced by the knowledge generated through this project. The interview guide was therefore constructed to offer participants opportunities to discuss both challenges and benefits of the work of self-managing attendant services.

The interview guides were further developed with reflexive awareness of my experience with self-managed attendant services, and the potential for my experience to shape the way work was conceptualized and discussed within the interviews. The interview guides were carefully screened by myself and Dr. Kinsella to adjust wording that reflected any judgment of work. Understanding that participants may not conceptualize their everyday activities as ‘work’, the questions name and ask about ‘work and activities’. The questions were also designed to invite participants to contribute more generalized descriptions of their experiences in order to capture contributions of work that might not be thought of as work. For example, question five in the interview guide for self-managers asks: “What type of work and activities do you do as part of the SMAS program in a typical day? Can you describe these in detail? Examples? Managing
attendants, scheduling activities, handling administrative aspects? What does a typical day look like for you?”

4.5.3 Reflexive journaling

Throughout the development of the project, reflexive journaling (Lincoln & Guba, 1985) was used to track the progression of ideas that shaped the research questions, methodology, study design, data collection, data analysis, interpretation, representation and plans for dissemination. This method was used to facilitate reflexivity by recording, and thus opening to scrutiny, the processes that shape the research (Malacrida, 2007). To this end, reflexive journaling has been used to craft a research project that carefully considers both the motivation for, and potential outcomes of, decisions guiding the direction of the project. Throughout the processes of data collection and analysis, reflexive journaling was used to keep a record of the fieldwork process; to recount and recall fieldwork experiences and details pertaining to the data that was collected, including informal observations within field sites and to facilitate reflexive consideration of ‘ethically important moments’ in the field (Guillemin & Gillam, 2004).

One example of this process and its impact on the research is the written record I kept during communications with the independent living centres (ILCs) as I began to recruit participants for the study. Throughout the early stages of the research, Dr. Kinsella and I deliberated on the appropriate time to contact the ILCs. On one hand, we wondered about a potential conflict of interest if the organizations involved in administering the program were formally affiliated with the research; we discussed the possibility that participants might not feel safe to speak freely if there was any perceived potential for reprisal or backlash from the program. On the other hand, we wondered about a potential conflict between the critical orientation of the developing project and the interests or responsibilities of the program and/or administering organizations; we discussed the potential for these responsibilities to constrict or shape the scope of the project, and for affiliation with the project to jeopardize the organizations’ relationships with their funders or with program participants. Ultimately, we decided that, in accordance with the methodological approach, it would be most appropriate to contact the ILCs once we had gained ethical approval from the REB.
On reaching out to the ILCs, I received some challenging responses. As I navigated sensitive communications with the ILCs, I made use of reflexive journaling to track and reflect upon the process. In a journal entry I recorded near the beginning of the recruitment process, I described a phone conversation in which a program staff person communicated some reservations about supporting the study. (For ethical reasons I have decided not to reproduce the journal excerpt here.) As I revisit this entry, I am struck by its power to illustrate numerous functions of the reflexive journal. In the passage, I recorded multiple examples of the vocabulary the program staff used in our conversation; a vocabulary I would become increasingly familiar with as I went on to interact with more participants in the study. I also made note of ethical concerns expressed by this program staff person, as well as some immediate reflection upon the involvement I anticipated the organization would have in the study. This passage forms part of my written record of the research process, but it was also instrumental to the research process. For example, I returned to this passage as I contemplated and drafted subsequent communications with the organization over the following weeks. In these ways, the reflexive journals I kept throughout this process provided an invaluable space to record and engage in real-time reflexive interrogation of the fieldwork process.

4.5.4 Field materials

Through online research, I acquired publicly available program documents pertaining to the Ontario Direct Funding (ODF) program. Publicly accessible, online information from a program website and other related provincial government websites were important sources of information about the ODF program. Documents in the data set included: a policy document, an application and associated guidebook, a general information pamphlet, the program website itself and a press release from the provincial government announcing expanded program funding. Additional documents were shared by some participants in the research process. Participants provided field materials, including: accountability and documentation forms (distributed by the program, some of them adapted by self-managers and/or a bookkeeper); one participant-generated schedule; and a training manual one self-manager had produced.
4.5.5 Data analysis and reflexive interpretation

Informal data analysis began as I reviewed my reflexive journals recorded throughout the interview process, including notes on emerging insights I recorded in the process of transcribing the interviews. The formal data analysis process utilized the qualitative data management software *Quirkos*. I followed an adapted version of the narrative interview reporting process Dierckx de Casterlé, Gastmans, Bryon and Denier (2011) developed to preserve the richness of qualitative data they suggest may be lost through exclusive use of data analysis software. Following Dierckx de Casterlé et al., I began with verbatim transcription of the interviews and a careful re-reading of each transcript. I then generated a narrative report of each interview, beginning with a description of the participant and noting salient contributions from the interview. (The narrative reports are not included here due to concerns they may allow for identification of participants). As I re-read the transcripts with the research questions in mind, I generated a list of emergent concepts that I then used to code the interview transcripts. An initial list of codes included: feelings about the program; praise; critique; suggestions; funding; what DF enables; work; application; interview; recruiting; hiring; training; managing; managing (accountant); firing; learning; attendants (the relationship); attendants (the job); agencies.

Once I began to code the interview transcripts, some of the initial concepts were divided, others were grouped, and several new concepts emerged. Throughout the process of coding the interviews, I spatially organized and re-organized the concepts (represented by separate coloured circles, or ‘quirks’) using the *Quirkos* canvas. The final list of concepts included: before (and after) DF; finding out about DF; applying; interview; starting DF; being a SM; learning; managing DF; work; increased funding to DF; DF program/history; accessing DF; clawing back; communication with CILT; communication with others; who else helps; bookkeeper; attendants; choice, flexibility and control; fear; stress; time; who gets funded; how much funding; what DF enables; overall impressions. (Several of these concepts contain sub-concepts that are not listed here. For a visual representation of the *Quirkos* canvas, see Appendix C.)

At this stage in the analysis, Dierckx de Casterlé et al. (2011) prescribe an in-depth analysis of the concepts generated that is articulated in the researcher’s own words
and grounded in the empirical data. To support this in-depth analysis of the concepts I drew further insights from Srivistava and Hopwood’s (2009) framework for analytic reflexivity—a process of ‘reflexive iteration’ that continuously asks three questions of the data: 1) What are the data telling me? 2) What is it I want to know? 3) What is the dialectical relationship between what the data are telling me and what I want to know? Following this framework, I ‘asked’ the list of concepts, “What are the data telling me?” I then developed a parallel list, asking myself the second question “What is it I want to know?” The questions I generated through use of the reflexive analytic framework are outlined in the following table (Table 3).

Table 3: Reflexive analytic framework

<table>
<thead>
<tr>
<th>Q1 - What are the data telling me?</th>
<th>Q2 – What is it I want to know?</th>
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<tbody>
<tr>
<td>Benefits of SMAS</td>
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<tr>
<td>What are the benefits?</td>
<td>What are the benefits?</td>
</tr>
<tr>
<td>Is there a way the benefits could be achieved without the work? Is that a desirable outcome? Are there benefits to the work itself?</td>
<td>Is there a way the benefits could be achieved without the work? Is that a desirable outcome? Are there benefits to the work itself?</td>
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<tr>
<td>Are the benefits rights? If so, is it just to make people work in order to obtain rights?</td>
<td>Are the benefits rights? If so, is it just to make people work in order to obtain rights?</td>
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<tr>
<td>Are there benefits to agency delivered services that are absent in SMAS?</td>
<td>Are there benefits to agency delivered services that are absent in SMAS?</td>
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<tr>
<td>The work of SMAS</td>
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</tr>
<tr>
<td>What is the work?</td>
<td>What is the work?</td>
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<tr>
<td>What aspects of the work are beneficial?</td>
<td>What aspects of the work are beneficial?</td>
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<td>What aspects of the work are stressful?</td>
<td>What aspects of the work are stressful?</td>
</tr>
<tr>
<td>How does stress related to the work of SMAS impact the lives of participants? What in particular makes SMAS stressful? Is it possible to reduce the stress and retain the benefits of SMAS?</td>
<td>How does stress related to the work of SMAS impact the lives of participants? What in particular makes SMAS stressful? Is it possible to reduce the stress and retain the benefits of SMAS?</td>
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<tr>
<td>What is the relationship between lack of supports/information and the stress/benefits of SMAS? Could the stress be reduced if better supports/information were available?</td>
<td>What is the relationship between lack of supports/information and the stress/benefits of SMAS? Could the stress be reduced if better supports/information were available?</td>
</tr>
<tr>
<td>Inequitable distribution of resources</td>
<td>Are participants prepared for the work? Could they be better prepared for the work?</td>
</tr>
<tr>
<td>What assumptions do the policy (written or lived experience) reveal?</td>
<td>What assumptions do the policy (written or lived experience) reveal?</td>
</tr>
<tr>
<td>What questions of equitable access to the program arise when people are not prepared to do the work of SMAS, and access is granted based on pre-existing capacities to take on the work? Do people with certain supports/information/life experiences/privileges gain preferential access?</td>
<td>What questions of equitable access to the program arise when people are not prepared to do the work of SMAS, and access is granted based on pre-existing capacities to take on the work? Do people with certain supports/information/life experiences/privileges gain preferential access?</td>
</tr>
<tr>
<td>Would access to the program be more equitable if people were</td>
<td>Would access to the program be more equitable if people were</td>
</tr>
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</table>
given more supports?
In the absence of supports to ensure equitable access, do situational factors contribute to SMs ability to participate/succeed with direct funding?

| Unpaid work | Who does the work? Are they paid to do it? (Are they paid fairly for the demands of the job?)
What assumptions about disabled people do the policies reveal?
What different (theoretical) frameworks aid in understanding unpaid work?
Would a more relational perspective understand unpaid work differently?

| Work that is tacit/invisible/hidden may not be accounted for | What is the significance of tacit/invisible/hidden work? |

I began the second list with a reflection on the research questions, in light of the emerging data. I also considered the question ‘what do I want to know’ in relation to the emerging analysis itself—creating space to explore new directions based on the emerging themes. This process led to an organic exploration of the ‘dialectical relationship’ between the first two questions: between what the data were telling me and what I wanted to know. As can be seen in the table presented above, at this point in the analytic process I began to recognize a need to turn back to the literature in order to help understand, explain and theorize some of the emerging insights and questions. Moving back towards the literature, I took care to remain open to a multiplicity of possible meanings, maintaining a broad “interpretive repertoire” (Alvesson & Sköldberg, 2000, p. 250) or range of perspectives through which the empirical data was considered.

4.6 Quality criteria

How do we know when we have specific social inquiries that are faithful enough to some human construction that we may feel safe in acting on them, or, more important, that members of the community in which the research is conducted may act on them? (Lincoln & Guba, 2000, p. 227)
4.6.1 Assessing the quality of reflexive research

In reflexive research, Alvesson and Sköldberg (2000) suggest there is increased need “for reflection in relationship to the interpreted nature of all empirical material” (p. 257-258). Development of guidelines for rigour in reflexive research thus also demands reflexive engagement, requiring more than a procedural checklist of criteria. This section draws on guidelines outlined for ‘new paradigm’ (Lincoln, 1995; Lincoln & Guba, 2000) and emancipatory (Lather, 1991; McCabe & Holmes, 2009) methodologies, which attend to the relational aspects of inquiry, its transformative nature, and its capacity to incite action. These guidelines inform an integrated strategy that values a multiplicity of perspectives, critical reflexivity and reciprocity.

4.6.2 Multiple perspectives

A primary aim of the research was to understand and represent multiple perspectives on the work of self-managing attendant services. Lincoln and Guba (2000) propose the notion of ‘fairness’ as a measure of validity that takes as a guiding principle the integration of multiple perspectives. Lincoln and Guba describe fairness as “a quality of balance”, wherein various “stakeholder views, perspectives, claims, concerns and voices should be apparent in the text” (p. 278). This notion of fairness resonates with Lincoln’s (1995) evocation of ‘voice’ as a quality measure, wherein quality research demonstrates “openness to multiple voices and interpretations of the work” (p. 282) and attends to “alternative voices” (p. 283) that frequently go unheard. Recruitment targeted a variety of stakeholder perspectives—namely stakeholders with lived experience and whose everyday lifeworlds are affected by the work of self-managing attendant services. Further, the participant group represents a range of perspectives on and diversity of experiences with the Ontario program. In the presentation of the data, I took care to represent these diverse perspectives—including conflicting or contradictory accounts.

4.6.3 Crystallization

Awareness and representation of multiple perspectives as a guideline for assessing quality is similarly evident in Richardson’s (1994) discussion of crystallization as a formulation of validity that recognizes both the multiplicity and partiality of perspectives.
Richardson offers crystallization as an alternative to the conventional validity criterion of triangulation, pointing out that “there are far more than ‘three sides’ from which to approach the world” (p. 522). Multiple methods were employed to pursue diverse perspectives, which were then woven together to construct multifaceted representations of the work of self-managing attendant services. The knowledge generated through this project is physically and temporally situated, such that the contributions of each participant, including my own contributions, are acknowledged as historically-situated and context-bound. The findings of this research should be interpreted with understanding that a different sample, in a different time and place may offer a different set of perspectives, as might a different researcher analyzing the data through a different lens draw different interpretations and conclusions (O’Byrne, 2007). The intent of this project was not to state absolute and immutable ‘truths’ about the work of self-managing attendant services—but to begin to understand that work and the significance it holds for those who perform it, with recognition that to name and describe the work of self-managing attendant services represents a first step in the endeavour to know more about it.

4.6.4 Reflexivity

Reflexivity is commonly invoked to demonstrate rigour in qualitative research since it demands awareness of the situated and partial nature of claims to knowledge (Finlay, 2002; Phelan & Kinsella, 2013); revealing not just the incompleteness of claims to knowledge but also the tendency for truth claims to mask and serve particular interests (Harding, 1991). A reflexive orientation entails recognition of the partiality of knowledges and the perspectives from which they are constructed, which Reason and Rowan (1981, as cited in Lincoln, 1995) describe as a “high-quality awareness” that aids in “understanding with great discrimination subtle differences in the personal and psychological states of others,” as well as “one’s [own] psychological and emotional states before, during, and after the research experience” (p. 283). To this end, transparency of the research process and remaining carefully faithful to the data represent measures “to protect our work from our own passions and limitations” (Lather, 1991, p. 69). Throughout this research process, reflexive journals were used to track the evolution
of my thinking about this project and about the work of self-managing attendant services. In self-reflexive writing I have been forthcoming and critical of my positionality relative to the research. I have engaged in ongoing reflexive dialogue with Dr. Kinsella, my supervisory committee, colleagues and friends. Reflexivity in the data analysis phase, as outlined above, was facilitated by combined use of two systematized analytic frameworks. The combined use of reflexive journaling and these analytic frameworks generated a textual record across which the progression of methodological, theoretical, practical and interpretive decisions can be traced. Such a “systematized reflexivity”, Lather suggests, “reveals how a priori theory has been changed by the logic of the data” (Lather, 1991, p. 67).

4.6.5 Community resonance and engagement

In studies that represent the perspectives of, and/or are oriented to serve particular communities, Lincoln (1995) suggests that communities themselves act as “arbiters of quality” (p. 280) of the research. Quality may be assessed in terms of the resonance or representativeness of knowledge generated in the research. It may also be measured in terms of its usefulness to the implicated community or communities. At various points throughout the process of completing this dissertation project I have subjected the research to the scrutiny of various communities of scholars by way of poster and paper presentations at local, national and international conferences. These presentations have created opportunities for dialogue with disability studies scholars, health professionals and scholarly communities, as well as some service users. Additional validation of the relevance of the research may be inferred from the acceptance of the third manuscript in this dissertation for publication by the Journal Disability & Society, in which relevant scholarly conversation are published. Feedback from the peer reviewers in this process clearly articulated that the topic is pertinent and that the research makes a valuable contribution to ongoing scholarly conversations in this area.

Throughout the process of designing the study and analyzing the data I have also engaged in dialogue with colleagues and friends who were not participants in this study, but who represent various stakeholder groups. Such dialogue has instilled a sense of confidence that this research is resonant and meaningful to members of the communities
affected by it. Future plans to continue with knowledge translation activities involving the circulation and presentation of the research findings among stakeholder communities (elaborated below) will increase the potential utility of the findings while continuing to create space for feedback from and dialogue with relevant communities.

4.6.6 Reciprocity

A final criterion by which the quality of this research may be assessed is reciprocity. Lincoln (1995) describes reciprocity as “a characteristic of high-quality, rigorous qualitative interpretive inquiry” (p. 283). Others suggest reciprocity is essential in the design of research with emancipatory aims (Lather, 1991; McCabe & Holmes, 2009), since “reciprocity implies give and take, a mutual negotiation of meaning and power,” and urges “that we consciously use our research to help participants understand and change their situations” (Lather, 1991, p. 57). Reciprocity in emancipatory research is suggested to require “self-disclosure on the part of the researcher” (p. 60) and opportunities for “at least a subsample of respondents” (p. 61) to help negotiate the meanings derived from the data. Strategies for reciprocal research design guided decisions that were made throughout the research process. Throughout the research, direction was taken from research participants. For instance, during recruitment, a number of participants expressed discomfort with one of the original dimensions of the study—participant observation as a method for data collection—and consequently this aspect was removed from the study. In the interest of prioritizing focus on participants’ own experiences, self-disclosure was not a planned part of research interactions. I was, however, open to speaking about my experiences with participants at their prompting. Generally, by the end of the interview, the topic of my relationship to the research came up and I discussed some of my experiences with some participants.

McCabe and Holmes (2009) further discuss “allowing the voice of participants to be heard in their own words; being open to questions and information-gathering from participants; adjusting the research agenda to reflect the ideas and concerns that are important to participants,” and “encouraging participants to self-explore and thereby gain new knowledge of themselves” (p. 1524). In numerous instances I allowed the participants to direct the flow of conversations that deviated from the prepared interview
questions, ceding control in a way that allowed participants to tell stories on their own terms and in their own words. To create space for participants to comment on my interpretations of their stories within the context of individual interviews, I was intentional about paraphrasing participants’ contributions back to them and asking clarifying questions (Brinkmann, 2013). In the presentation of the data, I took great care to illustrate themes through participants’ words, and to retain nuanced meaning communicated in their stories. While I cannot presume to know what participants took away from their participation in the study, I believe the interview provided an opportunity for participants to think, perhaps differently, perhaps critically, about potentially taken-for-granted aspects of their everyday lives. I similarly cannot predict what service-user, activist or research communities will do with the published outcomes of this research, but I have worked to conduct this research and will continue to work to disseminate this research in ways that will hopefully drive systemic change to the benefit of people who lent their time and knowledge to this study.

4.7 Ethical considerations

4.7.1 Procedural ethics

In compliance with standard procedural ethics protocol, approval to conduct the proposed research was be obtained from the Western Non-Medical Research Ethics Board (see Appendix D). Before any data was collected, all participants reviewed a detailed letter of information (see Appendix E) explaining the purpose of the study, procedures involved in the study, measures to ensure privacy and confidentiality, and risks and benefits of participation in the study, and signed a consent form (see Appendix F). Participants were invited to ask questions and to seek clarification. Interviews were digitally recorded and stored in password-encrypted files. The files are kept on a storage drive, alongside all other paper data collected inside a locked filing cabinet, in a locked office at Elborn College. To protect participants’ identities, participants’ names and contact information are stored only on a master list inside of the locked filing cabinet. On this list, names are associated with a number. All subsequent information provided by participants was associated with that number. The master list containing names is kept in a separate file.
The data collected during this study will be retained for 5 years and then destroyed. Only researchers associated with this project will have access to the information.

4.7.2 Ethics in process

In their discussion of ethical research practices, Guillemin and Gillam (2004) usefully distinguish between procedural ethics and ‘ethics in practice’. Procedural ethics encompasses those steps taken, usually during a preliminary stage, to obtain approval from an ethics committee and informed consent from participants; steps taken to “protect the basic rights and safety of research participants from obvious forms of abuse” (p. 268). Ethics in practice is a matter of the researcher’s ethical conduct when faced with the unforeseeable ethical issues that arise while the researcher is out in the field; those “‘ethically important moments,’ where the approach taken or the decision made has important ethical ramifications” (p. 265). Guillemin and Gillam believe that engagement with procedural ethics helps to lay the foundations of preparation for encounters with ethically important moments in the field but suggest that a commitment to reflexivity enhances a researcher’s ability to respond appropriately when ethically important moments arise. They recommend commitment to an extended reflexivity; reflexivity “in relation to interpersonal and ethical aspects of research practice, not just the epistemological aspects of rigorous research” (p. 277). Consistent with the methodological design of this research, reflexivity informed the development of the research proposal and continued to guide and develop ethical practice throughout the research process.

Throughout the conduct of this research, ethically important moments surfaced recurrently. Such moments required real-time reflexive deliberation to resolve. Each one created an important opportunity to reflect on the design and conduct of the study. One such moment, discussed above, was the challenging initial communications I had with the independent living centres. At the outset of the study design, Dr. Kinsella and I deliberated on the appropriate moment to approach the independent living centres. We debated whether it would be more appropriate to invite their involvement early on in the planning stages, or to wait until a proposal was drafted and/or ethical approval received. In accordance with the methodological approach that we thought would best respond to
my developing research questions, and apprehensive to approach potential participants prior to receiving ethics approval for a study, we decided to wait until ethics approval was obtained. With a significant investment of time and other resources made in the study already at that point, it was a jarring moment to be met with hesitation from the independent living centre staff. On one hand, I understood their reluctance: I was requesting access to an historically heavily, and often problematically researched population. Having gained an understanding of the history and ongoing politics of disability research, I also understood potential concerns about the absence of consumer control in the study. On the other hand, I had engaged in such careful deliberation on the methodological approach, I felt confident that it could be enacted in an appropriate and ethical manner. I also realized that it would be possible to proceed with recruitment through alternate avenues without their support; yet I felt strongly it would be valuable to see their perspectives represented in the research.

Through ongoing dialogue and communication, we were able to reach a mutually agreeable outcome. In the end, however, I wonder if it might have been better to be in contact with the organization sooner. If I had been in touch sooner, they might have declined to support the project, however I suspect their reasons and feedback at that earlier stage might have meaningfully informed an alternative approach.

Another ethically significant occurrence in the research was the response I received from one of the first prospective participants to see my recruitment materials, and the subsequent decision to remove participant observation as a data collection method. The prospective participant indicated that they would be interested to participate but were uncomfortable with the observation component. Since it was not ultimately used as a method of data collection, I did not discuss participant observation above. In the initial version of the study, however, participant observation was proposed (and ethical approval from the university received) as a method of data collection. In the research proposal and approved ethics protocol, I described the method as follows:

[Participants] will also be invited to participate in two 4-hour participant observation sessions. During participant observation sessions the researcher will
visit [participants] in their homes or at potential other locations where the work of self-managing attendant services takes place. The goal of participant observation sessions will be to observe the daily work of self-managing attendant services; to help understand context; to observe the work that is described in initial interviews; to develop questions for follow-up interviews; and to gain an additional perspective into the work of self-managing attendant services. During participant observation sessions, the researcher will spend time observing ‘a day in the life’ of participants. The researcher will attempt to be as unobtrusive as possible to participants’ routines, but will engage in informal conversation to establish rapport, take notes and ask questions when appropriate. With consent, conversations may be audio-recorded. Where possible, one morning/day and one afternoon/evening session will be scheduled. Participants will identify field materials (documents, documentation or organizational strategies) used to manage the work of ODF.

It was described in the original letter of information for participants as follows:

The study investigator will join you in your home or at another relevant location to observe the activities you do—on your own and with the support of other people—to organize your support services. These sessions will take place on two half-days (4 hours each) that will be arranged to suit your schedule. With your consent, the researcher will audio-record conversations during this time. Audio recording of conversations at observation sessions is optional. Observation sessions can take place with or without recorded conversations.

At the time I received resistance to participant observation from this prospective participant, I already had two interviews scheduled. Although the prospective participant was expressing concern about the time commitment this component would require, as I passed emails back and forth with this third prospective participant I began to feel it was inappropriate to use participant observation as a data collection method at all. As this prospective participant explained why the participant observation sessions would not work with their daily routine, I reflected back on my past employers’ daily routines and
was suddenly struck by a sense of inappropriateness about it. I proceeded with the first two interviews and let both participants know I had decided not to do participant observation, despite both of the first two participants indicating they were fine to proceed with the planned observation.

Reading these well-reasoned paragraphs now, a knot forms in my stomach. I have a much better sense now than I did in the earlier planning stages of this study about the history of disability research and the politics of objectification that may be implicated in the practice of observation. Ironically, I had migrated away from a participatory approach in part due to concerns about the commitment of time it would require; participant observation was supposed to represent a less involved alternative. As I discuss later on in the concluding chapter of this dissertation, I no longer believe participant observation was an appropriate choice of method for this study, and I would suggest it is probably not an appropriate choice for much research in the field of disability studies.

A final ethically important moment in the research I would like include here is the story of how I came to conduct 18 interviews with 19 research participants. I received a phone call from Paul, whose wife Joan had heard about the research through word of mouth. Paul explained over the phone that Joan wanted to participate but that, due to a neurological condition, her speech was sometimes hard to understand. Would it be okay, they wondered, if Paul helped to translate for Joan. I saw no problem with this suggestion. When I arrived to conduct the interview, I reviewed the study materials with Paul and Joan together and asked them both to provide written consent. At that time, I was not thinking about Paul as a true participant in the research but thought it necessary to obtain his consent nonetheless. What unfolded was an interview unique among the rest for its fusion of two perspectives: sometimes agreeing, sometimes disagreeing, sometimes adding or correcting details in a story. In the moment there was little I could do. Indeed, I struggled to understand Joan, but so too, it was my impression, did Paul. The opportunity created a unique space for reflection on dependency as it relates to communication. Theirs was a rich and interesting case, and I was glad to find that unique and unexpected experience. For ethical reasons, I am not sure such an interview could be planned, however I feel there was an important lesson involved in going with the flow of
the unexpected in the research process. Given his significant contributions and the additional perspective he offered (as a spouse of a self-manager and quite involved in the organization and management of Joan’s supports) I decided to include Paul as a separate research participant.

4.8 Strengths and limitations

4.8.1 Strengths

There were several strengths to the methodological approach taken to this study. After careful deliberation and extensive exploration of methodological literature, I opted to pursue reflexive ethnography. While I cannot claim to have innovated reflexive ethnography, the approach has been discussed relatively briefly in the methodological literature. Where reflexive ethnography has been discussed, it has been taken up in diverse ways by scholars writing from divergent philosophical perspectives. The variant I pursued drew primarily from the writings of Carolyn Ellis and Art Bochner (2003), with additional insights drawn from Patti Lather (2001a; 2001b) and Norman Denzin (2003). These writings lent a foundation to the development of a methodological approach centred around a critical feminist reflexivity. As I have elaborated in the concluding chapter of this dissertation, I have found this approach an effective means to pursue simultaneous critical and emancipatory objectives in the study. Having put this largely theoretical approach into practice, I would suggest it is a valuable means to conduct ethically rigorous research, particularly with marginalized populations, since it is centrally concerned with ongoing attention to operations of power that permeate the research process.

This study was oriented to explore multiple perspectives on the work of self-managing attendant services. While several stakeholder groups were consulted, the emphasis was clearly placed on the people who ‘live’ self-managed attendant services; for whom the work of managing attendant services constitutes part of their daily lives. The focus on self-managers as the primary participant group generated a large amount of data from the people who are formally and primarily responsible for the work of self-managing attendant services. The inclusion of a participant category for ‘primary support
personnel’ created space for a diversity of peripheral perspectives shared by people who are not formally responsible for the work of self-managing attendant services, but who do contribute to the performance of this work. A tertiary category of program administrators created space for the valuable perspectives of people who have some insider knowledge of self-managed attendant services and the program level and beyond. The participation of a bookkeeper was unexpected; though grouped with the program administrators, hers was another unique perspective since bookkeepers are employed by self-managers (like attendants) but have some accountability to the program whose rules govern their practice. Recruitment was challenging at times but resulted in a highly varied sample offering a diversity of unique perspectives.

In addition to the range of perspectives participants lent to this study, the unique positionality and perspective I lend to this study may also be considered a strength. In the literature on self-managed attendant services, I have not come across another study that openly claims an attendant perspective. My past experiences as an attendant have inevitably (and intentionally) shaped the research questions, the design of the research, and my interpretations. I have also brought a unique lens to this research as an Occupational Therapist and Disability Studies scholar—two identities that I have developed and begun to feel comfortable claiming throughout the conduct of this research. At the intersection of a health professional field and a field of critical scholarship that challenges conventional health professional approaches, I have had a unique opportunity to think and feel through tensions between these fields and their perspectives. Throughout the research process I found opportunities to cross-pollinate concepts and theories across a sharp disciplinary divide, through teaching and presentation at conferences in both fields. Simultaneous engagement in these distinct disciplines has shaped not only the design, but also the process, interpretation and representation of this research.

Another strength of this study is the context on which it focused. Despite an abundant literature on direct payments in the UK, there are very few studies that have taken self-managed attendant services in Canada as their focus. This owes, at least in part, to a lack of self-managed models in Canada. Such models, however, are increasing
in popularity in this country. This research has thus contributed important substance to a relatively small literature on self-managed services in Canada.

Finally, it is my perception that the participants in this study enjoyed the opportunity to talk about the work they do to self-manage attendant services and other experiences with the Ontario program. The stories participants shared were told with passionate enthusiasm; it was my impression, in many cases, that these were stories waiting to be told. The conversations unfolded in a fairly organic manner and felt comfortable. I genuinely enjoyed my interactions with participants and I believe they enjoyed our conversations as well.

4.8.2 Limitations

In addition to the strengths of the methodological approach taken to this study, there were certain limitations. While I have described the focus on the Ontario program as a strength above, I will also highlight this focus as a potential limitation of the research. While other provincial programs were not the focus of this research, I understand from the literature that there is significant variation in the way self-managed programs are organized across Canada. From the literature on non-Canadian self-managed attendant services, I interpret there to be significant variations across countries as well. Given these variations, the findings of the present study are in many ways limited to the specific context in which the present study took place.

Within this specific context of the province of Ontario, some challenges with recruitment indicate additional limitations. Limited representativeness of the sample, for instance, in that participants in this study came from small, medium, and large cities in one part of a large and varied province, and the same part of the province where the program’s administrative headquarters are based. It may be seen as a limitation that perspectives of participants in more remote areas, for example, were not included in the sample.

Through interactions with participants and in my experience working as an attendant during this research, I came to understand that category of ‘self-manager’
adopted for this study might create a false division: self-management, I learned, is not the exclusive domain of participants in a self-managed attendant services program. There are other ways in which people might become self-managers—for instance, if they need to hire additional supports to supplement publicly funded agency-managed supports. While it did work out that I had one participant in the study who was no longer a self-manager (who had returned to agency-managed supports after she was taken off of the self-managed program and placed in a nursing home, and then not approved to return to the program at a later date), I will suggest it was a limitation to learn only about the experiences of self-management of ‘self-managers’ in a direct funding program. I am aware now that there are more diverse situations in which people might become self-managers—perhaps at the same time as they receive agency-managed supports.

An additional limitation of this research may be seen to result from the single-interview approach. I met with each participant only one time, and while I made efforts to ask follow-up and clarifying questions during the interview, I believe there could be a benefit in pursuing a formal opportunity to revisit ideas with participants a second time.

4.9 Plans for dissemination

At the time of submission, the first two manuscripts presented in this dissertation are published and the third manuscript is in press. The first two manuscripts are published in diverse disciplinary collections: the first in an edited volume addressing the body in health professional practice, and the second in an edited collection exploring governmentality in Canadian health care contexts. The third manuscript is in press with Disability & Society, a distinguished Disability Studies journal and a key venue in which scholarly conversations about self-managed attendant services are ongoing. Throughout completion of this dissertation, I have presented the emerging pieces to diverse scholarly communities by way of paper and poster presentations at conferences in Disability Studies (Nordic Network on Disability Research, Canadian Disability Studies Association), Critical Health Perspectives (In Sickness and In Health), Occupational Therapy (Canadian Association of Occupational Therapists, Council of Occupational Therapists for European Countries and European Network of Occupational Therapy in
Higher Education Congress), and Health Professional Education (Centre for Education and Research Innovation, Western University).

To ensure the findings of this research reach a variety of stakeholder groups, I have plans to disseminate the findings in multiple formats. For the general purpose of disseminating the findings of the study in a broadly accessible format, I will create an infographic that I can share in digital and print formats. I will circulate this document to study participants, many of whom indicated interest in learning more about the findings of the research. I will also share this document with online disability studies communities that I participate in. I will share this document with the local and provincial independent living centres that supported this project and will also prepare a brief executive report to share with these organizations and their boards of directors. I will also request an opportunity to present the findings of this study to their board of directors. I believe that an opportunity to meet with this group will be important to gauge community reception of research and to invite feedback. Furthermore, out of respect to the independent living centres, as organizations that represent a significant stakeholder group, I wish to discuss avenues and plans for dissemination with them before proceeding.

4.10 References


5  “It’s like having another job”: the invisible work of self-managing attendant services

5.1  Introduction

‘Self-managed’ models for the organization of attendant services, such as Direct Payments in the UK and Direct Funding in Canada, require significant contributions of labour from ‘self-managers’ (service-users) who are responsible to recruit, hire, train and manage attendants (employees). Despite taking responsibility for what would otherwise be the paid work of agency staff, the responsibilities disabled people assume in the self-manager role are rarely framed as work. This paper presents findings from a qualitative study of the work of self-managing attendant services. The data illuminate numerous facets of the work, which significantly exceed the responsibilities outlined in policy and program materials. Based on these findings, we discuss potential reasons for and implications of the failure to recognize and acknowledge self-managers’ work.

5.2  Theorizing ‘work’

Disability studies scholars identify work, and specifically expectations for societal participation that accompanied the rise of industrial capitalism in the 18\textsuperscript{th} and 19\textsuperscript{th} centuries, as central to the historical and ongoing oppression of disabled people (Barnes & Roulstone, 2005; Thomas, 2007). A social model analysis of labour markets reveals intertwined material and ideological barriers to inclusion in mainstream employment, and consequences of exclusion (Barnes, 2000; Barnes & Roulstone, 2005; Wilson-Kovacks, Ryan, Haslam, & Rabinovich, 2008). Additionally, disabled people have historically been required to contribute labour in exchange for access to social supports (Gill, 2005; Mitchell & Snyder, 2015). Abberley (2002) observes a “logic of productivity” underpinning a “work-based model of social membership” (p. 135) that values some and devalues other human lives, with implications for citizenship in the 21\textsuperscript{st} century. This

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logic contributes to a concept of citizenship that expects economic participation, independence and self-sufficiency (Titchkosky, 2003); norms that may discord with and disadvantage the body-minds of many people, and especially those who live with disability. A burgeoning disability studies literature seeks to expand conceptions of work to include the range of efforts disabled people contribute to the performance and concealment of disability-related physical, cognitive and emotional labour (Church, Frazee, Panitch, Luciani, & Bowman, 2007; DeVault, 2014; Goodley, 2011; Liddiard, 2014; Scully, 2010), including the ‘extra work’ disabled people do as students (Easterbrook, et al., 2015; LaMonica, 2016; Waterfield, Beagan, & Weinberg, 2017) and as employees in conventionally ‘productive’ work environments (Bulk et al., 2017; Church et al., 2007; Hamraie, 2016; Wilton, 2008).

Arguments for the conceptual expansion of work frequently reference feminist writings on the unpaid, poorly paid, unrecognized and/or ‘invisible’ work women perform in the private sphere. Feminist theorizations have sought to name and to frame as work diverse contributions of effort, time and emotion conventionally performed by women in domestic and caregiving roles. By highlighting the effects of failing to consider these specific forms of labour as work, such critiques politicize the construction of some forms of labour as ‘something other than work’. Namely, they emphasize the economic disadvantage women incur when their significant contributions of labour—contributions that uphold the formal economy—are not recognized as work, if they are acknowledged at all. ‘Work’ from this perspective includes “what people do that requires some effort, that they mean to do, and that involves some acquired competence” (Smith, 1987, p. 166), and is understood to encompass “everyday practices in which people engage and that their labour produces. This includes formal participation in the labour market and activities that people do that they might not normally think of as work” (Bisaillon, 2012, p. 620). This conception of work incorporates “what people do” as well as “the consciousness that necessarily goes along with doing”: “planning”, “thinking”, “deciding”, “coordinating”, and so on (Smith, 2002, p. 46-47). It readily includes ‘care work’ (Glazer, 1993; 1990; Kittay, 1999), and the ‘emotional labour’ of managing emotions (Hochschild, 1983).
In the literature on self-managed attendant services, feminist perspectives have primarily informed conversations about the social and economic implications of self-managed models for attendants (Cranford, 2005; Leece, 2004; Ungerson, 2005; 2004; 1997a; 1997b). This literature evokes some tensions with the independent living philosophy that underpins self-managed models, however the convergence of feminist and disability studies perspectives has also led to identification of overlaps and parallels in the performance of feminized labour by both attendants and self-managers (Hughes, McKie, Hopkins, & Watson, 2005; Kelly, 2016; 2011; Kröger, 2009). Feminist efforts to expand definitions of work, and commonalities in the marginalization of women and disabled people in contemporary labour markets have also informed arguments for the recognition of self-managers’ work (Barnes, 2000; Barnes & Roulstone, 2005; Prideaux, Roulstone, Harris, & Barnes, 2009; Rummery, 2006).

Although self-managers’ contributions have seldom been theorized as work, numerous studies have identified contributions of labour and skill required to manage administrative tasks (Carmichael & Brown, 2002; Morris, 2004; Stainton & Boyce, 2004) and relationships with attendants (Glendinning, Halliwell, Jacobs, Rummery, & Tyrer, 2000; Kelly, 2016; Leece & Peace, 2010; Marfisi, 2002). A small number of articles have encouraged recognition of self-managers’ work, emphasizing individual (i.e. positive self-identity and participation) and societal (i.e. economic) benefits (Barnes, 2000; Barnes & Roulstone, 2005; Rummery, 2006; Prideaux et al., 2009). Critical analyses have interpreted self-managers’ contributions in the context of a neoliberal capitalist climate of austerity and in light of contemporary productivity norms and citizenship expectations (Hande & Kelly, 2015; Mladenov, 2017; Scourfield, 2007; see also Chapter 3 of this dissertation). Additionally, Kelly (2016) has discussed the complex ‘relational work’ self-managers and attendants contribute in their roles.

5.3 Research design and methods

Despite the emergence of some theoretical conversations about the work of self-managing attendant services, few studies have adopted an explicit focus on self-managers’ work. This study arose from observations by the first author during her employment as an attendant to individuals who organized their attendant services through
a self-managed model. The first author understood that, for her employers, the self-managed model represented an important opportunity to conduct daily life at a distance from the institutionalized supervision and guidance of agency-managed support services. Yet, the organization and management of attendant services appeared to require significant contributions of effort, time and skill; work that was carried out on top of household management and self-care activities, and occupations such as attending work and school. This study set out to better understand the nature and context of self-managers’ work.

A reflexive ethnographic approach (Denzin, 2003; Ellis & Bochner, 2003; Lather, 2001a; 2001b) was adopted to investigate the primary research question, “What is the work of self-managing attendant services?” Sub-questions included, “Who does the work, when and where?”; “How is the work represented by the people who perform it?”; and, “How is the work represented in official accounts?” The study foregrounded the experiences and perspectives of self-managers and their support networks, while also engaging in critical analysis of the socio-cultural context in which self-managed attendant services take place. As part of the reflexive methodology, the first author conducted an autoethnographic examination of her experiences as an attendant (see Chapter 2), including reflexive interrogation of her status as simultaneous insider and outsider to the community or ‘culture’. The first author recognizes her privileged position as a physically non-disabled researcher whose life and well-being are not vitally attached to the program and phenomenon investigated in this research, and in her positionality as an institutionally-affiliated researcher.

Literature on self-managed models in Canada (Spalding, Watkins, & Williams, 2006) and in other countries (Christensen, 2012; Ungerson, 2004) demonstrates parallels, but also significant variation between self-managed programs in diverse geopolitical contexts. The present study focused on the only self-managed attendant services program available to physically disabled adults in Ontario, Canada. The Ontario program, which launched in 1994, currently supports up to 1000 self-managers. It is funded through the provincial Ministry of Health and Long-Term Care (OMHLTC) and administered through provincial independent living centres. Data sources for this study include in-
depth interviews and publicly available program documents (an information booklet, an application form and accompanying guidebook, the program’s website, and a provincial policy document). Following ethical approval, and with the support of two provincial independent living centres, participants were recruited through emails, posters and word of mouth. Interviews were conducted with eleven self-managers, three attendants, two program administrators, one bookkeeper, one parent to a self-manager and one self-manager’s spouse. Participants’ length of experience with self-managed attendant services ranged from 1-20 years, and ages ranged from 25-75 years. Interviews were 36-142 (avg. 81) minutes long and were conducted in private locations of each participant’s choice.

Interviews were transcribed verbatim and the qualitative data management software Quirkos was used to code the data and to organize emerging themes. Guided by the research questions, the analysis was approached with openness to multiple possible meanings, intentional integration of various “stakeholder views, perspectives, claims, concerns and voices” (Lincoln & Guba, 2000, p. 278), and awareness of the researchers’ positionality. Reflexive journaling was used to track the progression of ideas as interpretations were reflexively integrated and allowed to inform future interpretations (Alvesson & Sköldberg, 2000; Srivastava & Hopwood, 2009). Dialogue with research team members throughout the analytic processes informed refinement of the findings and analysis.

5.4 Findings: the work of self-managing attendant services

The analysis revealed many facets of work involved in self-managing attendant services. While aspects of work were seen to be performed by self-managers and others who support them, this presentation of the data focuses on self-managers’ work. The findings illustrate three ‘layers’ of work: the administrative work outlined in policy and program materials; the supplemental work self-managers engaged in to support completion of administrative responsibilities; and the more abstract work self-managers undertook to navigate uncertainties. Although the themes are presented separately, they are closely related, and many examples could fit under more than one category. Pseudonyms are
used for all participants.

5.4.1 Administrative work: “it’s like having another job”

The self-manager’s primary role, according to a program information booklet is “to self-direct, which means they know their disability and needs, and can instruct their attendants as to how and when they need assistance”. The same resource indicates self-managers are required “to take on the extra management responsibilities the program demands”; “to take full responsibility for managing a budget”, “to hire (and fire, if necessary), train and supervise one or more attendant workers”, and “to schedule attendants”. Self-managers are further responsible for “managing and accounting for [their] funding”, and to “meet all the legal requirements associated with being an employer”. In the self-manager role, disabled people take on administrative work that in other models would be the responsibility of paid agency employees. While policy and program materials refer to self-managers as “employers”, these documents frame their responsibilities not as work, but as “capabilities”, “abilities” or “willingness” to take on certain tasks.

It is interesting to note that many participants depicted these same tasks and responsibilities as “work”, a “job”, or a “business”. Participants variously stated: “I see it very much as a job. It gives me my life and my independence…on the other hand, then I have a second or a third job” (Kimberly); “It’s like having another job…The reporting’s all understandable, it’s just another work” (Denise); “I run two businesses: my job and my direct funding business—which is considered a small business, by the way” (Marcie). Geraldine said of her daughter, “She’s running a business…It’s her attendant care services.” Notably, there was significant variation in the way participants characterized the burden of the work they described, with some minimizing any burden, and others discussing significant challenges. Lydia indicated “It’s not that big of a job, being on the program. It’s not like something that takes, you know, five hours of your day or whatever. It takes maybe one hour a week.” By contrast, Kimberly said, “It’s a lot of work…I never get time off. If I was paid for it, my cheque would be huge with the amount of overtime”. Mason related the burden of some negative tasks to a positive outcome, saying, “Some of it sucks … like having to let anybody go sucks. But, it’s part of the job and part of what I have to do, depending on how I want my life to go”. Mary
suggested the difficulty may increase with age or when extra support becomes needed, saying, “It’s a great program when you’re young, but it’s not at all when you need extra support care. And there’s way too much administrative work for the disabled person to be in charge of doing”.

5.4.2 Supplemental work: “I had to figure that out all on my own, and do it on my own”

Beyond the tasks and responsibilities outlined in program materials, participants’ accounts revealed supplemental work that self-managers undertook to manage their administrative responsibilities. We categorized these as: learning ‘the hard way’, imparting expertise, innovating creative solutions, and self-advocacy. Unlike the administrative work that appeared in official accounts, participants tended not to discuss these extra forms of work when asked to describe their responsibilities in the self-manager role. Rather, descriptions of these supplemental forms of work were embedded in participants’ accounts and revealed in participants’ broad descriptions of activities related to self-managing attendant services.

5.4.2.1 Learning “the hard way”

Most participants reported little to no experience managing people or money prior to starting up on the program. Mason said of applying for the program, “It was a tough process. I think I was 17 or 18 … and at that age I had really not managed anyone”. Ed, one of few participants to report having some relevant work experience, described a process of trying to stretch resources by hiring a live-in attendant as “a big disaster … that was partly our learning curve”. Karen suggested a lack of formal resources was similarly challenging, saying,

[the program] kind of just left you … like, oh, figure it out … I definitely didn’t like that … They give you a package … It was mostly like, how to pay people, things like that. It wasn’t like, oh, here’s how you can set up how to get your shifts done. Here’s how you can speak with your employees and stuff like that.

Lydia similarly said,
They gave you a template of a resume and that was it … I had to figure that out all on my own and do it on my own. And I’ve never even had a job. I’ve never even been employed by anyone or fired by anyone. I had no idea what to look for.

Program materials and administrators’ accounts both indicated that there are resources available to support self-managers. Peter, an administrator, said, “when people start there’s a very good financial kit that we provide them”. Other participants indicated the available resources did not fully address self-managers’ learning needs. Ed suggested a formal support role could be useful to prepare new self-managers, like a social worker or a trainer … to help people through the first few months, come visit them a few times and ask them … where are your files, how do you organize your files and how’s your banking going? Or, not just ask, but teach them … That might enable some [more] people … to make it on the program.

Marleigh, an attendant, also suggested that such a support role could reduce the burden on self-managers “to start all over and have to learn the hard way”.

5.4.2.2 Innovating creative solutions

One way participants compensated for limited formal guidance was to innovate creative solutions. Karen described a strategy learned from a friend to use on-call shifts, “three times a day, for all my bathroom breaks. [For example,] I have from 12:30 to 2:30, so sometime within that two hours I call you for a one-hour paid shift”. Karen’s on-call strategy overlapped with another tactic: hiring from a student population. Karen explained,

a lot of people don’t like that [on-call approach]. They’re like, I want a 9-5 job, I want to be paid full-time, and that’s exactly why the university students work great. They only need to come in for one hour a day. They’re doing it more for the experience, being able to put it on their resume.

Lydia said she strategically employed students to save money, “since I didn’t know if how much I pay an hour was on par with other [personal support workers], so I thought
students would expect less money”. She also said she hired students to help mitigate the oftentimes complex relationships that can develop with attendants:

they’re all students, and I did that purposely because I like having new people, like, once a year, or once every six months … sometimes they just become … too comfortable and they won’t see this as a job anymore and see me as their employer. And, in those cases they don’t even do their job properly, in which case I have to let them go.

Lydia also said she sometimes hired health professional students to reduce the need to teach technical skills, since “a lot of them are either in nursing school or [physical therapy] and stuff so they know how to use a sling, they know how to use a Hoyer lift”.

Multiple participants described creating material resources, such as checklists, contracts and training manuals to reduce the recurrent work of training new attendants as employees inevitably moved on. Marleigh recalled a video her employer had developed for prospective attendants to reduce the number of times she needed to repeat information. Marleigh also shared a 10-page training manual her employer had developed, detailing precise expectations for employees. Geraldine similarly described a manual her daughter developed to instruct attendants, and to teach them how to communicate challenging information; for instance, “about skin integrity … she’s even devised a system to [describe], how pink is pink and how red is red. They have, like, bubblegum, or blush pink, so that way she can judge as well”. Several participants made innovative use of digital technology, from online platforms such as Kijiji, Craigslist and a federal government ‘job bank’ website to recruit prospective attendants, to Survey Monkey and Google Docs used to interact virtually with employees, to collect information and work out scheduling.

5.4.2.3 Imparting expertise

Another form of supplemental work related to the teaching or training of attendants and peers. Kimberly explained that “part of self-managing attendants is educating attendants yourself instead of having pre-educated attendants coming to you”. While policy and
program materials indicated that it is self-managers’ responsibility to train attendants, Kimberly showed how educating attendants extends beyond telling attendants how she likes things done, to include

training them in self-directed care … saying, I appreciate your advice, even though you may be [trained as] a nurse or … a social worker or a [personal support worker]. I know this is how you were trained to do it, and this is how you may do it, but this is how I like it. It’s a very hard concept for people … ‘cause sometimes they already have an idea in their mind and it’s like, no, no, no. We need to negotiate this.

In addition to training attendants, a peer teaching role was also reported. The program information booklet lists “peer networking and advice” as a valuable resource for new self-managers, facilitated through “an informal group of [program] participants willing to share information and experiences”. Explaining that she’s “constantly asking my friends questions of how they run [their attendant services]”, Karen was one of several participants who emphasized the necessity of informal supports. Additionally, Judy explained that some self-managers impart expertise as voluntary members of the interview panels that determine access to the program: “The selection panel usually has at least one person with a disability…[and] 90 percent of the time it’s…another self-manager”.

5.4.2.4 Self-advocacy

The process applicants navigate to access the program requires prospective self-managers to develop a service plan by anticipating planned and unplanned support needs. As Judy explained, “It’s what you negotiate, that’s your budget. You have to be able to forecast”. Participants described the application process requiring not only self-knowledge, but also self-advocacy skills. Reflecting on the process of helping a friend apply, Marleigh described the application as a “dramatic” process of questioning:

asking how many hours do you need in the morning? For what? Break it down, break it down, break it down. What are you going to do with that 15 minutes?
You’re gonna brush your teeth and this and this and this and this? How many hours do you need for lunch? What are you going to do with that time?

Kimberly similarly recalled, “in the interview they were all over me, and they were like, why does it take you ten minutes to pull your pants down? Everything is down to the minute”. Kimberly illustrated the importance of advocating for herself to ensure adequate resources, saying “Some days it might take me ten minutes, some days it might take me two minutes. But I go for the ten because I don’t want to run out”.

Kimberly further spoke to the importance of thoughtfully framing needs,
saying, you get a certain amount of money for a very specific personal care only, but … there’s a grey line … I consider personal care turning on and off my computer, because my computer is my emergency source, it’s my everything. So, I need it in order to do my personal care. The money is for personal care only, but…as long as you can justify it to the powers that be, they’re okay with it. So, you get very creative with your definition and your justifications.

Judy also noted that, while strictly speaking attendant services are intended to support self-care activities, there is some flexibility—but “you have to have a really solid rationale”. Anita, a bookkeeper, said that she promotes self-advocacy among her clients, telling them “you have to be a little bit more persistent to [the program]. If you don’t insist on what you want, then you’re stuck. So, you have to speak up, that’s what I keep telling them. You have to speak up. I cannot speak up for them”.

5.4.3 Navigating uncertainties: “it’s a bit nerve racking”

Factors beyond individual control were frequently reported to threaten or disrupt the balance of resources that enable success with self-managed attendant services. The work of navigating uncertainties was seen in the completion of various administrative responsibilities, such as: ‘finding good people’, and doing ‘a lot of mental math’. Navigating uncertainties extended to include: the ‘balancing act’ of stretching funds to meet needs, and vulnerability to contextual factors that threaten access to self-managed attendant services.
5.4.3.1 “It’s difficult finding good people”

Many participants spoke about the challenges of managing attendants, from attracting and retaining attendants to work a difficult job with odd hours and low pay, to arranging vacation coverage and making difficult decisions about firing. In Marcie’s words, “It’s a bit nerve racking…if somebody leaves me and I’m in charge of finding someone, there’s a moment of [mock screaming] ‘ahhhh’. Who do I call, right?” Geraldine discussed how difficult it can be to find good workers, especially when

there’s a deadline because a person’s leaving, and you need to fill that and it’s so hard to find somebody right away … I think there have been a few awesome gems, and then some that you grit your teeth, but … there aren’t 50 people applying for the job … It’s difficult finding good people.

For Paul, who plays a significant role in managing his wife Joan’s attendant services, “The biggest problem with direct funding is that you’re in charge … and if there isn’t any help around, or it’s hard to find, we bear the brunt”. Paul and Joan said they’d struggled long-term to find workers. As Paul put it, “There’s never been a super abundance of help”. A number of participants indicated that it was particularly difficult to find and keep staff who were available to work over the holidays. Mary said of a close friend who is also a self-manager,

his staff are young, and … they want time off at Christmas and other holidays … times like summer holidays even. When that comes around, they have a really difficult time getting staff, maybe even no one. And [his mom], who is in her mid-70s … and her husband is 78, they have no other choice but to take care of [him]. So, I guess that’s the major downfall I see with direct funding. Like, holidays and weekends are really stressful.

5.4.3.2 “It requires a lot of mental math”

Kimberly also said she found the holidays a stressful time, but for her the source of stress was managing the budget, since

even though a person doesn’t work, they’re still entitled to a portion … So,
figuring that and calculating that … And then the person that actually works, making sure they’re getting their time and a half. You think holidays are a joyous time. Not with direct funding. It’s stressful.

Karen also described organizing payment to require “a lot of mental math”, because they give you six hours, but if you’re not paying the maximum rate, like, it’s not really six hours, it’s more than that. But I can’t—I don’t know how to calculate that in my head … when everyone’s getting paid at different rates, everyone is doing something different, like that’s where it’s getting hard, but I can’t—that just makes more work on me.

Geraldine articulated an additional layer of complexity in the potential for budgeted hours to be used up in unpredictable circumstances:

you can’t guess that if [my daughter] goes to a doctor’s appointment with [an attendant] that she’s going to be taken right away, so right there, that could eat up an extra hour or so. Or, if there’s a problem with bowel treatment … if she does go over [time], she’s going to have to find another way to take care of it.

Geraldine’s example reveals how unpredictable events in everyday life can cause extra work for self-managers, who operate on schedules that factor in carefully rationed time with attendants.

5.4.3.3 “My life is a balancing act”

Multiple participants spoke with concern about the vulnerability of their situation, and the challenges of self-managing supports. One example was relying on unpaid workers to compensate for limited resources. As Kimberly explained, “my parents are getting older now, so they can’t help me. My dad has his own issues, so does my mom … I already spend most Saturday nights with them to balance the hours and to give people a break—but more to balance the hours, “cause I would run out”. In her words, “My life is a balancing act with constant stress in making everybody else happy but myself”. Ed, too, spoke about the stress of finding workers, the pressure to minimize the burden of unpaid
work he put on his wife and children, and the desire to find trustworthy workers he felt comfortable to have in the family home he shares with his pre-teen daughters. Ed said,

I feel more the stress at that point from trying to assure my family everything will be okay … my wife is worried about picking up the pieces if I don’t get a worker … the stress comes from, you want to please—make sure that everyone around you is happy. It’s not just …what if I’m stuck without a worker, right? But now it becomes more, I gotta make sure to have a worker, [and] make sure everyone around me is comfortable with the new worker.

Mason explained he was narrowly able to stay on the program when a friend agreed to act as his attendant, and to let him move in to his home. Mason said of his friend, who does most of his paid attendant work and sometimes more than what he’s paid for, “if [he] wasn’t as nice as he was, yeah, I’d be stuck … I’d have to pay someone, and I can’t pay anyone ‘cause I’m on [social assistance]”. Alan and Gary, like several other participants, both said they were not too worried about their current situation, as they felt well supported by a reliable caregiver or team of supports; yet they both acknowledged the potential vulnerability of their situations, were it not for those supportive people who contributed, at least part of the time, in an unpaid role.

5.4.3.4 “People…don’t realize how fragile it is”

An overwhelming majority of participants described self-managed attendant services as an essential program without a comparable alternative. Peter summarized the benefits saying, “We wanted much greater autonomy in these essential supports in our daily lives, and that’s what we have”. As a publicly-funded program, however, self-managed attendant services are vulnerable to provincial budget cuts and funding reallocation. At the program level, administrators make difficult decisions regarding allotment of funds. Judy said they do their best to be creative and accommodate as many people as possible yet acknowledged that the organization must work to strike a balance between meeting the needs of existing self-managers and keeping up with an ever-expanding waitlist. Judy was one of several participants to mention the financial benefit of self-managed programs that keep disabled people out of costlier institutional environments, yet her narrative
betrayed a sense of uncertainty about the program’s stability. Despite optimism that funding increases have occurred steadily over the past several years, Judy expressed frustration with the possibility that individual actions could endanger the program: “personally, I get upset when people on the program … don’t realize how fragile it is and they don’t realize that if they do stupid things it could jeopardize the whole program and how much effort we’ve taken to get this in place”. Kimberly, expressed similar concerns at an individual level, stating she was afraid to reach out to the program to ask for help, for fear that asking questions could lead to perceived incapacity: “They give you the number and they encourage you to call them … but you’re afraid … because always, in the back of your mind, there’s this question of are they going to deem me unable”.

Mary’s account affirmed that such fears may be legitimate in some circumstances, as she discussed being removed from the program and placed in a nursing home at a time when she was struggling to manage while waiting for a decision about a funding increase.

5.5 Discussion

This study’s findings revealed an abundance of tasks and responsibilities performed by self-managers, that far exceeds those depicted in policy and program materials. While some responsibilities were explicitly acknowledged and named as ‘work’, participants’ accounts revealed that many more were tacit and not recognized as work. This discussion explores multiple forces that may be seen to render self-managers’ work ‘invisible’, and the broader implications of invisible work.

5.5.1 Space, time and ‘invisible work’

Invisibility is a common theme in cross-disciplinary conversations about disability-related work. Several studies have described the ‘invisible work’ of living with disability (Church et al., 2007; DeVault, 2014; O’Connor, Young, & Johnston Saul, 2004). While feminist analyses theorizing the invisibility of care work have tended to focus on the work of non-disabled ‘caregivers’ (Glazer, 1993; 1990; Kittay, 1999), a number of studies have built on the concept of ‘invisible work’ elaborated by Strauss and Star (Star, 1991; Star & Strauss, 1999; Strauss, 1985) to describe responsibilities increasingly expected of health care ‘patients’ (Lin, 2009; McCoy, 2009; Oudshoorn, 2008; Senteio &
Veinot, 2014). Self-managers’ work is distinct from self-oriented responsibilities in the entrepreneurial and managerial aspects of hiring and managing staff; but, like both other- and self-oriented forms of care work, the physical spaces in which it occurs and the discursive spaces it occupies prevent its recognition. Like other forms of invisible work (DeVault, 2014; Glazer, 1990; Star & Strauss, 1999), self-managers’ work takes place in private spaces. Program materials indicate that attendant services may be provided “at home, at work, or in the community”, but policy limits the scope of self-managed attendant services to support with activities that promote personal health and household maintenance. Even when it is performed in public spaces, self-managers’ work pertains to the feminized tasks of bodily care, and so is discursively located in a space that is outside of work (Hughes et al., 2005). The construction of self-managers’ work as ‘something other than work’ is further reinforced in the program materials, which do not adopt a language of work to describe the self-manager role but do identify work as a spatial context where attendant services may (not) take place.

In addition to physical and discursive space, temporal aspects may also be seen to contribute to the invisibility of self-managers’ work. Several studies note the impact on visibility when there is a discord between the perceived and actual time, effort and/or skill required to complete tasks (McIntosh, 2000; Oudshoorn, 2008; Randell, Wilson, Woodward, & Galliers, 2010). In the present study, when self-managers were asked to quantify their time spent on tasks associated with self-managing attendant services, many participants suggested the temporal burden of work was insignificant. Yet participants articulated significant cognitive and emotional efforts that appeared to be omitted from their estimates of time. Lydia, for instance, estimated the work of self-managing attendant services took her about one hour each week, but she portrayed the work of becoming and being a self-manager as both onerous and unremitting. As work that may be largely cognitive and/or emotional in nature, self-managers’ work parallels forms of care work that Lanoix (2013) suggests go unseen since they are not materially substantive. Like care work, certain characteristics of self-managers’ labour may prevent it from being understood as work. These processes that render self-managers’ work invisible in a broad sense might also prevent self-managers themselves from characterizing, or even understanding their own labour as work.
5.5.2 Self-presentation and ‘hidden work’

While some of the work self-managers do may be invisible to self-managers, it is also possible that self-managers downplay or even hide aspects of their work in order to meet expectations or norms of self-presentation. Program materials, for example, may be seen to communicate norms or expectations of independence and self-responsibility. Despite persistent uncertainties and insecurities, and reliance on formal and informal supports to complete various responsibilities, participants suggested it was important to demonstrate and reinforce one’s capacity to self-manage attendant services independently. Kimberly expressed fear that asking for help could be interpreted as an indication of inability, and so reinforced an outward appearance of competence by seeking the support of family or friends, rather than reaching out to request formal supports. One consequence of Kimberly’s calculated self-presentation was to further conceal contributions of work already invisible in their absence from policy and program materials, such as the work of navigating uncertainties.

While obscuring other aspects of work, practices of self-presentation may also be understood to constitute work in themselves. Several studies have invoked the concept of ‘emotional labour’ (Hochschild, 1983) to explain disabled persons’ efforts to self-present in ways that meet the expectations of (non-disabled) others, to achieve goals or meet needs, including to procure and maintain supports (Goodley, 2011; Kelly, 2016; Scully, 2010). According to Scully (2010), such labour must “be hidden from the nondisabled partner in order to be effective” (p. 26). As Kimberly explained it, effective self-presentation also required her to hide worry; an emotional response she and other participants reported given imminent variables that threatened to disrupt the balance of resources self-managers work hard to orchestrate. Jowsey, Strazdins, and Yen (2016) describe worry as a “largely hidden” (p. 256) component of informal care work that draws on resources of energy and time. In their account of “the invisible work of day-to-day living” with disability (p. 213), O’Connor et al. (2004) situate worry and stress as emotional work alongside physical and cognitive forms of work “required to manage seemingly simple tasks and routines”; work that they suggest disabled people may feel pressured to hide in the interest of crafting a ‘normalized’ self-presentation.
Several authors have described intentional concealment of work done to manage disability-related needs—including the work of managing and interacting with attendants—for the express purpose of constructing a more ‘normal’ self-presentation that minimizes disability-related difference (Church et al., 2007; O’Connor et al., 2004; Pearpoint, 1990). In a social context where disabled identities are heavily stigmatized, there is significant motivation for disabled people to invest work towards ‘passing’ as non-disabled; a practice that can require significant contributions of labour towards a disavowal of disability (Linton, 1998; Morris, 1991; Scully, 2010). Inasmuch as it urges self-managers to self-present in ways that cohere with contemporary expectations of autonomous, self-sufficient, enterprising and managerial citizenship (Mladenov, 2017; Scourfield, 2007; see also Chapter 3 of this dissertation), self-managed models may be seen to encourage investments of labour towards the construction of self-presentations that cohere with ableist norms of neoliberal citizenship (Goodley, Lawthom, & Runswick-Cole, 2014).

5.5.3 Self-responsibility, citizenship and ‘workfare’

One specific way in which self-managers are impelled to meet societal norms of self-presentation is through invocation of neoliberalist discourses of self-responsibility, austerity and cost-containment (Rose, O’Malley, & Valverde, 2006); discourses that “position lay people as ready and willing to actively engage in their own healthcare and promote their own health, in the attempt to shift the burden of such responsibilities from the state to the individual” (Lupton, 2013, p. 266). To the extent that they are able, “people seeking services are increasingly asked to contribute to the work of large organizations” (DeVault, 2014, p. 779). In contemporary healthcare contexts, several studies describe such ‘work transfers’ (DeVault, 2014; Glazer, 1993; 1990) as processes that render work invisible as women and families are required to take on labour that has previously been the domain of paid healthcare workers (Glazer, 1993; 1990) and patients are increasingly prompted to ‘self-monitor’ (Lin, 2009; Lupton, 2013; Oudshoorn, 2008) and ‘self-manage’ (Brijnath & Antoniades, 2016; Deering, 2016) chronic conditions. In the context of self-managed attendant services, a similar process is evident in the transfer
of work that would otherwise be the responsibility of organizations or agencies to disabled people, who are positioned as ‘self-managers’.

Paradoxically, while scholars focused on work and welfare have pointed out a broad failure to characterize self-managers’ labour as work (Barnes, 2000; Barnes & Roulstone, 2005; Prideaux et al., 2009), Foucauldian analyses suggest the productive nature of self-managers’ work is acknowledged, if only implicitly. In characterizing self-managed attendant services as a form of ‘workfare’, Mladenov (2017; 2015) highlights a trend to condition receipt of welfare benefits on demonstration of efforts to meet productivity norms. Like other analyses approached from the perspective of Foucauldian governmentality theory (Scourfield, 2007; see also Chapter 3 of this dissertation), Mladenov recognizes in self-managed attendant services an appeal to self-managers to approximate norms of neoliberal citizenship by demonstrating their capacity for productive labour. Although it remains differentiated from work in a conventional sense, and invisible given the lack of explicit acknowledgement, it might be said that the productive nature of self-managers’ labours is already recognized to some extent.

5.6 Implications of ‘invisible work’

The concept of ‘invisible work’ is well-theorized and is suggested to contribute to the ongoing marginalization of minority group members: to whom responsibility for invisible forms of work frequently fall, and whose labour often goes unrecognized when it exceeds dominant constructions of work (Kittay, 1999). Invisible work (Kittay, 1999), including work in the context of self-managed attendant services (Hughes et al., 2005), has been said to uphold fictions of independence—fictions that reinforce an ableist society, which privileges individuals who can do more and without assistance. The requirement for self-managers to self-present as independent may be seen to belie important interdependencies, in ways that mirror and reinforce non-disabled norms (Goodley, 2011; Hughes et al., 2005; Scully, 2010). Attending to invisible work and working to make it visible may offer a way to enact meaningful resistance to “discussions of political and social justice that take as their starting point the public lives of men” (Kittay, 1999, p. 2); “a hypothetical being—usually male, unencumbered, physically and cognitively intact—enables the elaboration of patterns of rights and liberties which may bear little relation to
the realities of life for the majority of citizens” (Shakespeare, 2006, p. 135). According to Kittay, “This starting point has determined not only moral, social and political theory; it also has determined the shape of public policy” (p. 2). Recognizing self-managers’ invisible work is thus an important step towards creating policy that is effective, equitable, and accessible to those it is intended to support. As this study and others have shown, if the work of self-managing attendant services becomes too onerous it may constitute a barrier to the important opportunity to increase autonomy and self-determination.

These findings resonate with other studies that have suggested self-managed models offer a vital alternative to conventional agency-managed attendant services but do so in a way that restructures disability policy: at the potential expense of reducing important social services (Morris, 2004) and eroding social service infrastructure (Mladenov, 2015; Scourfield, 2007), while distancing self-managed models from their revolutionary principles (Hande & Kelly, 2015; Riddell et al., 2005; Scourfield, 2007). Several scholars have raised concerns about a tendency for market logic underpinning self-managed models to trump its intent to increase service user autonomy (Hande & Kelly, 2015; Leece & Peace, 2010; Mladenov, Owens, & Cribb, 2015; Pearson, 2000; Pearson et al., 2005), and other austerity policies have similarly been observed to reduce self-direction to self-management and self-reliance (Roulstone & Prideaux, 2012; Mladenov, 2015); trends that cast doubt on the emancipatory potential of self-managed models (Brijnath & Antoniades, 2016; Hande & Kelly, 2015; Mladenov et al., 2015). Work transfers, for example, have been observed to provide “invisible support for continuing profits in the health services industry” (Glazer, 1990, p. 496). Though the political argument for, and rising popularity of self-managed models is surely linked with their supposed potential to save costs (Slasberg & Beresford, 2015; Spandler, 2004), awareness of self-managers’ unrecognized, unacknowledged, hidden or otherwise invisible work adds an important dimension to contemporary critiques challenging the propriety of claims to cost-efficiency (Mladenov et al., 2015; Pearson & Ridley, 2017; Slasberg & Beresford, 2015; Slasberg, Beresford, & Schofield, 2012). Insofar as it is understood in terms of self-responsibility, self-managers’ work may be seen to evade critique as a form of invisible work, while at the same time supporting neoliberal
economic practices that systematically disadvantage disabled people (Goodley et al., 2014).

Consistent with existing research, participants in this study simultaneously emphasized the necessity of self-managed models and a need for enhanced formal supports (Carmichael & Brown, 2002; Glendinning et al., 2000; Maglajlic, Brandon, & Given, 2000; McGuigan et al., 2016; Morris, 2004). A call for supports may seem to contradict efforts to correct a well-documented historical oppression of disabled people at the hand of medical ‘experts’ and health ‘professionals’ (Kelly, 2016; Linton, 1998). Yet, requiring self-managers to contribute unpaid and largely unrecognized labour that would otherwise be the responsibility of organizations and agencies risks replicating an historical trend to require disabled people to contribute labour in exchange for access to social supports (Gill, 2005; Mitchell & Snyder, 2015). The conversation around self-responsibility exposes a tension between a long-fought rejection of paternalistic ‘care’, and the real need many people have for adequate supports to survive and to thrive. We contend this tension can offer generative insights towards the development of effective supports, awareness of exploitive histories, and adoption of anti-oppressive policies. Further, such insights may meaningfully inform educational programs for professionals who support disabled people in a variety of capacities: as attendants/support workers, in the health professions, in public health domains and in policy.

An important caveat to the call to increase visibility of self-managers’ work is that, while “bringing invisible work into view may help to advance projects of social justice and inclusion” (DeVault, 2014, p. 775), it has also been suggested that invisible work at times remains invisible for good reasons. Star and Strauss (1999) observe that invisible work may be desirable or strategic, for instance to elude the purview of “a more bureaucratic, reductionist set of organizational values” (p. 23). Indeed, self-managed models enact a deregulation that increases self-managers’ freedom to organize services according to their own preferences. Deregulation, however, has been noted to reduce workplace protections for attendants (Church, Diamond, & Voronka, 2004; Cranford, 2005; Leece, 2004; Ungerson, 2005; 2004; 1997a; 1997b). While working ‘under the radar’ (DeVault, 2014) may enable key freedoms for self-managers, it also holds
potential to endanger the well-being of attendants. The value in foregrounding disabled persons’ expertise may be similarly undermined if the perspectives and interests of other marginalized stakeholders are overshadowed, and extra work responsibilities imposed on disabled people. We identify an additional tension here between competing interests and forms of expertise, which we suggest might also meaningfully inform improvements to existing self-managed models, and the future development of more inclusive approaches.

Lastly, we acknowledge that a call to increase visibility of work may be seen to undermine intentional practices of self-presentation, with potential to impede disabled persons’ autonomy. Here, we confront a pervasive tension between individuals’ rightful will to normative participation in contemporary societies and scholarly and/or activist calls to resist structural ableism. Scully (2010) aptly notes that while practices of self-presentation may be employed by disabled and non-disabled people alike, a power differential may be seen to effect a reduction of disabled persons’ autonomy; while anyone may choose to manipulate their self-presentation, disabled people are typically at a systemic disadvantage, such that manipulated self-presentation may constitute a survival tactic. Although strategic self-presentation can be practically and materially beneficial, we suggest it is important to recognize ways in which such practices might add to the labour self-managers take on and hide, and ways in which such practices render the work self-managers do further invisible. Scully’s (2010) insights inform our contention that it is at least worth noting the potential complicity of such practices in perpetuating the systemic marginalization of disabled people, as well as the potentially detrimental effects of inauthentic self-presentation (Goodley, 2011; Kelly, 2016; Linton, 1998; Scully, 2010).

5.7 Conclusion and future directions

The findings of this study support current literature cautioning the potential for invisible work to perpetuate inequalities affecting marginalized groups, including both self-managers and attendants. Participants in this study articulated a range of tasks and responsibilities involved in self-managing attendant services, qualifying a definition of work that includes informal, unpaid and undocumented labour performed in private spaces. Self-managers’ work was observed to be invisible in many ways and at multiple
levels. Self-managers’ work also appeared to become invisible through specific processes that cohere with a neoliberal economic approach—an approach that is known to disadvantage people who live with disability (Goodley et al., 2014). The focus of this article has been to identify and describe the work disabled people do in the self-manager role, and to explore the key finding that self-managers’ work is often invisible. Future research is needed to better understand disabled persons’ lived experiences of invisible work, and the implications of invisible work in disabled persons’ everyday lives.

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“Everything isn’t about time. We’re people at the end of the day”: clock time, crip time and the relational work of self-managing attendant services

6.1 Introduction

Self-managed attendant services are well-known to increase opportunities for autonomy and self-determination in attendant services and in everyday life (Carmichael & Brown, 2002; Glendinning, Halliwell, Jacobs, Rummery, & Tyrer, 2000a; Kelly, 2016; Stainton & Boyce, 2004; Yoshida, Willi, Parker, & Locker, 2004). While self-managed models have often been billed as a cost-effective alternative to conventional agency-managed attendant services (Clark, Hagglund, & Sherman, 2008; Lord, 2010; Stainton, Boyce, & Phillips, 2009; Yoshida et al., 2004; Zarb & Nadash, 1994), an increasing number of critical analyses have questioned the veracity of claims to cost-efficiency (Pearson & Ridley, 2017; Slasberg & Beresford, 2015; Spandler, 2004). Several critiques highlight a tendency for market logic to impede the achievement of emancipatory outcomes for disabled people (Hande & Kelly, 2015; Leece, 2010; Mladenov, Owens, & Cribb, 2015; Pearson, 2000; Pearson et al., 2005; Spandler, 2004), while gendered analyses problematize issues with compensation (Kelly, 2016; Leece, 2010; 2004; Leece & Peace, 2010; Ungerson, 2005; 2004; 1997) and workplace protections for attendants (Church, Diamond, & Voronka, 2004; Cranford, 2005; Leece, 2010; Marfisi, 2002; Riddell et al., 2005; Scourfield, 2005; Spandler, 2004). Others have interpreted self-managed models in the context of neoliberalized healthcare, wherein individuals are increasingly asked to take personal responsibility for disability-related needs, often without acknowledgement of the potential burden on energy, time and skill (Mladenov, 2017; Scourfield, 2007).

This literature consistently reinforces the promising potential of self-managed models, while seeking improvements by way of ongoing critique.

A significant literature has described complexities associated with the distinctive relationships that develop between self-managers and attendants, which blur boundaries between kinship, friendship and employment (Christensen, 2012; Cranford, 2005; Glendinning, Halliwell, Jacobs, Rummery, & Tyrer, 2000b; Kelly, 2016; Leece & Peace, 2010). In a recent study of self-managed attendant services in Ontario, Canada, Kelly
(2016) suggested relationships are central to the achievement of positive outcomes in attendant services and identified a gap in the current literature with regard to “the ways in which relationships enable autonomy” (p. 169). Specifically, Kelly pointed to the ‘relational work’ self-managers and attendants perform in the context of self-managed attendant services. This paper presents findings from a study of the work self-managers and others do to organize and manage attendant services in Ontario, Canada. The findings illustrate the vital role of relational work to achieve desired outcomes. The discussion explores relational work through a temporal lens, highlighting the personal resources relational work requires, and the compensatory function of relatively invisible and gendered relational work amidst a context of austerity-driven systemic constraints. Implications for policy and practice are discussed.

6.2 Relational work

The concept of relational work has been discussed in a range of disciplines (DeFrino, 2016). One theory of relational work, developed by Fletcher, Jordan and Miller (2000) in a study of female engineers that observed uniquely relational forms of work performed by women in the workplace, emphasizes the important role of connection, support, relationships and interdependence in the achievement of workplace outcomes. Observing a similar phenomenon in nursing, DeFrino (2009) applied Fletcher et al.’s framework to theorize non-technical yet skilled processes that nurses, other health professionals, and patients engage in, which benefit workers and patients and support effective achievement of organizational objectives. Fletcher et al.’s original theory and DeFrino’s elaboration both highlight the gendered nature of relational work, as work that is conventionally performed by women or in feminized roles. They also discuss the invisibility of relational work. Fletcher et al. situate invisibility relative to a “myth of independence” that obscures “the large network of relational connections that actually sustains [workplaces]” (DeFrino, 2009, p. 296). DeFrino further posits that relational work is “devalued and disappeared” (p. 300) in a biomedical healthcare model that emphasizes outcomes but overlooks processes that support their achievement. DeFrino contends that the systemic failure to recognize relational work effects negative consequences for those who perform it, including disempowerment, moral distress, and burnout.
The term ‘relational work’ has also been used to describe an emotional and interpersonal form of work done ‘between’ self-managers and attendants (Kelly, 2016). Kelly’s use of the term differs somewhat from the concept theorized by Fletcher et al. (2000) and elaborated by DeFrino (2016; 2009), yet demonstrates important parallels. Kelly (2016) distinguishes relational work from the “automated ‘arms and legs’ tasks” (p. 75) that feature prominently in many descriptions of the attendant role, a metaphor that is intended to distinguish self-managers as decision makers and directors from attendants who receive instructions and carry out physical tasks (Shakespeare, 2014). In practice, however, the emphasis on technical tasks obscures “the intricate, relational side of personal support [that] is also a necessary component of attendant work” (Kelly, 2016, p. 76). Relational work in this context denotes the skilled and complex work of navigating self-manager-attendant interactions. Kelly draws parallels to Hochschild’s (1983) concept of emotional labour but notes that relational work in this context exceeds emotional labour since such work “is about not only managing one’s own emotions to produce a state of mind in others but also managing an ongoing relationship” (p. 81). Kelly further emphasizes the collaborative nature of relational work, as “an active, two-way process that must be done by both the attendants and the people who require support” (Kelly, 2016, p. 89).

The conception of relational work elaborated by Kelly (2016) may be seen to extend to a number of other disability-related and relational forms of work. Ignagni (2011), for example, characterizes the ‘dialogical work’ young people do to ‘accomplish citizenship’ as a ‘two-sided’, mutually responsive, and mutually beneficial form of work that is enacted between disabled youth and the people who support them. Mutual benefit is also a common theme among studies that have explored support workers’ performance of care work in the context of the blurred boundaries between familial and professional relationships that occur in-home support settings (Stacey, 2005)—the relational character of which, Stacey suggests, draws workers in while leaving them vulnerable to exploitation. In their discussions of labour performed within disabled or ‘crip’ communities, Piepzna-Samarasinha (2017) and Piepzna-Samarasinha, Milbern, and Wong (2017) describe emotional labour, care work and ‘crip labour’ as distinct but related informal work forms that disabled people do to support one another; work that is
frequently unacknowledged beyond the networks of people who perform it. These forms of work are relational in the sense that they occur within and between relationships. They may also be seen to be distributed in a relational manner that considers both individuals’ capacities and needs. As in the theories of relational work elaborated by DeFrino (2016; 2009) and Fletcher et al. (2000), these relational forms of work are often noted to be performed predominantly by women (Stacey, 2005) and/or by (queer) femmes (Piepzna-Samarasinha, 2017; Piepzna-Samarasinha et al., 2017).

6.3 Disability, temporality and work

Time is a construct so pervasively ingrained in industrialized Western societies that we don’t often notice or question its presence or function. Time is a resource people possess that is finite but renewable, holds social and material exchange value, and can be distributed inequitably along lines of gender, ability and socio-economic status (Hochschild, 1997; Strazdins, Welsh, Korda, Broom, & Paolucci, 2016). Time also serves as an overarching structural framework, such that “life has become timed and this has been internalized, thus controlling most daily activities” (Deery, 2008, p. 343). Though often implicit, time is central to neoliberalist logics of austerity and efficiency that shape health and social care in contemporary Western societies. A normative temporal orientation to ‘clock time’ is evident in processes of objectification, quantification and standardization that depersonalize human needs and the tasks associated with their completion (Davies, 1994; Lanoix, 2013). Without regard for subjectivity and situated temporalities of the people who both have and meet needs, these processes not only overlook, but may be seen to exacerbate inequities in the distribution of temporal and other associated resources.

Time has surfaced as an integral theme in feminist analyses of work, which highlight personal resources of energy, time and skill that are often not recognized when work occurs outside of normative conceptions of work as employment (Davies, 1994; DeVault, 2014; 2008; Glazer, 1990; Hochschild, 1997; 1983; Kittay, 1999). Critical feminist analyses of academic culture in neoliberal universities have observed gendered (Berg & Seeber, 2016; Mountz et al., 2015) and disability-related (Hamraie, 2016; Waterfield, Beagan, & Weinberg, 2017) inequities in ever-increasing demands on time,
suggesting temporal and other associated resources are taxed at a higher rate for social and cultural minorities who must perform extra work above and beyond formal workplace requirements to survive—and even more so to thrive—in competitive professional environments. In contrast to the hegemonic and linear concept of clock time, feminist scholars have suggested ‘process time’ (Davis, 1994; Lanoix, 2013) and ‘relational time’ (Deery, 2008) as alternative temporal orientations that account for subjective and embodied variations in pace.

Well-theorized in the field of disability studies, ‘crip time’ similarly accounts for natural variations in the temporal and other related resources that people need and can access to accomplish everyday activities (Kafer, 2013). Lived experiences of crip time challenge the naturalized assumption that clock time can be used to quantify, standardize and organize life. Crip time describes the unpredictable, at times defiant nature of human bodies, and attends to the added layer of unpredictability that is a reality of many ‘crip’ lives. Kafer describes crip time as “a reorientation to time” that requires reimagining our notions of what can and should happen in time, or recognizing how expectations of “how long things take” are based on very particular minds and bodies. We can then understand the flexibility of crip time as being not only an accommodation to those who need “more” time but also, and perhaps especially, a challenge to normative and normalizing expectations of pace and scheduling. Rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds. (p. 27)

Crip time is a relational phenomenon that arises as non-normative bodies interact with and participate in social worlds that anticipate a particular version of ‘normalcy’ (Kafer, 2013). It extends well beyond conversations of planning and scheduling to challenge assumptions about time use in the present and the future (Kafer, 2013; McRuer, 2010). Of particular relevance for the present study, crip time highlights the potential for lived experiences of disability to critique and resist the neoliberal imperative that individuals accept, serve and embody economic values such as austerity and efficiency; a modern lifestyle that some suggest is more accurately a ‘slow death’ (Berlant, 2007), and one that
kills some—including those who live with disability—at an accelerated rate (Goodley, Lawthom, & Runswick-Cole, 2014).

### 6.4 Methodology

The broad aim of this study was to understand the work self-managers and those who support them do to organize and manage attendant services. The research was informed by a critical disability studies theoretical framework (Goodley, 2011; Shildrick, 2009; Titchkosky, 2011; Tremain, 2005) and feminist theories of work (Hochschild, 1997; 1983; Kittay, 1999; Smith, 2002; 1987). Critical disability studies perspectives encourage attention to socio-cultural structures and patterns that shape lived experiences of disablement. Feminist theories of work expand common conceptions of work beyond those that are paid or performed in public spaces. In keeping with this critical framework, reflexive ethnography (Denzin, 2003; Ellis & Bochner, 2003; Lather, 2001a; 2001b) informed the design of this study, which examined a diversity of perspectives on the work of self-managing attendant services. The reflexive ethnographic approach foregrounded critical consideration of social relationships at various levels: in the work of self-managing attendant services, and in the planning and execution of the research.

The reflexive ethnographic approach responds to calls for “a new paradigm of research” focused on “empowerment and reciprocity; changing the social relations of research production; changing the focus of attention away from disabled individuals and onto disablist society” (Morris, 1992, p. 158). Reflexive ethnography enables researchers to “use their own experiences in the culture reflexively to bend back on self and look more deeply at self-other interactions” (Ellis & Bochner, 2003, p. 211). This approach provided space for the principal author to situate herself with respect to the research by acknowledging past and ongoing experiences as an attendant, friend and ally to several individuals who use attendant services. Reflexive journals were used to engage in ongoing consideration of the first author’s contextual sensitivity to participant perspectives in the research process, and her position as “a non-disabled person holding certain cultural assumptions about disability” (Morris, 1992, p. 159). The reflexive methodology encourages recognition of the research process as an active process of knowledge generation and included ongoing interrogation of the embodied situatedness
and interpretive positionality of the researchers (Kinsella & Whiteford, 2009; see also Chapter 2 of this dissertation).

With approval from the research ethics board at Western University, participants were recruited via ads posted in public locations (libraries, grocery stores) and with the support of administrative staff at independent living centres in two separate cities. Publicly available documents pertaining to one self-managed attendant services program in Ontario, Canada were retrieved online. Semi-structured, in-depth interviews were conducted with nineteen participants affiliated with the program, including: eleven self-managers, three attendants, two program administrators, one bookkeeper, one parent to a self-manager, and one self-manager’s spouse. Self-managers ranged in age from 24-75 years. A majority of participants had college or university education, and were employed, volunteering, looking for work, attending school, or were retired. All interviews were audio-recorded and transcribed verbatim. The qualitative data analysis software Quirkos was used to organize and code interview data. Codes were grouped to develop themes around the primary research question, “What is the work of self-managing attendant services?” Sub-questions included, “Who does the work, when and where?”; “How is the work represented by the people who perform it?”; and, “How is the work represented in official accounts?”

6.5 Findings

The analysis revealed many facets of the work of self-managing attendant services. This paper focuses on a key finding that self-managers and attendants perform relational work to increase autonomy in the context of austerity-driven systemic constraints. The data show how self-managers used personal resources to maximize efficient use of program funding and how attendants joined self-managers in their efforts to manage resources efficiently. Self-managers, in turn, were seen to give of personal emotional and material resources to demonstrate recognition and appreciation of attendants’ efforts. Efficient resource management was seen as both a focus and a product of relational work performed by self-managers and attendants. The data are organized into five themes, each representing processes that support efficient resource management: managing limited resources, maximizing time, attendants respecting self-managers’ time, self-managers
recognizing attendants’ efforts, and valuing relationality. Pseudonyms are used for all participants.

6.5.1 Managing limited resources: “you haven’t always got the same choice”

Setting important context to interpret the work of self-managing attendant services, several participants in this study described disability-related constraints on personal resources of energy and time. As Kimberly explained, “I have to deal with … stuff that able-bodied people have to deal with, and double that with my disability-related needs”. Gary described the role of energy and time in shaping his participation in everyday life, saying

we all have lots to give or that we want to be involved in, and you haven’t always got the same choice. If it takes a long time to get ready to do something, then by the time you do all that then you’re tired or there’s no time left.

Participant accounts demonstrated how attendant services can increase the pace of activities with potential to increase participation in everyday life. In Gary’s words,

it helps speed up lots what somebody can do. Like, say, help me get ready for bed, change my socks or put slippers on, or just turn the covers over. All them simple things. [An attendant] can do it in five minutes, where it would take me half an hour.

As Mary similarly explained, “for me to do something [without support], I’m looking at four times as long”. Other participants highlighted increased flexibility in time use with self-managed attendant services. Ed, for example, suggested, “I can do more. I can get more done in terms of, I’m able to commit to things and plan for things that I wouldn’t be able to without [this program] because of the flexibility”.

When applying to the program, prospective self-managers are required to “list the major activities for which you would schedule an attendant” and “enter the time required, in hours” on the application form. On acceptance to the program, a personalized budget of up to 212.2 hours per month is negotiated, based on the individual’s self-assessment of
needs. Program materials formally delineate a range of appropriate uses for funding, but program administrator Judy suggested it is ultimately the responsibility of self-managers to decide how funds are spent. Judy explained there is some flexibility with regard to eligibility criteria, in that “we wouldn’t build [certain activities] into somebody’s budget … [but] if you’ve sort of fit that in to your pre-existing envelope, you know, nobody’s going question that”.

While participants indicated attendant services could improve opportunities for participation by increasing pace and flexibility, numerous examples showed the potential for limited funding to constrain participation in valued activities. Two self-managers, for example, discussed having insufficient support hours to allow for participation in physical exercise. Mason expressed frustration that he was “not allowed to exercise” since his request for funding to support exercise was denied. Gary explained he “used to go to the gym a couple times a week to exercise”, but “cut that out a year ago because there wasn’t enough time”. Gary suggested exercise was important to him because “I felt like going to the [gym] was a big step in slowing down the rate that my disease has on me”. Marcie, a third self-manager, described a daily workout as part of a regular routine her attendants would support, but characterized that physical activity as “physiotherapy”. Notably, the only form of exercise listed in program materials under “allowable services for funding” are “routine range of motion exercises”. In another example, although “meal preparation” is listed as an eligible activity, Mason discussed feeling pressured to save time by “eating microwaved dinners so I had more time for other stuff”.

Participants described several strategies adopted to manage limited personal and program resources. Marcie discussed planning ahead and taking stock of relational resources saying, “I always think ahead, like, ‘what do I do if’, and ‘who do I call’ and ‘who do I know’”. Paul, who helps meet many of his wife Joan’s attendant needs, illustrated a strategy to prioritize more immediate or pressing needs: “I didn’t have enough time this morning to put the braces on … Joan needed to eat … so [the attendant], when she comes in tonight will put the braces on”. Self-manager Kimberly discussed “determining when I really need the hours” and “calculating your days so that everything fits”. On top of predictable support needs, participants also identified a number of factors
that could “eat up extra hours” (Geraldine), such as traffic (Karen), illness (Marcie) and medical appointments (Geraldine). Geraldine, who described herself as the “office manager” of her daughter’s attendant services, illustrated the important role relational resources such as a supportive family could play to compensate for limited personal and program resources. She further suggested that material resources could impact the time it takes to participate in activities, for instance if someone is able to afford to hire transportation versus having to wait for public transit. In her words, “we all can’t get an Uber taxi. Sometimes you have to wait for the streetcar”. Geraldine was one of several participants to indicate material resources were important to fill gaps in program funding.

6.5.2 Maximizing time: “think about efficiency”

Participants regularly described the work they did to manage attendant services in temporal terms: as recurrent, difficult to predict, and time-consuming. Self-manager Karen said of payroll, for example, “it’s every single two weeks, like, you don’t get time off to do that”. Ed pointed out the unpredictability of the work, saying “it comes and goes. When there’s turnover then there’s a fair bit of work there for a while. It’s hard to quantify, though, in terms of how many hours”. In the context of limited personal and program resources, participants frequently discussed the need to maximize resources; to minimize personal energy and time spent to organize and manage attendant services, and to maximize use of attendant support hours. Karen, for example, said she could delegate tasks to attendants to reduce her own workload, explaining that “everybody can fill out their hours, so I’m not having to do it”. Karen noted, however, that despite delegation, the work still takes time: “it’s ultimately my responsibility to double check it … some people don’t do their hours or they accidentally add in something, so that takes time”.

To maximize limited support hours, the program materials entreat self-managers to “think about efficiency”. This was reflected in Judy’s suggestion that self-managers are responsible to make the most of limited hours. In her words, “you have to coordinate your blocks of time”. Kimberly described time management as key in the context of limited resources, saying “everything is down to the minute”. Gary described organizing his personal schedule as a means to manage limited support hours by “getting up at the same time and doing the same things” day-to-day, combined with multi-tasking: “I get a
bath three nights a week … that’s usually an hour and a half, and they also usually do laundry at the same time”. Some participants described opportunities to “stretch out” (Karen) the budget by paying attendants at a lower rate. As Karen explained, “they give you six hours, but if you’re not paying the maximum rate, like, it’s not really six hours. It’s more than that”. Similarly, Kimberly described her strategy to recruit live-in caregivers from overseas as a “unique way of maximizing the hours that you have” since “they can also get paid a bit less … under [Canadian immigration law]”.

Numerous participants articulated an additional strategy to save time by taking steps to reduce attendant turnover in order to keep the same attendants employed over a longer period of time. Attendant turnover was frequently described to strain personal resources due to the associated need to recruit, hire and train new attendants. In Karen’s words, “it takes a lot for me to set up the paperwork, schedule, train them”. Self-manager Alan explained keeping the same attendants for longer was a way to minimize expenditure of personal resources of energy and time while maximizing attendant support hours, owing to the reduced need to direct attendants and micro-manage tasks: “After a while they know what to do … they know their way around, they know the routine”. Brenda, an experienced attendant, also named efficiency as a key trait of longer-term attendants and one that may come with experience. In her words, “[my employers] trust me to do the stuff, and I’m quicker. I’ve been doing it a long time. I’m really efficient”.

6.5.3 Attendants respecting self-managers’ time: “it’s not about me”

While experienced attendants were said to save time by working autonomously and efficiently, each of the three attendants who participated in this study also emphasized a motivation to work efficiently out of respect for their employer’s time as a defining duty of their job. Marleigh portrayed several ways that respect for time features in the attendant job description:

Show up on time, if not five minutes early. Clean, well groomed, with my own shit in gear … be a good listener … take direction well … be as efficient as possible … [My employer] taught us to be silent butlers, you know? Like, stand,
hang out … wait for the next direction … it’s not about me. It’s about helping the person, pulling off as efficiently and as much as possible what they need to pull off.

In another example, Mark communicated understanding the value of his employer’s time, saying “I didn’t put the pillows in the bed properly and, like, I had to do it all over again. And that’s stressful, you know? Like, slowing down someone’s day”. Brenda described adjusting her behaviour to demonstrate respect for her employer’s time, saying:

I used to fight with him ... But then I thought, what am I doing? … I’m coming here, complaining … How is this helpful, you know? And so, if the garbage is full, I take the garbage out. When the floor is filthy, I mop the floor … I ask myself, now, if I was in this situation, who would I want coming in my door every time? … So, I don’t do it anymore. I don’t complain … there’s no room for that.

Several participants described how attendants’ respect for self-managers’ time included a willingness to support a broader range of activities; a disposition that was described in contrast to past experiences with agency-managed supports. Marleigh said of agency staff,

I see them saying no to certain things, you know. They seem to have a booklist of things that they don’t do: cat litter, or they don’t pick up plants that have fallen over, or whatever, right? Well then who the hell does? Who is gonna pick up the cat litter for this person that just wants to have a cat?

Participants suggested self-managed attendant services are able to support an increased scope of activities as compared with agency-managed models, but also portrayed a willingness to support self-managers’ participation in activities of choice. As Alan explained, agency-employed staff are trained to understand their role in a way that differs from how attendants are trained by self-managers:

The title is PSW, personal support worker … usually they know what to do with handicapped people. I tell them … what I need, what has to be done, and they do it or they don’t. I’ve seen some good people but usually, they don’t do much.
They try to get away with lots of things … The [staff], they would come, they would sit most of the time and play with their phone, on their games … they don’t think, they don’t cook, they don’t clean. They’ll dress me, they help me dress and wash, and beside that, that’s it … the people that I have now, they do everything I need to be done.

6.5.4 Self-managers recognizing attendants’ efforts: “who’s gonna take a job like that?”

The duration of attendants’ employment appeared to support self-managers’ objectives to manage time efficiently. Yet, several participants suggested high rates of turnover may be endemic to a job that offers limited compensation for precarious work. As Kimberly described the issue:

They want someone to come in for an hour to get up, and an hour to put you to bed, and an hour to groom. They want the person to go and come. Well, it’s very hard to get people that way. No one is going to get paid seven hours but take fourteen hours to do the job … part-time, no benefits, and no real room for growth. Who’s gonna take a job like that? They will in the short term, especially if it’s the only job they can find … But long term, you can say goodbye to them in one or two years.

On top of issues with scheduling, several participants expressed dissatisfaction with the remuneration available for attendants. Ed, for example, suggested compensation was disproportionate to the quality and quantity of work attendants do:

some of these are very hard-working people bouncing from job to job, I mean, from client to client, and without benefits at all … I would like money to be there for increases in the rate of vacation pay … for sick pay, or even, ideally … extended health care benefits, dental, vision.

To mitigate system-level constraints of limited hours of work and material compensation for work, self-managers described strategies adopted to demonstrate appreciation for attendants’ work, often including personal emotional or material
resources. Lydia, for instance, said she would take time to support employees emotionally, “just listening and letting them cry and letting them unburden themselves”. Gary showed appreciation for his workers by hosting an annual potluck barbeque for current and past employees, and Mark discussed informal benefits his employer offered, such as paying for meals or transportation to show gratitude for working extra hours or hard-to-cover shifts. Another strategy that was seen to demonstrate recognition of attendants’ efforts was flexible scheduling. In Mary’s words, “I offered [my attendants], as an incentive when they were hired, if you have to take your kid to school or you have a doctor’s appointment, maybe we can work around it”. Marcie also described a collaborative flexibility between and among attendants, saying “my one employee, her husband has cancer, so a lot of her flexibility is out the window right now. So, [another attendant] sort of fills in if [that attendant] has to cancel because she has to take her husband to the hospital”. As the latter example shows, a relational approach to the organization and management of attendant services was seen at times to extend beyond a single self-manager-attendant dyad, to include a broader network of attendants.

6.5.5 Valuing relationality: “we’re people at the end of the day”

Alongside criticism waged at systemic constraints, participant accounts stressed positive outcomes of participation in self-managed attendant services. Attendants, for example, acknowledged the precariousness of their work but attributed unique benefits to the role. As Brenda explained, “I have to have multiple jobs that obviously pay more than what [direct funding] pays. Nobody can work fulltime doing this kind of work, because there is no eight-hour shift”. In spite of this, Brenda continues to work as an attendant. She described the job as “incredibly satisfying, incredibly gratifying”, and emphasized relational aspects: “this is the most intimate work I’ve ever done … we have our own language … we get along really well. I know [my employer] inside and out. I can tell by the look on his face what’s going on … we’re really, really, really strongly connected … It’s a very intimate, very satisfying, very unique type of work”. Tempering issues with job security and compensation, attendants contrasted benefits of their job with pitfalls of mainstream work environments. Mark, for example, characterized the attendant role as an
unusual opportunity to “gain good life experience”, describing his employer as “a good role model in a lot of ways” and adding,

it’s fun. I have a lot of fun when I work there most of the time … I love my boss and I get along with her really well … It’s a nice counter balance to the work that I do [elsewhere] … because I have to think about someone else and care about somebody else to do a good job … I like that this job compels me to think about other people.

Self-managers also highlighted relationality in both critique and praise of the self-managed model. Mason, for instance, was one of several participants to suggest that a greater number of support hours would be required to truly enable him to make choices about the use of his time in his everyday life. His critique suggests a failure on the part of the program to recognize his individual support needs:

[paid support] hours should be more aimed towards what you do in your life, rather than how many hours [the program] thinks you need … if they could take what somebody did in a day and what they need help with and did hours that way, then it would run a lot better.

Kimberly described a similar tension in explicitly temporal terms, suggesting time-based resource allocation shrouds individual needs. As she put it, “in real life everything isn’t about time. We’re people at the end of the day”. Despite concerns about limited resources, participants overwhelmingly portrayed the self-managed model as a vast improvement over alternative support options, and an unparalleled opportunity to increase participation in everyday life. In Lydia’s words,

It made me have a life. Because otherwise [pause] I don’t know where I’d be. I don’t even really want to think of it … Whereas right now, I can not only go to school, but, you know, one day have a career, have a life … the ability to just, do what you want to do and not be based on other peoples’ schedules. Like, when you’re with an agency, you’re based on their schedule. It’s not based on your schedule. This is based on my life.
These examples demonstrate the value placed on relational recognition, and prioritization of individual needs ahead of program or system constraints.

6.6 Discussion

These findings illuminate the central role of relational work in the achievement of positive outcomes in self-managed attendant services, including autonomy and self-determination for self-managers, quality and flexibility in work life for attendants, and cost-savings at the system level. Despite its central role in the achievement of positive outcomes, relational work is not addressed in policy and program materials. Furthermore, existing literature has tended to attribute positive outcomes to self-managed models, without recognition of the personal resources of energy, time and skill that self-managers and attendants contribute. To illustrate the personal resources relational work requires, the compensatory function of relational work to patch gaps in the system, and its relative invisibility in self-managed attendant services, the following discussion considers the relational work self-managers and attendants contribute by attending to the theories of temporality outlined above. A normative temporal orientation to clock time is suggested to obscure the performance of relational work in self-managed attendant services, while relational work is suggested to demonstrate a resistive temporal orientation to crip time.

6.6.1 Clock time: efficient resource management amidst systemic constraints

In the present study, a temporal orientation to clock time was evident in the discourses of efficiency that drove the organization and management of attendant services. Program materials impelled self-managers to “think about efficiency”, while administrator Judy described the responsibility of self-managers to “coordinate blocks of time”. As highlighted by one self-manager, Kimberly, “everything is down to the minute”. An orientation to clock time was also seen in the dominant ‘needs-based’ distribution of social supports, in which ‘needs’ are constrained by the availability of resources. In the context of strained public resources, Slasberg and Beresford (2017) suggest “a ‘need’ is only a need if there is the resource there to meet it” (p. 1263). In this context, eligibility criteria qualify needs. Despite the certain reality that many individuals requiring support
with self-care and household maintenance activities also require support to participate in other kinds of activities, the Ontario program is structured to support only self-care and household maintenance activities. Participant accounts indicated there is some flexibility in how budgets are spent since, as Kimberly explained, self-managers are responsible for “determining when I really need the hours” and “calculating your days so that everything fits”. Gary was one of several participants to describe prioritizing needs in the context of limited resources, explaining he “cut [exercise] out a year ago because there wasn’t enough time”.

The discussion about exercise that arose in the present study elucidates a grey area in the practice of determining eligibility for self-managed attendant services. As elaborated above, Marcie reported using attendant supports to do physiotherapy exercises, but Mason said his request for funding to support exercise was denied. Since self-managers do have relative authority to determine how their funding package is spent, it is possible that Marcie’s exercises were not technically eligible, but that she had managed her budget so as to prioritize exercise. As previously noted, however, while exercise is not included where program materials communicate allowable activities, “range of motion exercises” are. This distinction between personally-motivated exercise and exercise prescribed by a health professional may be significant in light of observations that attendant services remain medicalized despite a persistent user-led drive to demedicalize them (Cranford, 2005; Kelly, 2016; Krogh & Johnson, 2006; Marfisi, 2002). In a Canadian study of home support services, Krogh and Johnson (2006) observed administrative practices to medicalize disabled lives, such that “home support largely becomes focused on providing only those services that are viewed by administrators as essential for physical survival, rather than those that facilitate community involvement and full citizenship” (p. 160). Krogh and Johnson (2006) posit a relationship between discourses of economic efficiency and systemic constraints, naming medical and economic reductionism as “recent neoliberal trends” that “have undermined the funding and quality of home support services” with “negative effects … on the lives of people with disabilities” (p. 151).
Clock time may be effective to promote efficient time management, but this research supports others who have argued it is not a universally applicable framework (Davies, 1994). An abundant literature has critiqued the neoliberalist practice of applying industrial logic to human services sectors, noting a disconnect between disembodied planning and lived realities (DeVault, 2008). In the present study, for example, personal budgets were allocated based on fixed amounts of time assigned to discrete activities. Self-managers used clock time to organize schedules and manage funds, but strategies to predict, budget and plan ahead were limited in their capacity to cope with the unpredictable in everyday life: illness, traffic and wait times for transit or medical appointments. The practice of budgeting time for activities also overlooks the emotional and communicative acts of negotiation between support receivers and providers that determine how tasks can be accomplished in ways that work for both parties (Lanoix, 2013); the emotional labour, for example, that Brenda described in the self-reflective process of deciding to pick up someone else’s slack rather than complain to her employer, or that Lydia described in the act of lending a sympathetic ear to attendants. Clock time does not account for variations in everyday life, and especially variations associated with subjective human needs. It does not account for the work self-managers contribute to the organization and management of attendant services and overlooks the relational work attendants perform.

6.6.2 Crip time: bending the clock to meet human needs

In contrast to clock time, crip time is fundamentally grounded in human needs. It is a temporal orientation in which body-minds, rather than clocks, determine the pace of everyday life. In the present study, crip time was evident in self-managers’ depictions of the role of personal resources to hinder or promote participation in everyday life. As Gary put it, “if it takes a long time to get ready to do something, then by the time you do all that then you’re tired or there’s no time left”. While crip time accounts for the natural rhythm of body-minds, it is importantly not body-minds alone but body-minds in interaction with physical and social environments that can be seen to influence pace and the amount of time activities take (Kafer, 2013). In the following excerpt, Mairs (1996) portrays the intertwined effects on time of individual and socio-environmental factors:
Getting a job is one thing. Getting to it is another. Not everyone can run out the door, a coat in one hand and a piece of toast in the other, jump on to a bicycle or into a car, and join the morning rush to the office. Many disabled people do drive … but plenty do not, and the lack of public transportation often constricts a life more sharply than any disability does. (p. 93)

This passage illustrates the non-normative temporality of a disabled body, specifically in interaction with features of built and social environments that privilege non-disabled bodies. The focus of this passage on work (taken as an exchange of temporal for material resources) further illustrates the potential impact of crip time (though perhaps more accurately, the general lack of awareness of crip time in normative social structures) on social and economic participation.

Participants in the present study suggested attendant services served as a sort of temporal resource, helping to increase participation by increasing pace. In Mary’s words, “for me to do something [without support], I’m looking at four times as long”. Ed suggested not just pace, but flexibility in scheduling had a positive impact: “I can do more. I can get more done in terms of, I’m able to commit to things and plan for things that I wouldn’t be able to without [this program] because of the flexibility”. While increased opportunities for participation were sometimes attributed to attendant services in general, or the self-managed model specifically, it was also apparent that not only the model but the people enacting the model were to credit. Attendants, on one hand, communicated awareness and respect of limited resources. Mark expressed sensitivity to the precious value of temporal resources, attributing stress to the prospect of “slowing down [his employer’s] day”, while Brenda and Marleigh both named efficiency as a core responsibility of attendants. Self-managers, on the other hand, strategically nurtured relationships with attendants, offering emotional and at times supplementary material supports. These findings resonate strongly with Kelly’s (2016) suggestion that relational work functions to foster and maintain relational ties between self-managers and attendants that in turn promote the achievement of positive outcomes.
While self-managers may teach or foster a relational focus in attendants, it is also possible that attendants develop a secondary understanding of disability experience in and through their work. As crip time is said to be viscerally understood by people who experience it, attendants may also gain intimate knowledge or understanding of disability through peripheral experiences of disability; a phenomenon Kafer (2013) calls ‘crip affiliation’. In the present study, crip affiliation may be seen to underpin the emotionally-charged accounts of some attendants and others who support self-managers, such as Marleigh’s expression of frustration at the unwillingness of some agency staff to support disabled people with activities they view to be beyond their job description, or Brenda’s account of ‘silently’ choosing to put her own needs aside in the interest of getting the job done efficiently. Crip affiliation may be seen to represent a different kind of relational work that is oriented to a recognition of human need. Brenda, for instance, discussed an embodied awareness and pattern of communication with her employer, saying “we have our own language … we get along really well. I know [my employer] inside and out. I can tell by the look on his face what’s going on”. Self-managers’ efforts to reward attendants’ contributions may similarly be seen to demonstrate deep recognition for, in Ed’s words, “very hard-working people bouncing from job to job [or] from client to client, and without benefits at all”. These examples help to highlight the uniquely skilled relational work that both self-managers and attendants perform.

6.7 Implications

This discussion has focused on a disjuncture between normative conceptions of clock time as a dominant structural paradigm and the temporal realities around which time is negotiated in self-managed attendant services and in everyday life. Self-managed models create space for the achievement of favourable outcomes, but the structures of such models are not necessarily themselves indicative of beneficial outcomes (Slasberg & Beresford, 2015). The findings of this study suggest that relational work performed by self-managers and attendants—work that takes time to accommodate diverse needs—is vital to the achievement of positive outcomes in self-managed attendant services. Despite its centrality to the success of self-managed models, relational work appears to be unaccounted for at program and system levels. The relative invisibility of relational work
may be seen as detrimental to those who perform it, with implications for policy and education.

As this and other analyses of relational forms of work have shown, relational work requires contributions of energy, time and skill (DeFrino, 2016; 2009; Ignagni, 2011; Kelly, 2016; Lanoix, 2013; Piepzna-Samarasinha, 2017; Piepzna-Samarasinha et al., 2017; Stacey, 2005). Given the realities of crip time that shape and may significantly restrict the temporal resources of some disabled people, failing to recognize self-managers’ contributions risks further marginalizing individuals whose personal resources may already be strained. To the extent that energy and time in particular hold material exchange value, there may also be material consequences (i.e. lost opportunities to participate in gainful employment) to lending energy and time to unpaid work (Strazdins et al., 2016), including the work of self-managing attendant services. Strazdins et al. suggest there may also be health consequences associated with unbalanced time use when people who are temporally disadvantaged strive to meet normative standards. While the focus on crip time highlights the inequitable distribution of temporal and other related resources in relation to disability, attendants may be similarly affected along lines of gender, age, race or socio-economic status (Cranford, 2005; Kelly, 2016). Self-managers and attendants often hold membership in social groups that are precariously employed and hold extra caregiving responsibilities, both of which may further tax temporal and other associated resources (Piepzna-Samarasinha, 2017; Piepzna-Samarasinha et al., 2017). To the extent that it requires additional, unrecognized and uncompensated resources, relational work may be seen to tax the already-strained temporal resources of self-managers and attendants.

The call to recognize relational work should not be taken to mean that responsibility for relational work must be taken away from self-managers and attendants. As DeFrino (2016) explains, people often enjoy, and may derive important meaning from its performance. Without recognition and formal acknowledgement, however, DeFrino suggests relational work can lead to burnout, moral distress and disempowerment. A significant policy implication of this work is therefore the need to recognize and formally acknowledge the performance of relational work, the role it plays in self-managed
models, and the resources people need to support its performance. This finding is of particular significance given ongoing calls for increased resources to support self-managers in their role (Carmichael & Brown, 2002; Glendinning et al., 2000b; Morris, 2004; Stainton & Boyce, 2004).

This research has shown self-managers and attendants working collaboratively and creatively to achieve desired outcomes amidst systemic constraints. Where the performance of relational work subverts formal regulations, however, self-managers in particular are vulnerable to reprimand. While service users and workers may indeed derive meaning from engagement in subversive acts performed in the interest of fostering greater autonomy (Stacey, 2005), persistent rule breaking may also be seen to indicate a need for policy change. Direction may be taken from existing studies suggesting attendant services require increased funding to meet stated objectives (Mladenov, et al., 2015; Slasberg & Beresford, 2015), and that attendant services would be better managed outside of the realm of health policy (Kelly, 2016; Krogh & Johnson, 2006).

Finally, to the extent that relational work is skilled (DeFrino, 2016; 2009; Kelly, 2016; Lanoix, 2013; Piepzna-Samarasinha, 2017; Piepzna-Samarasinha et al., 2017; Stacey, 2005), fair and equitable policy must recognize the value of resources self-managers and attendants contribute to support the success of such models; for instance, via appropriate (material) compensation (Piepzna-Samarasinha, 2017). It may also be beneficial to develop training programs for self-managers and attendants that explicitly address relational skills. Self-managed models intentionally create opportunities for service-users to hire workers without formal training, and self-managers often prefer to hire attendants who have not been trained within medically-oriented education programs (Kelly, 2016; Marfisi, 2002; Yoshida et al., 2004). This research draws attention to a relational skillset that may be meaningfully integrated support worker training programs. While the capacities that support relational work may be difficult to teach (Kelly, 2016), this research suggests the integration of relational skills into formal support worker education programs merits further research.
6.8 Conclusions and future directions

This research adds to a growing body of critical scholarship that recognizes the value of self-managed attendant services as a vital alternative to conventional models yet encourages ongoing discussion about improvements to a model that has demonstrated great potential to achieve desirable outcomes. This paper has focused on key findings that discuss self-managers’ and attendants’ contributions of relational work to organize and manage attendant services and the ways conceptions of time figure prominently into such work. Relational work, and adequate time to perform it, were shown as vital to the achievement of autonomy and self-determination, particularly within a context of austerity-driven systemic constraints. An organizing framework of clock time was seen to obscure self-managers’ and attendants’ contributions of energy, time and skill. In recognition of the actual time (and other related resources) required to perform relational work, crip time was explored as an alternative temporal framework that might meaningfully inform future policy and program planning. Relational work was described as important and meaningful, but also potentially burdensome, particularly when it is not recognized, acknowledged or supported. Future research might explore ways to support the performance of relational work in self-managed attendant services, including opportunities to teach self-managers and attendants about relational work.

6.9 References


Zarb, G., & Nadash, P. (1994). *Cashing in on independence: comparing the costs and benefits of cash and services for meeting disabled people’s support needs.* Derbyshire, UK: BCODP/PSI.
7 Discussion and conclusions

This chapter concludes the dissertation with a discussion of the original contributions and implications of this work. In addition to a discussion focused on the studies that comprise this dissertation, this chapter addresses reflexive insights on the research process and directions for future research.

7.1 Integrated manuscripts

This dissertation is comprised of four integrated manuscripts. Together, these manuscripts document a research process: questions arising in a practice context transported to the academy; exploration, selection and refinement of appropriate theoretical lenses and methodological approach; focused investigation of the original question; intertwined with metaprocesses of learning, growth and (self-)discovery. Theoretical threads developed in the first two studies are tacitly interwoven throughout the third and fourth manuscripts linking conversations about work as invisible, relational and temporal, to broader questions about flows of power in society and the legitimacy of diverse ways of knowing and being in the world.

The first manuscript (Chapter 2, entitled Embodied reflexivity: knowledge and the body in professional practice) illustrates my position relative to the study through an autoethnographic exploration of my positionality as an attendant. This study developed around a reflexive story I wrote about a wound, and focused on epistemic tensions between myself, my employer, and the medical world that is responsible to oversee matters of the human body and especially those that are disability-related. Through this study, which entailed an exploration of situated and non-dominant ways of knowing, I began to articulate a developing critical feminist lens, and to advance a conceptualization of embodied reflexivity as a means of knowledge generation.

The second manuscript (Chapter 3, entitled Self-management and the government of disability: reinforcing normalcy through the construction of able-disabled subjectivities) was inspired by the work of Shelly Tremain and others who have applied Foucauldian governmentality theory to the study of disability. Foucault’s writings on
biopower and biopolitics provided a framework to examine disability as a social phenomenon and Tremain’s application of Foucauldian theory to questions of disability led me down a path towards critical disability theory. This second manuscript entails a theoretical examination of self-managed attendant services through the lens of Foucauldian governmentality theory, setting the stage for a critical empirical examination of self-managed attendant services in Ontario. In the second manuscript, I articulated the critical disability studies theoretical framework that permeates this dissertation.

The third manuscript (Chapter 5, entitled “It’s like having another job”: the invisible work of self-managing attendant services) is the first of two presentations of the empirical contributions of this dissertation. In this manuscript, I bring critical feminist and critical disability studies perspectives on work into conversation to explore a key finding that many dimensions of the work of self-managing attendant services are invisible. The analysis suggests that self-managers’ work is often represented as ‘something other than work’, if and when it is represented at all. The discussion examines forces that may be seen to render this work invisible.

The fourth manuscript (Chapter 6, entitled “Everything isn’t about time. We’re people at the end of the day”: temporality and the relational work of self-managing attendant services), also draws on critical feminist and critical disability studies perspectives to examine findings from the empirical study. This paper advances considerations of relationality and conceptions of temporality in the work of self-managing attendant services. The analysis suggests that self-managers and attendants contribute personal resources of energy, time and skill to the performance of relational work. The discussion explores the function of relational work to increase autonomy in the context of austerity-driven systemic constraints.

7.2 Emergent themes

Across, around and between the four studies that comprise this dissertation, five key themes characterizing the work of self-managing attendant services emerged: (1) neoliberal self-responsibility; (2) tensions around resource sufficiency; (3) invisibility;
(4) relationality; and (5) temporality. These themes highlight some of the original contributions of the dissertation and are briefly discussed below.

7.2.1 Neoliberal self-responsibility

The second manuscript of this dissertation (Chapter 3) applied governmentality theory to critically examine the phenomenon of self-managed attendant services from a critical disability studies perspective. The use of governmentality theory in this paper helped to elucidate the social role of self-managed attendant services as an opportunity for disabled people to approximate citizenship norms; not only of autonomy and self-determination, but of self-responsibility. Historically, disability has been stigmatized by labels of need and dependence; realities of everyday life that are shrouded by dominant discourses of self-responsibility and independence. Through the lens of governmentality, self-managed models can be seen to create opportunities to demonstrate ‘normalcy’ as self-responsibility and independence, distancing from historical constructions of disabled people as needy and dependent. While individuals may value and pursue opportunities to achieve societal norms, such norms may also be seen to perpetuate the marginalization of people who choose not to or are unable to achieve them.

The results of the ethnographic study help to illustrate this tension between critical disability studies theory and lived experiences of everyday life. The data show that some self-managers derive important meaning from opportunities to self-manage, including related opportunities to participate in and contribute to mainstream society. At the same time, however, the data reveal numerous challenges faced by self-managers and their support networks related to the work of self-managing attendant services; challenges that critical social theory can help to us to understand. A critical disability studies perspective, for example, helped to make visible a normalizing function of self-managed models. Historically, the achievement of ‘normalized’ lifestyles was a goal of the independent living movement (DeJong, 2001). From a disability studies perspective, however, there is a tension between the pursuit of normalcy and the objective to legitimize and value diverse ways of being in the world, since the pursuit of a conventionally defined ‘normal’ body, mind or lifestyle implies disavowal of bodies, minds and lives that are marked by disability. Indeed, the pursuit and achievement of
normalcy may have important implications for individuals, such as self-perception and social acceptance. At the same time, insights from critical disability theories that address operations and flows of power in society (Shildrick, 2009; Titchkosky, 2011; Tremain, 2005) help to illuminate connections between individual experiences of marginalization and broader social discourses. This tension is evident in the present study, which has shown how self-managers may at once benefit from and experience marginalization related to the ‘normalizing’ function of self-managed attendant services.

Application of critical feminist perspectives further helped to show a tension between the dominant societal discourse of self-responsibility and experiences of interdependence, marginalization and privilege in everyday life. Foundational feminist writings about women’s work (DeVault, 2008; Hochschild, 1997; 1983; Kittay, 1999; Smith, 2002; 1987), for instance, highlight ways in which women often provide invisible supports that keep social lives running smoothly. Contemporary feminist analyses describe work performed by women (Berg & Seeber, 2016; Mountz et al., 2015), (queer) femmes (Piepzna-Samarasinha, 2017; Piepzna-Samarasinha, Milbern, & Wong, 2017) and disabled people (Hamraie, 2016; Waterfield, Beagan, & Weinberg, 2017) that is not required of privileged groups. Consistent with existing literature on self-manage attendant services (Marfisi, 2002; Morris, 2004; Slasberg & Beresford, 2015; Slasberg, Beresford, & Schofield, 2012; Spandler, 2004), this research has shown that the opportunity to self-manage attendant services is conditional upon access to sufficient resources: personal resources of energy, time and skill, as well as social resources, such as family or friends who can fill in gaps, and/or material resources to pay for additional supports. The discourse of self-responsibility may be seen to obscure interdependencies and inequitable access to resources—both of which condition access to self-managed attendant services. The discourse of self-responsibility may also be seen to divert societal responsibility to ensure rights are protected, shifting responsibility to individuals and their networks. Insofar as it contributes the framing of the work of self-managing attendant services as something other than work, the discourse of self-responsibility may also be seen to obscure the work self-managers and others contribute to organize and manage attendant services.
7.2.2 Tensions around resource sufficiency

Resource sufficiency was a key theme identified in the second manuscript that reverberated throughout the findings of the ethnographic study. Disabled people have historically been constructed as people with ‘needs’ that exceed those of the average person. Throughout history, societies have acknowledged a social responsibility to contribute collective resources to meet disabled persons’ needs. Tensions have long existed, and persist in the present day, with regard to the allocation and use of collective funds to meet disability-related needs. The independent living movement (ILM), for example, arose as disabled people and allies opposed the way collective resources were being used to ‘manage’ disabled lives, following a medical model and within segregated institutions. The ILM argued for a shift in emphasis from professional to individual expertise, especially in areas of everyday life that do not benefit from medical or professional supervision. The movement contested a pervasive paternalism that constrained disabled persons’ autonomy, in support services and in everyday life, and argued that disabled people could live better lives according to their own values and preferences and integrated into communities (DeJong, 2001). In addition to a philosophical paradigm shift, ILM also articulated a need for adequate resources to achieve the goals of autonomous and self-determined community living (Yoshida, Willi, Parker, & Locker, 2004).

Self-managed attendant services developed out of, and in many ways embody, the independent living philosophy (Kelly, 2016; Yoshida et al., 2004). For instance, self-managed models support de-institutionalized community living. This research supports the findings of previous studies that suggest self-managed models afford a greater degree of autonomy and self-determination in support services and in everyday life as compared with agency-managed attendant services (Clark, Hagglund, & Sherman, 2008; Mattson Prince, 1997; Mattson-Prince, Manley, & Whiteneck, 1995; Stainton & Boyce, 2004). Praise for successes of self-managed models, however, may be seen to overshadow a necessary conversation about resource sufficiency, perhaps because the question of resources represents a core tension between the competing interests of public budgets and disabled persons’ needs (Slasberg & Beresford, 2015). The potential for self-managed
models to save costs has certainly factored into political support for such models, perhaps even more so, Hand and Kelly (2015) suggest, than their celebrated capacity to increase autonomy and self-determination. The findings of my research resonate with an abundant literature that has discussed a tendency for resource insufficiency to stifle the achievement of emancipatory outcomes (Leece, 2010; Mladenov, Owens, & Cribb, 2015; Pearson, 2000; Pearson et al., 2005). This dissertation adds to current conversations about resource sufficiency by drawing attention to the work, and associated resources of energy, time and skill, that disabled people and those who support them contribute—not only to organize and manage attendant services, but to do so amidst a discourse of economic austerity that is shaping many Canadian health and social services (Krogh & Johnson, 2006). The findings of this study highlight ways in which resource constraints not only impede opportunities for autonomy and self-determination, but also create more work for self-managers and the people who support them.

7.2.3 Invisibility

Invisibility is the first of two prevalent themes arising from the ethnographic study that characterize the work of self-managing attendant services. Invisible work was observed in relation to two interrelated processes: exclusion from representation in official policy and program texts, and construction of the self-manager role as ‘something other than work’. As elaborated in the third manuscript (Chapter 5), the self-manager role was seen to involve a wide variety of tasks and activities to organize and manage attendant services. While official program materials outline the responsibilities of the self-manager role, qualitative data generated through this study offers a rich and more comprehensive portrait of the work self-managers do to organize and manage attendant services. This work appeared to be invisible at the level of policy and program given its lack of representation in official texts. Some tasks are listed in policy and program documents, however the work of carrying them out is never explicitly acknowledged. There is remarkably little discussion in these materials of the energy, time and skill required to do the work of self-managing attendant services; taken-for-granted resources that enable the organization and management of self-managed attendant services. Notably absent from official representations was any discussion of emotive or relational aspects of the work.
Where self-managers’ responsibilities were addressed in program materials, they were represented as something other than work. The third manuscript (Chapter 5) theorizes invisible work, drawing insights from critical disability studies and feminist perspectives on work. From a critical disability studies perspective, the construction of self-managers’ contributions as something other than work may be interpreted in light of socio-historical factors, such as an historical trend to construct and categorize disabled people as receivers of assistance, and therefore unproductive or non-contributing members of society. From this historical perspective, disabled people are imagined as non-workers. As the story about Judith Snow in the second manuscript (Chapter 3) shows, this construction has persisted in contemporary times, despite the participation of many disabled people in the workforce.

In the context of self-managed attendant services, I have argued that self-managers’ contributions are rendered invisible by the discourse of self-responsibility; since disabled people are imagined to be both unproductive and recipients of social support, self-managers’ work is rationalized as a reciprocal contribution—disabled people demonstrating self-responsibility for supports that would otherwise be publicly funded. Of note, the skills required to self-manage attendant services parallel skills that are conducive to participation in mainstream employment. In other words, disabled people who are eligible to self-manage attendant services are also likely to be employable. Of the eleven self-managers who participated in this research, three were retired, two were employed in full-time positions, one was employed part-time, one was self-employed, one was a recently graduated student, doing volunteer work and looking for paid work, and another was currently a student. Indeed, the potential for self-managed attendant services to support employment is a recurrent theme in the literature (Morris, 2004; Yoshida et al., 2004). As discussed in the third manuscript, self-managers may minimize or hide the work of managing attendant services, as a matter of constructing a normalized self-presentation. From a disability studies perspective, socio-historical constructions of disability may therefore be seen to render self-managers’ work invisible in complex ways.
Feminist theories of work further helped to elucidate the function of socio-historical constructions of work to render the work of self-managing attendant services invisible. The third manuscript (Chapter 5) outlines how feminist theories have helped to expand conceptions of what constitutes work, including work that is done ‘behind the scenes’, outside of the temporal boundaries of conventionally-defined work, and work that sustains life (rather than markets). Feminist theories of work also subsume in their definitions emotional and communicative efforts. The fourth manuscript (Chapter 6) theorizes the work of self-managing attendant services as a form of relational work, a feminist theory of work that captures invisible (perhaps more accurately unrecognized or unacknowledged) processes of emotion and communication that contribute to the achievement of desired outcomes. The data presented in the fourth manuscript show how relational work, as one particular form of invisible work, was instrumental to achieve the desired outcomes of autonomy and self-determination. The fourth manuscript also showed how relational work performed between self-managers and attendants was of particular value in the context of strained resources at system and program levels, given that resource scarcity has been shown to constrain opportunities for autonomy and self-determination. Theories of relational work (DeFrino, 2016; 2009; Fletcher, Jordan, & Miller, 2000; Kelly, 2016) supported the identification of potential negative impacts when the performance of relational is allowed to remain invisible, and underscored the importance of properly recognizing and acknowledging relational work.

### 7.2.4 Relationality

Relationality is the second of two salient themes arising from the ethnographic study that characterize the work of self-managing attendant services. The theme of relationality developed first out of the observation that self-managers do not perform the work of self-managing attendant services alone, and second, the finding that many participants performed work in ways that took the preferences and needs of other people into account. A growing literature has described characteristics of the unique relationships that develop within self-managed attendant services, and especially between self-managers and the attendants they employ (Christensen, 2012; Cranford, 2005; Glendinning, Halliwell, Jacobs, Rummery, & Tyrer, 2000; Kelly, 2016; Leece & Peace, 2010; Marfisi, 2002). As
outlined in the fourth manuscript, this literature describes a complex web of benefits and challenges of a unique relationship that is at once professional and intimate. Kelly (2016) has adopted the term ‘relational work’ to describe ongoing efforts by self-managers and attendants to manage the relationships they share. In the present study, self-managers and attendants were often seen to factor in the preferences and needs of another person, engaging in a mutual process of balancing self and other needs. As elaborated in the fourth manuscript, relational work was seen as vital to support resource management and the achievement of autonomy and self-determination within a context of constrained or limited personal and program resources. In this study, I have broadened Kelly’s conception of relational work by linking her discussion of relational work in self-managed attendant services to an interdisciplinary conversation about relational work (DeFrino, 2016; 2009; Fletcher et al., 2000). Of particular relevance to the present study, these works discuss both the invisibility of relational work and the tendency for relationality to mask interdependence.

The prevalence of relationality as a theme in my analysis is especially interesting in light of a dominant discourse of ‘independence’ in self-managed attendant services, which may be seen to stem from the independent living philosophy that underpins the self-managed model. As discussed in the fourth manuscript, a prevalent metaphor representing attendants as ‘arms and legs’ has been useful to distinguish self-managers as directors and decision makers from the attendant role to provide physical support (Kelly, 2016; Shakespeare, 2014). Data presented in the third and fourth manuscripts, which portray the attendant role as more than simply the physical work of carrying out assigned instructions, support insights arising from the embodied reflexive account presented in the first manuscript (Chapter 2); while attendants may be taught to put their ‘selves’ aside in the interest of following directions, it is both physically impossible and probably undesirable that attendants carry out tasks in a purely physical manner. Self-managers and attendants alike are people with emotions, preferences and needs that cannot reasonably be ignored in the interest of carrying out the rote tasks of support work. As the findings of this study show, systems and programs may overlook the relational dimensions of the work. The accounts of self-managers and attendants, by contrast, showed ways in which energy, time and skill were required to navigate complex
relationships. As discussed in the fourth manuscript, and consistent with Kelly’s (2016) findings, relational work may therefore be seen to fill significant gaps in formal resources. From the perspective of Kafer’s (2013) relational model of disability, the relational work of self-managing attendant services—perhaps more so than the self-managed model itself—may therefore be seen to enable autonomy and self-determination.

Importantly, the theme of relationality challenges a dominant discourse of independence that has been observed to facilitate erasure and devaluation of the attendant role (Leece, 2010; Marfisi, 2002; Ungerson, 1997). Literature focused on attendant perspectives has met with some contest (Morris, 1997), revealing a tension that may be understood in light of the historical context of abuses carried out in the name of caregiving, out of which the attendant role developed. The independent living movement’s staunch claim to independence and rejection of professional expertise may be seen to shape a construction of the attendant role as menial and unskilled; a construction with potential implications for the physical, emotional and material well-being of attendants (Kelly, 2016; Leece & Peace, 2010; Marfisi, 2002). Indeed, this study like some others before it has noted a tension in that attendant wages are central to the cost—and potential cost-effectiveness—of self-managed models. At the system level, it is cost-effective to argue that the attendant role is menial and unskilled. The data from this study suggest, however, that the work—and particularly the relational work—attendants contribute is skilled, and its performance draws on additional (largely unacknowledged and uncompensated) personal resources of energy and time. As Kelly has argued, relational work can mean that attendants are always on call and that they sometimes work without pay.

Notably, despite an apparent lack of recognition at the program level, self-managers in this study were seen to recognize and to take steps to acknowledge attendants’ contributions. As discussed in the first manuscript, self-managers may, in some instances, place greater value on the skill possessed by their attendants than by trained medical professionals. The relational character of the work of self-managing attendant services resonates strongly with Hughes, McKie, Hopkins, and Watson’s
(2005) description of the self-manager-attendant relationship as ‘dyadic’. The findings of this study support Hughes et al. and others (Kröger, 2009; Kelly, 2016; 2011) in acknowledging a space for relationality within or alongside a dominant discourse of independence. This is of marked significance given a shared potential for marginalization of both self-managers and attendants within a broader system that profits from their work.

7.2.5 Temporality

Exploration of the prominent themes of resource sufficiency, invisibility and relationality in the work of self-managing attendant services led to the identification of temporality as an additional theme. While conversations about resource sufficiency typically focus on system-level provisions of funding and other social supports, the identification of invisible and relational forms of work opened a conversation about personal resources implicated in the work self-managers and attendants do to organize and manage attendant services. Energy, time and skill were all identified as personal resources that support the work. Time, however, stood out among the rest. As discussed in the fourth manuscript, time is unique in that it may be seen to subsume other resources. Energy, for instance, factors into the time required to complete tasks, as skills factor in to resource management. Furthermore, time holds material exchange value; it can be lost, but is renewable daily (Strazdins, Welsh, Korda, Broom, & Paolucci, 2016). Perhaps most importantly, time as a resource is distributed inequitably along lines of gender, ability and socio-economic status—a characteristic of time that is often taken for granted (Strazdins et al., 2016). This study’s findings threw into sharp relief the relationship between time and autonomy, as participants discussed choices constrained by energy and speed, and the important role of attendant services to enable (more expedient) use of time to foster participation in (a greater number of) valued activities.

This study also shed light on the potential for the work of self-managing attendant services to tax already-limited temporal resources. This conversation, addressed explicitly in the fourth manuscript, is enriched through the adoption of a temporal lens informed by crip time (Kafer, 2013) and other feminist sociological conceptions of time (Davies, 1994; Deery, 2008; Hochschild, 1997; Lanoix, 2013; Strazdins et al., 2016)—theoretical work that highlights inequities in the distribution of temporal resources and
diversity in embodied experiences of time. The findings of the present study add to these conversations by demonstrating the temporal implications of participation in self-managed attendant services, such as the temporal resources self-managers and others contribute to the work of self-managing attendant services. In the third manuscript, the work of self-managing attendant services is described as one of several possible forms of disability-related work (work that inherently takes time to complete). The fourth manuscript engages a more explicit exploration of temporality, discussing the role of self-managers’ and attendants’ temporal resources to subsidize system-level resources (i.e. funding), and the impact of resource scarcity on self-managers’ autonomy (i.e. in time use).

Transcending the discussion of time as a material resource, Kafer’s (2013) work on crip time also attends to the interplay of embodied experience and social discourses, as they influence what people want and are enabled to do. In the second and third manuscripts I have explored the impact of discourses of productivity on the social construction of the self-manager role as an opportunity to demonstrate self-responsibility, or to otherwise approximate societal norms. In the fourth manuscript, I have interrogated systemic constraints on the range of activities self-managed attendant services are allowed to support. Across these analyses, I have observed a tendency for ableist assumptions about disability to shape self-managers’ social participation: rationalizing self-managers’ performance of unpaid work and limiting self-managers’ participation in activities of their own choosing. In other words, I have observed a tendency for ableist assumptions about disability to shape self-managers’ temporal autonomy.

While several scholars have developed conceptions of crip time, Alison Kafer’s (2013) work was foregrounded in this study for the emphasis she places on the intertwined nature of temporality and relationality. Of particular relevance to this research, Kafer’s discussion of ‘crip affiliation’ creates space to consider intimate, experiential and embodied understandings of disability possessed by someone who does not herself live with a disability. In the context of the present study, this work lends a useful frame to conceptualize the autoethnographic accounts included in this dissertation: accounts which help to illustrate ways in disability shapes lives—not just of those who
live with a disability of their own, but also those who live with (i.e. who regularly interact with or are around) disability in a more general sense. As discussed in the fourth manuscript, feminist sociological theories of time suggest that temporal resources are inequitably distributed along multiple lines (gender, ability, socio-economic status), several of which are likely to affect precariously employed, feminized and frequently racialized attendants. Marginalization along temporal lines may therefore be seen, at times, to affect attendants in similar ways as it does self-managers. While marginalization experienced by self-managers and attendants are surely not ‘the same’, the discussion of temporal resources and societal constructions and/or expectations of temporality elucidate a possibility that self-managers and attendants share uniquely relational ways of being in and understanding the world. While tensions between the interests of self-managers and attendants have represented a prominent theme in the literature on self-managed attendant services, this research contributes to an emergent trend to highlight commonalities in the interests and plights of both groups.

7.3 Reflexive insights on the research (and) process

7.3.1 Finding myself in a study of ‘us’

At the outset of this dissertation, I did not understand the potential issues with my positionality as a non-disabled researcher conducting disability research. As I forayed into the disability studies literature I learned about the role research has played in the historical objectification, medicalization and essentialization of disabled people. I was mortified to recognize a parallel in my positionality as a non-disabled researcher come to study the experiences of disabled people. Through engagement with disability studies literature that encourages participatory approaches, I came to feel quite uncomfortable in this space. I questioned the appropriateness of the role I had stepped into and grappled with this problem as I sought answers in literature on critical and emancipatory methodologies. I heard a clear call in disability studies for service user-led research. Meanwhile, critiques of participatory approaches opened a whole new world of questions. What contribution of work will this require of participants? Within the confines of the institution, how can I ensure people are fairly compensated for their contributions? Is there enough time to do this well within the confines of a doctoral
study? Is it ever actually possible to shed the powerful status of institutionally-affiliated researcher? The activist rallying cry still stuck with me: ‘nothing about us without us’. Ultimately, with a practical and theoretical rationale, I proceeded with a methodology that was reflexive: although it was not perfect, in that participants did not set the research agenda or to participate in analysis, I was guided throughout the project by returning constantly to the mantra: ‘nothing about us without us’.

Like many before me (if not most? if not all?), I struggled a great deal through the process of completing this dissertation. The physical and psychological stress at some point became too much for me to navigate. I sought help and was treated for depression first, then anxiety, then an eating disorder. I managed to keep up with my work, for the most part. But as I tried out medications and therapies, took time to see specialists and attended support groups, I began to recognize a dire need to find space and time—to dedicate personal resources—towards my mental health care. I considered taking a leave but was in the midst of data collection and was afraid of the potential consequences of delaying the doctoral process further. Not to mention fears surrounding disclosure to my doctoral program. As I sat and talked with research participants during this time, I felt inside of myself a visceral reaction to their stories. They described extra disability-related work of navigating the health care system, of taking time to take care of extra bodily needs, of curating a supportive social network, of navigating a complex and sometimes unsafe social world. I recognized a connection between these stories and something in my own lived experience; a deep understanding of what it is like to live with a sometimes-challenging body-mind. I do not identify as having a disability and I do not presume I could ever comprehend the nuances of another person’s lifeworld, yet these parallel experiences ignited something in me that caused me to think differently about my relationship to my research. I began to grapple with a new question related to those words still-etched into my consciousness: ‘nothing about us without us’. Who, I began to wonder, is ‘us’?

Around this same time, I received an invitation to step back into an attendant role. I had left full-time attendant work behind when I moved to London to pursue graduate studies. Now a registered occupational therapist, the invitation to return to work as an
attendant brought up questions: was it odd for me to continue work as an attendant now? On the other hand, still a student and lacking steady income, I knew attendant work was a great opportunity to make some money. On an emotional level, I missed the work—work I recalled enjoying and believed I was good at. What I did not anticipate was the incredible interpretive opportunity that would come with this return to an attendant role during the analysis and interpretation stages of this research; the opportunity to think the scholarship through a practice lens. Through the parallel experience of working as an attendant as I pursued emergent themes of invisibility, relationality and temporality and explored related theoretical writings, my sense of connection to this research intensified. While I contemplated these themes, a relationship with a new employer blossomed and I began to understand Hughes et al.’s (2005) description of the self-manager-attendant relationship as a ‘caring dyad’; of self-manager and attendant as interdependent parts of a whole.

I struggled for some time to reconcile my feeling of connection to self-managers’ experiences. I noticed parallels in my embodied experiences of invisible and relational work, first as a woman in an androcentric-patriarchal society, and second in my role as a mental health ‘patient’. I remained apprehensive of the strength of this connection, however, especially as I contemplated my non-disabled embodiment and related privilege. It did not feel right to claim I could understand my participants’ experiences because of my experiences as a woman or as a patient. By contrast, it did feel right to assert my first-hand understanding of self-managed attendant services based on my experiences working as an attendant. I could not presume to understand the nuances of the lifeworlds of the participants in this research, or even of the women I have worked for as an attendant. I am, however, confident that I possess a unique and profound understanding of the nuances of the self-manager-attendant relationship, and the work that occurs within the lifeworlds that are shared by self-manager-attendant dyads. This is the arc I followed in coming to recognize myself within the ‘us’—an assertion that felt uncomfortable at first, but which, now that all is said and done, I argue is a vital contribution to the literature on self-managed attendant services, and an insight of great importance for disability studies.
7.3.2 Reflexive [auto] ethnography: navigating a simultaneously insider/outsider positionality

The evolution of my understanding of my own positionality relative to this research has further shaped my understanding of reflexive ethnography as a methodological approach. At the outset of this research, I recognized the relevance of my experience with self-managed attendant services primarily as the spark that ignited this inquiry. Given my professional experiences as an attendant to women who self-manage attendant services, autoethnography represented a plausible approach. I was, however, concerned that autoethnography would centre my voice and perspectives at the expense of potential others. On reflection, I was also not yet convinced of the legitimacy of my membership in this group. A more conventional approach, I supposed, would better support my objective to understand a diversity of perspectives on the phenomenon of work in self-managed attendant services. Reflexivity, I expected, would allow me to be open about and critical of my experiences working as an attendant within a self-managed model.

As I have already discussed, Ellis and Bochner (2003) describe a ‘continuum’ of reflexive ethnographic approaches, ranging from research that starts with the researcher’s experience, to focused investigation of the researcher’s engagement in the research process. When I proposed to use reflexive ethnography, I imagined this research on the former end of this spectrum: a project emerging from my experience. As my understanding of my own relationship to this topic has evolved—as I have come to recognize myself as a member of the subcultural group that is the focus of this investigation—the way in which I imagine this continuum has changed, too. Unexpectedly, my participation in the research has become a focal point: not central, but present. Where I initially imagined this research to occupy a fixed location upon the continuum Ellis and Bochner describe, I see now that this research spans a range.

By claiming space to consider the intertwined nature of my positionality relative to the research and this methodological approach, I have arrived at a much richer understanding of reflexive ethnography itself. When I designed the reflexive ethnographic study, I chose methods that aligned with the methodological approach, as I understood it then; seeing reflexive ethnography as a ‘type’ of ethnography, I assumed
participant observation was an appropriate method. I did not think critically about the use of participant observation until a prospective participant raised concerns about it. While the prospective participant’s concerns related to the time this method would require, I was suddenly struck by a multitude of issues with the method. Instinctively, I knew it had to go. What, though, would the study lose with omission of this method?

Participant observation has traditionally been used by ethnographers to gain a highly contextualized understanding of the research field; to “discover, describe and represent the world of the researched” (Li, 2008, p. 101). As Davies (1999) notes, however, participant observation is not usually a primary method of data collection; rather, the practice was developed by researchers who sought to gain in-depth understandings of cultural contexts in which they had no prior experience. During the design phase of this research I conceptualized myself as an outsider, separate from the population that would be studied. Through the conduct of the research, however, I came to see this relationship differently. My membership in this culture became clearer to me as I spent time in the field: the homes of the participants I visited and the public spaces where I met attendants felt strangely familiar; as I listened to their stories I realized that I already possessed a deep, at times visceral comprehension of many of the contexts and situations that they described, cultivated through my many years of first-hand experience working as an attendant. While I initially selected reflexive ethnography as an alternative to autoethnography, I now understand why these approaches are often discussed together in the literature (see for example, Denzin, 2003). Perhaps they are not discrete methodological approaches, but part of one continuum.

7.3.3 The gatekeeper-stakeholder paradox: navigating complex power relationships

The researcher must attend to many points of view. The paradox is that a multitude of opposing truths, needs, and standpoints, all partial, coexist at the same time. Because of this conundrum, ethnographic research is filled with ethical dilemmas. By analysing contradictions and discrepancies, the ethnographer, I believe, can provide a more subtle understanding of the complexities of differing perceptions of reality and responsibility and of an organization’s social construction of knowledge and power. Inclusion of
paradoxes may not sit comfortably with the binary world found in much of positivism, but it is very much a component of standpoint theory and field research. (Weinberg, 2002, p. 93)

As discussed in the methodology chapter, Dr. Kinsella and I decided not to contact the independent living centres before gaining ethical approval from the university. In navigating this decision-making process, we weighed numerous factors. One was my positionality relative to the ODF program: while I was intimately familiar with the everyday lifeworlds of my employers, I had no formal affiliation with the program. Like any other attendant, I was employed by self-managers directly. In addition to lacking any formal personal connection to the ODF program, and with awareness of a power relationship between the administrative body and program participants, I was wary of asking my existing personal contacts (self-manager/employers) to become involved. I was further apprehensive of the reception I might expect from the administering organization, in my dual role as a non-disabled researcher and as an attendant. The Centre for Independent Living in Toronto (CILT) is a “consumer-controlled” organization with a mandate to be run “by people with disabilities for people with disabilities” (CILT, 2018); a mandate that resonates strongly with the politics of disability activism and research that emphasize service-user control and participation in research. As a non-disabled researcher unknown to the organization, I was concerned the organization might be hesitant to establish a relationship with me, especially before I had drafted a formal plan for the research. I was further unsure whether it would be a help or a hindrance to disclose my positionality as an attendant. Although I was perhaps only subtly aware of this tension at the time, I now recognize a tension in the independent living philosophy and reflected in self-managed models, between the interests of self-managers and attendants. Fearing outright rejection from the organizations, I decided to wait at least until I had a draft research proposal to present to the organizations before initiating contact.

Another factor that weighed in our decision to delay contacting the organization was concern about a potential conflict of interest, given CILT’s simultaneous roles as gatekeeper and stakeholder. As the centralized administrating organization, CILT acts as
a gatekeeper for access to the ODF program. From my perspective as a researcher, CILT also represented a gatekeeper with access to multiple participant groups: including both self-managers and program administrators. At the same time, however, we wondered if there was potential for tensions to arise between the critical orientation of the developing research project and the organization’s responsibility to manage relationships with both self-managers and funders. We wondered if CILT’s responsibilities to these groups might shape the organization’s contributions to the project. If we were to partner with CILT, for example, we wondered: How would the organization respond if participants spoke critically of the program? Would affiliation with the organization deter participants from speaking openly? And, would there be any concerns about potential repercussions for participants if there were to be an inadvertent lapse in confidentiality? In light of this web of power relationships, we decided to seek ethical approval from the ethics review board at Western before proceeding to contact the organizations.

Our decision to defer contacting CILT until after ethical approval was obtained brought its own set of challenges. Gaining ethical approval from the institution took a great deal of effort and time; with a better understanding of the practical resources required to amend the ethics protocol, and with dissertation milestones passing, it felt less feasible at this point to invite feedback on the research design from the organization. In retrospect, I wondered if our estimation that the research would be better received with institutional validation was accurate; or, if potentially, it was instead read as threatening? It was not until I contacted CILT that I learned about their board of directors and research committee. Knowing of that committee now, I would likely attempt to communicate with that group before proceeding with a future research project that involved the organization. Yet, I wonder … might there still be a resistance on the part of the board to support research that adopts a critical stance? And, if there is resistance from an organization’s board, does that mean the research should not take place?

I have not yet found firm answers to these questions, but I have found some guidance from researchers with parallel experience. In the literature on self-managed attendant services, research from conflicting viewpoints has engaged in a productive—albeit tense, at times—conversation about the sometimes-competing interests of self-
managers and attendants (see for example, Ungerson, 1997a; Morris, 1997). I have found further validation in a burgeoning literature (outlined in the literature review and manuscripts comprising this dissertation) that applies critical social theories to critique self-managed attendant services. I have also drawn insight from researchers in diverse fields navigating parallel theoretical tensions. Weinberg (2002), for example, discusses numerous ethical tensions that arose in her ethnographic study of the lived experiences of policy on a stakeholder population, including what she describes as an ethical tension between her “responsibility [as a feminist] to challenge hegemonic ideology” (p. 79) and the ‘realities’ of the institutional setting that was the focus of her research. In her research, Weinberg encountered the same potential problem I anticipated, of collecting data that “reflected negatively on an agency that I respected” (p. 79); a situation that led her to “explore the dilemmas of maintaining a relationship of trust while being truthful to uncomplimentary material” (p. 79). Describing tensions parallel to those I have encountered in my own research, Weinberg suggests resolution of the issue was reached through development of a ‘dialectical’ relationship with the director of the organization that was the focus of her study.

Weinberg (2002) describes her dialectical relationship with the organization’s director as “a new synthesis of personal knowledge that occurs for individuals from collecting information brought by the other party in the relationship” (p. 87). On completion of her project, taking care to broach the conversation with humility and respect, Weinberg brought her findings to the director to discuss; importantly, creating space for each party—the researcher and the director—to share her perceptions with the other. The result, Weinberg suggests, was of mutual consciousness raising; a small but meaningful “step towards praxis and change for a more equitable world” (p. 94).

With these insights from Weinberg (2002) in mind, I have decided that my next step on completion of this dissertation is to take the results of the study back to CILT. There, I will attempt to foster a sort of dialectical relationship to pursue next steps for dissemination. Perhaps, as did the director in Weinberg’s case, the organization will be moved to act on some of the research findings. Perhaps, as Weinberg also reported, the organization’s feedback will lend important contextual insights that I was not able to
ascertain from my perspectives, as researcher or attendant. I have proceeded to submit the findings of this study to an academic journal where relevant conversations are taking place, yet I hold close a concern expressed in early communications with CILT that critique could lead to unforeseen, potentially unfavourable outcomes. Despite their potentially powerful position relative to self-managers, CILT is a stakeholder in this research, and one with a valid and valuable perspective. Indeed, it has proven a complex endeavour to navigate the power relationships in this ‘hierarchical field setting’ (Weinberg, 2002); but an important opportunity, nonetheless. Following Weinberg, I have and will continue to take as a guiding light allegiance “to the claims of the [participants] and to the potential betterment of the [organization]” (p. 89).

7.4 Implications for disability studies

7.4.1 A critical-empirical study of work

This study makes an important contribution to a limited body of work on self-managed attendant services that has focused specifically on ‘work’. Several existing studies have identified contributions of labour and skill required to manage administrative tasks (Carmichael & Brown, 2002; Morris, 2004; Stainton & Boyce, 2004) and relationships with attendants (Glendinning et al., 2000; Kelly, 2016; Leece & Peace, 2010; Marfisi, 2002). While some of these studies identify a need for greater supports, few have directly problematized the work of self-managing attendant services, and none have conducted focused studies to examine that work. A few studies have named and theorized self-managers’ contributions as work. One scholarly conversation has centred around the individual (i.e. positive self-identity and participation) and societal (i.e. economic) benefits of self-managers’ work (Barnes, 2000; Barnes & Roulstone, 2005; Rummery, 2006; Prideaux, Roulstone, Harris, & Barnes, 2009). Another has interpreted self-managers’ contributions in the context of a neoliberal capitalist climate of austerity and in light of contemporary productivity norms and citizenship expectations (Hande & Kelly, 2015; Mladenov, 2017; Scourfield, 2007). This dissertation makes an important contribution to this primarily theoretical conversation by advancing understandings of ‘work’ through the perspectives of those who do the work associated with self-managing attendant services.
By adopting a balanced approach to explore multiple perspectives, this research serves to bridge the aforementioned conversations about work in self-managed attendant services. In line with the first conversation, this study’s ethnographic data highlights individual and social benefits of self-managers’ work. Interpreted through a critical perspective, however, the data also invokes the second conversation, around connections between the benefits associated with the work of self-managing attendant services and a ‘neoliberal ableist’ social environment (Goodley, Lawthom, & Runswick-Cole, 2014). In the third chapter of this dissertation I argued that the self-manager role may be meaningfully interpreted in light of a societal expectation that disabled people can and should strive to demonstrate normalcy by overcoming disability to lead normalized lives. Positive self-identity derived from achievement of ‘super-crip’ (Titchkosky, 2003; Shildrick, 2009; Withers, 2012) or ‘able-disabled’ (Titchkosky, 2003) status must also be understood in light of pressures for disabled people to achieve neoliberal citizenship by doing extra disability-related work; work that is framed not as work, but as self-responsibility. Paradoxically, then, while self-managers may derive meaning from the work they perform in the self-manager role, that meaning may also be understood as a function of ableism—namely, when meaning is derived from the achievement of societal standards of productivity and independence.

The emergence of this study’s data at the intersection of conflicting theoretical perspectives on the work of self-managing attendant services highlights a tension in the field of disability studies: between the aims of theory and activism to instigate social change, and the material realities of living in an ableist world today. Shakespeare (2014), for example, has cautioned against a preference in the field for theoretical arguments over empirical research. Speaking of attendant services specifically and in the Canadian context, Church, Diamond and Voronka (2004) suggest “the voices of experience from Canadians with disabilities interacting with personal support workers is woefully lacking” (p. 50). In their view, “Without such textured expressions of how current policies are lived out in Canadian communities, discussions of policy and its impact runs the risk of remaining abstract and disembodied” (p. 51). In light of such claims, this study, with a focus on the everyday lived experiences of people who perform the work of
self-managing attendant services, makes an important contribution to the field of disability studies.

7.4.2 A relational methodology?

In the crafting of this research, I took great care to respond to calls within the field of disability studies for a methodological approach that acknowledges the fraught history of disability research. Amidst calls for emancipatory-participatory designs (Barnes, 2009; Morris, 1992) and critiques of participatory methods (Barnes, 2009; Lennie, Hatcher, & Morgan, 2003; Oliver, 1997; Shakespeare, 2014), I grounded this reflexive methodology in feminist theoretical insights on the generation of knowledge; namely, the situated and partial nature of claims to knowledge and the tendency of truth claims to mask and serve particular interests (Harding, 1991; Shildrick, 1997). Reflexivity was adopted as a principle to guide “a continuous process of critical scrutiny and interpretation, not just in relation to the research methods and the data, but also to the researcher, participants, and the research context” (Guillemin & Gillam, 2004, p. 275). A reflexive stance acknowledges that “we often do not know what we are seeing, how much we are missing, what we are not understanding or even how to locate those lacks” (Lather, 2001, p. 486).

The critical reflexive methodological approach adopted for this study aimed to ‘multiply perspectives’ (Lather, 2007), and to recognize my positionality as a researcher; acknowledging that, in the words of Richardson (1994), “What we see depends on our angle of repose” (p. 522).

To acknowledge the limitations of every vantage point and relatedly, the partiality and positionality of claims to knowledge, holds important implications for disability studies research. The call for emancipatory-participatory approaches arose from a fraught history of oppression, marked by objectification and exploitation of disabled people, and the total marginalization of subjective accounts social and practice spheres dominated by objectivist science. Indeed, a major project of disability studies has been to ‘flip the script’ of conventional approaches that study disability as an individual phenomenon to studying the disabling tendencies of particular socio-cultural environments (Linton, 1998). Without disputing the absolute necessity of centring the perspectives of people who live with disability, this research has led me to consider the potential range of
perspectives that may be marginalized when only one set of perspectives (i.e. service-user perspectives) are foregrounded. This insight is largely informed by a subset of literature on self-managed attendant services that emphasizes the perspectives of attendants; a literature that highlights the potential for exploitation and marginalization of attendants who are likely to represent marginalized groups (Christensen, 2012; 2010; Cranford, 2005; Leece, 2010; 2004; Leece & Peace, 2010; Ungerson, 2005; 2004; 1997a; 1997b). The independent living movement fought to create space for service-user perspectives, long-silenced by professional voices. Informed by the independent living philosophy, self-managed attendant services enact that shift. However, a combined lack of training and lack of organized workplace protection creates a vulnerable situation for attendants. I therefore suggest it is important to create space within disability studies methodologies to consider, invite and examine the voices, perspectives, interests and needs of a variety of stakeholders who ‘live with disability’.

In line with others who have encouraged a focus on the relationships at the heart of self-managed attendant services (Graham, 2015; Kelly, 2016) and in light of the findings of the present study that the work of managing attendant services is performed relationally between self-managers and attendants, it will be important for disability studies to consider methodological approaches that attend to the relational nature of disabled lives. This insight echoes the suggestions of other disability studies scholars (Price & Kerschbaum, 2016; Tregaskis & Goodley, 2005), whose methodological reflections highlight the challenges disability raises for conventional research methodologies and practices. These authors discuss possibility associated with disability-informed methodological approaches, including the methodological value in centring interdependence, lived experience, and flexibility—including the flexibility to adapt conventional methodological approaches in ways that accommodate both researchers and participants who live with disability.

Throughout this dissertation I have adopted a preference for the phrase ‘living with disability’ as a potentially more inclusive alternative to the notion of ‘living with a disability’; a way to capture in simple language the notion of ‘crip affiliation’ (Kafer, 2013). In keeping with the social model of disability, the term ‘disabled person’
importantly conveys the notion that people are disabled (or not) by the physical and social worlds with which they interact. The notion of living with a disability does not cohere with the social model, since this language implies a conception of disability equated to diagnosis or impairment. ‘Living with disability’ may be seen to align with a political-relational model of disability that acknowledges the capacity for environments to enable or disable, as well as the dynamic nature of dis/en-abling environments that are made up of and shaped by the people who inhabit them—people who may be more inclined to act inclusively when they are attuned to the realities of life with disability (Kafer, 2013). Appreciation of the diverse ways in which people may live with (i.e. interact with or be affected by) disability holds implications for disability studies methodologies. A relational understanding of disability requires a relational approach to research that acknowledges and attends to the diversity of preferences and needs of people who, in the broadest sense, ‘live with disability’.

7.5 Implications for policy and practice

7.5.1 Considering work in policy and program design

This study has generated a multi-perspectival portrayal of the work of managing attendant services, including a range of responsibilities that are outlined in program policy and materials, and an additional set of tasks and activities that are not formally acknowledged. The argument that these responsibilities, tasks and activities indeed constitute work holds implications for policy pertaining to self-managed models: first, concerning assumptions inherent in the expectation that disabled people can and should perform this work; and second, concerning questions of equitable access to programs that require significant contributions of work. The findings of this study support existing literature on self-managed attendant services that has shown self-managed attendant services are favoured as a cost-effective alternative to agency-managed services. By exploring the work self-managers and their support networks do to organize and manage attendant services, this study has shed light on the role of this work to subsidize costs associated with attendant services. That this work may indeed hold meaning for people who perform it is not, I have argued, reason enough to construct it as something other than work. Given the range of personal resources self-managers and others contribute to
the organization and management of attendant services, policy and program designs must: acknowledge the work people do; consider the meaning of that work for the people who perform it; and do so with consideration for the material and other resources this work requires of the people who perform it.

Beyond data that illustrate the work of self-managing attendant services, this dissertation also engages multiple theoretical perspectives to analyze this work. Feminist social theories and critical disability studies have helped to shape a conception of this work as one among many forms of extra and/or invisible work that disabled people frequently perform. Disability studies and Foucauldian governmentality theory have supported an interpretation of the work as a contribution disabled people are expected to perform in exchange for access to social supports; an expectation that may be rooted in stereotypical constructions of disabled people as unproductive, unemployable and burdens to social welfare systems. At policy and program levels, these insights signal a need for reflexive consideration of the way self-managed models are imagined and implemented. Programs ought to be structured with regard for the lifeworlds of the people who participate in them and whose lives they are designed to support.

Indeed, the Ontario program is unique among self-managed models in that it is largely run by a service-user community; however, the program is restricted by funding allocation decisions made at the provincial level (Yoshida et al., 2004). This study supports the findings of others (Mladenov et al., 2015; Slasberg & Beresford, 2015) who have suggested the achievement of beneficial outcomes in self-managed models requires adequate resources provision. The information that this dissertation has generated may be usefully applied to challenge assumptions that might otherwise guide the policy and program development; assumptions, for instance, about the kinds of activities attendant services are suited to support.

7.5.2 Accepting supports: towards a more relational program design

This research indicates a clear need to develop resources self-managers and others can access to support the work they do in the context of self-managed attendant services. The
accounts of work responsibilities this research presents provide valuable information for the development of resources to meet gaps identified by current self-managers and others involved with self-managed attendant services. At the program level, additional opportunities for training, a more formal system for counseling, or a broader range of supports may be offered to help self-managers at various stages (at the outset and ongoing), and to support self-managers to navigate complexities of the role. The findings of this research may usefully inform the project of updating existing and/or developing new print and electronic resources to reflect a more comprehensive description of the responsibilities required.

As some participants in this study discussed, there may be additional opportunities to create jobs within self-managed programs, where people with lived experience (i.e. experienced self-managers) may formally impart guidance and expertise. The development of appropriate resources requires a space in which people can feel safe and comfortable to ask for help, without fear of reprisal if they are perceived to be insufficiently independent to carry on in the self-manager role. A more accessible self-managed model may require a more relational approach, which promotes discussion of the fundamental needs of program participants and acknowledges the (often invisible) interdependencies that sustain self-managed models. These suggestions echo the scholarship of Claire Ungerson and Janet Leece, both of whom have argued for greater consideration and/or protections for attendants and a need to develop self-managed models that respect the contributions and needs of both self-managers and attendants.

7.6 Implications for education

7.6.1 Health professional education

The findings of this research may be of interest to health and social care practitioners, whose professional practices require nuanced understanding of the everyday lifeworlds of clients, including recognition extra, invisible and relational work disabled people perform within (and beyond) self-manager roles, and the resources required for such work. These forms of work are often taken for granted yet form part of the context practitioners take into consideration to inform clinical decision-making. Practitioners may work with self-
managers, or clients who might consider a self-managed model. Practitioners may also be in a position to recommend a self-managed model to clients, or advocate for such models at a system level. Additionally, the application of a critical disability studies lens to analyze a health and social services model may serve to illustrate the value in—and the challenges of—adopting a social or political-relational model of disability in practice.

7.6.2 Attendant/support worker education

Distinct from health professional education, this research also holds potential to inform the ongoing development of support worker education programs. As previously discussed, many self-managers prefer to hire attendants without formal training. Most importantly, self-managers often prefer attendants who have not been inculcated in a medical model of disability. In addition to training attendants in the particularities of their everyday routines, participants in this study discussed a need to orient attendants to a more political-relational model of disability. Some participants described the work of educating attendants as burdensome or challenging. Others discussed the challenge of finding attendants who were not already trained in a medical model or who were open to learning. A potential implication of these findings for the future development of self-managed attendant services programs may be an opportunity to provide some centralized education for attendants (i.e. an orientation to the independent living philosophy). Education of this sort could not stand in for the sort of training self-managers do to orient attendants to their personal routines and preference but might reduce the burden on self-managers to continuously orient new staff to the self-managed model. Beyond self-managed models, this research has also highlighted an opportunity to develop support worker training that better reflects an independent living philosophy, and a political-relational model of disability. Attendants in self-managed models, and support workers elsewhere, may further benefit from formal orientation to the topics of invisible and relational work, as well as the temporal implications of living with disability.

7.7 Conclusions

The impetus for this research came from an observation that self-managing attendant services requires work. At the outset, I assumed extra work was problematically
burdensome for the people who perform it. I have learned throughout the research process that this can and may often be the case. However, I have gained a nuanced understanding of the meaning such work may hold for the people who perform it. In particular, I have come to appreciate a somewhat irreconcilable tension between the immediate need to work with the best options for support that are available today, and a need to pursue ongoing reflexive consideration of existing models in order to develop even better options for the future. People doing their best to survive today may not have the resources to fight for ongoing change. They may also be afraid to jeopardize access to a current best option in pursuit of an unknown future development. Furthermore, while many disabled people may find important meaning in the opportunity to self-manage attendant services, many more may wish to increase autonomy and self-determination in attendant services, but be unwilling or unable to take on extra work. Equitable access to the autonomy and self-determination many people currently access through self-managed models may therefore require the development of alternative models that adhere to similar principles.

7.8 Directions for future research

7.8.1 Exploring alternative self-managed models

While there is always room to innovate novel approaches to the organization and management of attendant services, reinvention may not always be necessary. Current alternatives to self-managed models (i.e. agency-managed attendant services) may hold potential to provide services in more user-centred ways. To offer one example, Christensen (2012) describes a Norwegian model that is self-managed but does not involve direct employment. Service-users under this model retain control to define “who the care workers are, how and when they do the work” (p. 402); while Norwegian self-managers retain the role of manager, however, they shed the role of employer and the associated responsibilities to organize and pay workers that define the self-manager role in marketized North American and UK models. Instead, attendants are employed through a number of channels; increasingly, they are employed by a not-for-profit, user-led co-op (Christensen, 2012). Christensen’s research suggests that the direct-employment model fosters more volatile relationships between self-managers and attendants; relationships
that, in light of the present research, might be seen to increase relational workloads for self-managers and attendants. The Norwegian model, Christensen argues, balances the power dynamic in a manner that is safer for both parties. One beneficial direction for future research on self-managed attendant services might be to explore the strengths and shortcomings of various models currently in use around the globe.

7.8.2 Seeking service-user expertise to develop supports
Consistent with previous research findings, the findings of the present ethnographic study suggest that self-managers lack vital supports to succeed in the self-manager role. These findings have highlighted specific ways in which system-level shortcomings transfer work responsibilities to individuals and their support networks. One question I posed in interviews that I was not able to discuss at length in the presentations of the findings was, “If you had the opportunity to make any changes you wish to the current program, what might they be?” In response to this question, several participants discussed innovative strategies programs might adopt to address shortcomings in the supports that are currently available. This data sheds light on the knowledge and expertise that many experienced self-managers possess; knowledge that holds potential to inform ongoing improvements to self-managed models. Future efforts towards program evaluation may ask questions of this nature, oriented to solicit meaningful feedback and experience-based expertise.

7.8.3 Focusing on attendant education
One consequence of the work involved in self-managing attendant services is inequitable access to the model’s potential benefits for people who cannot or choose not to accept responsibility for the associated responsibilities. Consistent with the findings of other studies, the findings of this research suggest self-managed attendant services are attractive to service users for the opportunity to self-select workers; specifically, several participants discussed the challenge of working with support workers who have been trained according to a medical model. If self-managed attendant services will never represent an option for all people who require attendant supports, there is a need to improve alternative options (primarily, agency-managed services). Where support worker education is a standard qualification for agency-managed support work positions, support worker education may represent a logical target for intervention. To the extent that
support workers are trained by their agencies or are expected to meet agency policies, agencies themselves might also be appropriate targets for intervention. Future research in this area might evaluate dominant ideologies and approaches in support worker education and work environments, and/or seek opportunities to increase awareness of disability studies perspectives in this field.

7.8.4 A relational approach to (self-managed) attendant services

Support worker education and work environments may be logical targets, but intervention at this level may be limited by broader structural issues affecting the people who perform support work. Research in Canada (Church et al., 2004; Cranford, 2005; Kelly, 2016) and in non-Canadian contexts (Ungerson, 1997b) suggests support work is often performed by members of marginalized groups. It is possible that the material conditions workers live in affect their capacity to perform support work. This research has emphasized the relational work of self-managing attendant services, a phenomenon which sees some self-managers and some attendants invest significant personal resources to support one another. To the extent that the well-being of self-managers and of attendants are fundamentally intertwined, understanding and attending to the lifeworlds of attendants may represent an important consideration. Future research in this area might seek to gain a better understanding of support work from the perspective of the people who perform it, and to better understand their working lives and needs.

7.9 References


Church, K., Diamond, T., & Voronka, J. (2004). In profile: personal support workers in Canada. Ryerson University: RBC Institute for Disability Studies, Research and Education.


Strazdins, L., Welsh, J., Korda, R., Broom, D., & Paolucci, F. (2016). Not all hours are equal: could time be a social determinant of health?” *Sociology of Health & Illness, 38*(1), 21-42.


Appendices

Appendix A: Recruitment materials

RECRUITMENT POSTER

INVITATION TO PARTICIPATE IN RESEARCH

- Do you or does someone you know use the direct funding program to fund support services? Are you a recipient, attendant, primary support personnel or someone who administers the program? If so, we would like to talk with you about your experiences and insights about the program.

- The Direct Funding Program administered by the Centre for Independent Living in Toronto (CILT) has served over 1,000 people in nearly 20 years since its inception. Little is known however about the experiences of direct funding recipients.

- You are invited to participate in a study at Western University that will explore the work that direct funding recipients, and those who provide direct-funding recipients with support, contribute to sustaining an individual’s attendant services. The goal of this study is to better understand the work of self-managing attendant services. The study results will be useful in the creation and maintenance of policy that remains relevant, effective and accessible.

- **We are currently looking for direct funding recipients, attendants and other primary support personnel, and program administrators to participate in this research.** You will be invited to participate in a 1-2 hour interview. Interviews will take place at your home, at Western University, or at another location of your choice that is suitable for a recorded interview.

- If you would like more information about this study or would like to receive a letter of information about this study please email ekatzma2@uwo.ca or phone (519) 719-0621.
LETTER OF INVITATION TO CILT/ILCLA

Dear [name removed to protect privacy],

The purpose of this letter is to inform you of a current research project entitled “Understanding the work of Self-Managed Attendant Services” and to request the support of CILT/ILCLA for the purposes of recruiting research participants to the study.

Please see the attached “Letter of Information” for a detailed description of the study.

The support of CILT/ILCLA is requested in the following way:

• Granting access to channels of advertisement that are likely to reach potential participants (i.e.—newsletters, physical and virtual poster space).

The study investigator, Erika Katzman, will be in touch by phone within the next 2 weeks to discuss the specifics of this request. If you require any further information regarding this research project or the assistance being requested please contact the study investigator, Erika Katzman (ekatzma2@uwo.ca), or Dr. Elizabeth Anne Kinsella, the co-investigator and supervising researcher (akinsell@uwo.ca). We look forward to connecting with you about this important project in the near future.

Erika Katzman, PhD Candidate, Health Professional Education Field,
Health and Rehabilitation Sciences Graduate Program,
Faculty of Health Sciences, Western University

ekatzma2@uwo.ca, (519) 719-0621
Appendix B: Interview guides

INTERVIEW GUIDE FOR ODF RECIPIENTS

At the start of the interview, any questions about the study will be discussed. A Letter of Information will be given to the participant, and written Informed Consent will be obtained. The interview guide will offer structure to the interview, however the interview will also be guided by the natural flow of conversation between the participant and the researcher.

Introduction

I am interested in hearing your thoughts, feelings and understandings about the ODF program, particularly the everyday activities and work that you undertake in your role as an ODF recipient. I have some prepared questions, but I’d like this interview to be flexible, and for us to have a discussion about your perspectives. If you have anything you would like to say as we begin I invite you to share any initial thoughts to get us started. Or if you prefer, we can begin with some questions that I would be interested in discussing with you.

Questions

1) In order for me to best understand the activities and work that you undertake as part of the program it would be helpful to hear about the areas of your everyday life that are supported by the program. Would you be comfortable sharing information about your disability and the areas in which you require support?

2) Could you tell me how you first became involved in the ODF program?
   a. How did you hear about it?
   b. What was the application process like?
   c. Was it difficult to get funding/approval?
   d. Was there a waiting list?

3) Could you tell me what your experiences have been like being involved in the ODF program?

4) What attracted you to the ODF program?
   a. Ie. Particular values? Convenience? Autonomy?

5) What type of work and activities do you do as part of the ODF program in a typical day? Can you describe these in detail?
   a. Examples? Managing attendants, scheduling activities, handling administrative aspects?
   b. What does a typical day look like for you?

6) What type of work and activities do attendants do to assist or support you in a typical day? Can you describe these in detail?
   a. Examples? toileting, dressing, meal preparation, computer assistance etc.
   b. What does a typical day look like for your attendants?

7) What work or activities does participation in the ODF program entail for you?
   a. What is it like to be the employer and manager of your attendants?
      i. Who are your attendants now?
      ii. Who have your attendants been in the past?
      iii. How do you find your attendants?
         1. If different, how have you found them in the past?
         iv. Does anyone else help out or provide support?
      b. What is involved in directing and interacting with attendants?
i. Can you give specific examples of what this involves in a typical day? Week? Month?
c. What other responsibilities does participation in the program require?
   i. When do you take care of these responsibilities?
   ii. How much time does it take?
   iii. How do you take care of these responsibilities?
   iv. Does anyone help you to take care of these responsibilities?
   v. What is it like to take care of these responsibilities?
   vi. How do you feel about these responsibilities?
8) Can you walk me through a typical day, including your interactions with attendants, and pointing out when and where you take care of any additional responsibilities you have described?
9) Does the funding you receive cover all of the support you require? If not, how else do you arrange for support?
10) Can you tell me what your overall impression of the ODF program is?
   a. How has it affected your everyday life?
11) If you think back to your understandings about the program before you became involved, has your perspective changed since being involved with the program? If so, how?
12) What do you think are the most important aspects of the program?
   a. Strengths?
   b. Challenges?
13) If you had the opportunity to make any changes you wish to the current program, what might they be?
14) Is there anything else you’d like to share with me that would help me to better understand the everyday activities and work that you and various parties undertake within the ODF program?
INTERVIEW GUIDE FOR ATTENDANTS AND PRIMARY SUPPORT PERSONNEL

At the start of the interview, any questions about the study will be discussed. A Letter of Information will be given to the participant, and written Informed Consent will be obtained. The interview guide will offer structure to the interview, however the interview will also be guided by the natural flow of conversation between the participant and the researcher.

Introduction

I am interested in hearing your thoughts, feelings and understandings about the ODF program, particularly the everyday activities and work that you undertake in your role as an attendant. I have some prepared questions, but I’d like this interview to be flexible, and for us to have a discussion about your perspectives. If you have anything you would like to say as we begin I invite you to share any initial thoughts to get us started. Or if you prefer, we can begin with some questions that I would be interested in discussing with you.

Questions

1) Could you describe your role in relation to the ODF program?
   a. How long have you been an attendant?
   b. How many people have you been employed by?
   c. What types of disabilities have your employers had?
   d. What types of disabilities do your current employers have?
   e. What does your role entail?
2) Can you tell me how you came to be an attendant/primary support personnel in an ODF funded situation?
3) Can you tell me what your experiences have been like as an attendant funded by the ODF program?
4) Is this role a job for you?
   a. How is it like other jobs you have had?
   b. How is it different from other jobs you have had?
   c. Who is your employer? Your manager?
   d. Do you have co-workers?
   e. What do you do if you are facing a challenge with your employer, manager, or co-workers?
   f. What do you do if you need time off? What if you are sick or have an emergency?
   g. Are you compensated for some or all of the time you spend at work? How?
   h. Where does the work take place? Where does the work take you?
5) Can you walk me through a typical day that you work, from when you arrive to when you leave?
   a. What kinds of things do you do to provide support?
   b. How do you know what to do and when?
   c. Do you spend time at work or with your employer for which you are not paid?
   d. What kind of guidance, training or supervision do you receive?
   e. Are there any aspects of your role that feel stressful? Can you describe these?
   f. Are there any aspects of your role that are particularly fulfilling?
6) What work and other activities does your employer do as part of the ODF program?
7) Can you tell me what your overall impression of the ODF program is?
   a. What is it like to work in this type of a program?
8) If you think back to your understandings about the program before you became involved, has your perspective changed since being involved with the program? If so, how?
9) What do you think are the most important aspects of the program?
   a. Strengths?
   b. Challenges?
10) If you had the opportunity to make any changes you wish to the current ODF program, what might they be?
11) If you had the opportunity to make any changes you wish to your current work situation what would they be?
12) Is there anything else you’d like to share with me that would help me to better understand the everyday activities and work that you and various parties undertake within the ODF program?
INTERVIEW GUIDE FOR PROGRAM ADMINISTRATORS

At the start of the interview, any questions about the study will be discussed. A Letter of Information will be given to the participant, and written Informed Consent will be obtained. The interview guide will offer structure to the interview, however the interview will also be guided by the natural flow of conversation between the participant and the researcher.

Introduction

I am interested in hearing your thoughts, feelings and understandings about the ODF program, particularly the everyday activities and work that support it’s operation. I have some prepared questions, but I’d like this interview to be flexible, and for us to have a discussion about your perspectives. If you have anything you would like to say as we begin I invite you to share any initial thoughts to get us started. Or if you prefer, we can begin with some questions that I would be interested in discussing with you.

Questions

1) Could you describe your role in relation to the ODF program?
   a. What are your roles and responsibilities?
   b. What kinds of activities do you typically do related to the program?
      i. Administrative? Policy? Involvement with participants?
   c. What does a typical day of work look like for you?
   d. What (if any) is your involvement with ODF recipients?
   e. What (if any) is your involvement with attendants?

2) Could you describe what your experiences have been like being involved in the ODF program?

3) Could you walk me through the process of applying to become a participant in the ODF program?
   a. What paperwork, process is involved?
   b. What are the criteria for acceptance into the program?
   c. Which qualities should a prospective self-manager demonstrate?
   d. Which qualities are likely to prevent acceptance to the program?
   e. Are there factors (i.e. situational, budget, political) outside of the individual’s determined ability to self-manage attendants that influence acceptance to the program?
   f. How are decisions made about eligibility? Who is involved in these decisions?

4) What attracts people to apply to the program?

5) Once accepted, how long do participants typically remain with the program?
   a. Under which circumstances, or for which reasons, do participants leave the program?

6) What type of activities or work are typically involved on a regular basis for participants (ODF recipients) in the program?

7) What type of activities or work are typically involved on a day to day for attendants who are hired through the program?

8) Can you tell me about any positive feedback you receive from program participants?

9) Can you tell me about any negative feedback you receive from program participants?

10) Do you ever interact with, or receive feedback from, people (i.e. attendants, family members, health practitioners) who support program participants? If so, what kind of feedback?

11) Can you tell me what your overall impression of the program is?
12) If you think back to your knowledge or feelings about the program before you became involved, has your perspective changed since being involved with the program? If so, how?

13) What do you think are the most important aspects of the program?
   a. From an administrative perspective?
   b. For program participants?
   c. From a societal or disability rights perspective?

14) Who funds the ODF program, and in your opinion is the funding adequate to meet the needs?

15) If you had the opportunity to make any changes you wish to the current program, what might they be?

16) Is there anything else you’d like to share with me that would help me to better understand the everyday activities and work that various parties undertake within the ODF program?
Appendix C: Quirkos canvas
Appendix D: Ethical approval

Western Research
Western University Non-Medical Research Ethics Board
NMREB Amendment Approval Notice

Principal Investigator: Dr. Anne Kinnelle
Department & Institution: Health Science/Occupational Therapy, Western University

NMREB File Number: 166995

Study Title: An investigation into the work of self-managed attendant services in the lives of people with disabilities: A reflexive ethnographic study (Buy 10: Understanding the work of Self-Managed Attendant Services)

Sponsor:

NMREB Revision Approval Date: February 22, 2016
NMREB Expiry Date: May 28, 2016

Documents Approved and/or Received for Information:

<table>
<thead>
<tr>
<th>Document Name</th>
<th>Comments</th>
<th>Version Date</th>
</tr>
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<tbody>
<tr>
<td>Revised Western University Protocol</td>
<td></td>
<td>2016/01/06</td>
</tr>
<tr>
<td>Revised Letter of Information &amp; Consent</td>
<td></td>
<td>2016/01/06</td>
</tr>
</tbody>
</table>

The Western University Non-Medical Science Research Ethics Board (NMREB) has reviewed and approved the amendment to the above named study, as of the NMREB Amendment Approval Date noted above.

NMREB approval for this study remains valid until the NMREB Expiry Date noted above, conditional to timely submission and acceptance of NMREB Continuing Ethics Review.

The Western University NMREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the Ontario Personal Health Information Protection Act (PHIPA, 2004), and the applicable laws and regulations of Ontario.

Members of the NMREB who are named as investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The NMREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000941.

Ethics Officer/Chair of Riley Himon, NMREB Chair

This is an official document that contains the original as your file.
Date: 30 April 2018
To: Dr. Anne Kinsella
Project ID: 106095

Study Title: An investigation into the work of self-managed attendant services in the lives of people with disabilities: A reflexive ethnographic study (Lay title: Understanding the work of Self-Managed Attendant Services)

Application Type: Continuing Ethics Review (CER) Form

Review Type: Delegated

Meeting Date: May 4, 2018
Date Approval Issued: 30/Apr/2018
REB Approval Expiry Date: 28/May/2019

Dear Dr. Anne Kinsella,

The Western University Research Ethics Board has reviewed the application. This study, including all currently approved documents, has been re-approved until the expiry date noted above.

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University NMBREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the Ontario Personal Health Information Protection Act (PHIPA, 2004), and the applicable laws and regulations of Ontario. Members of the NMBREB who are named as investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB. The NMBREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000041.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Daniel Wypnowski, Research Ethics Coordinator, on behalf of Prof. Randal Graham, NMBREB Chair

*Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).*
Appendix E: Letters of information

LETTER OF INFORMATION FOR DIRECT FUNDING RECIPIENTS

Study Title: Understanding the Work of Self-Managed Attendant Services

Study Investigator:

Erika Katzman, PhD Candidate, Health Professional Education Field,
Health and Rehabilitation Sciences Graduate Program,
Faculty of Health Sciences, Western University
Email: ekatzma2@uwo.ca; Phone: 519-719-0621

Co-Investigator and Supervisor:

Dr. Elizabeth Anne Kinsella, PhD, Associate Professor,
School of Occupational Therapy, Health Professional Education Field,
Health and Rehabilitation Sciences Graduate Program,
Faculty of Health Sciences, Western University
Email: akinsell@uwo.ca; Phone: 519-661-2111 x81396

Invitation to Participate
Thank you for expressing interest in this study. You are being invited to participate in research on self-managed attendant services (SMAS) in Ontario. This research looks at the work that various people (direct funding recipients, attendants, friends, families, etc.) do to help manage attendant services. You are being invited to participate in this research project because of your first hand knowledge of self-managed attendant services and your experiences with the program. Your participation will help to advance knowledge about the work of SMAS.

Purpose of this Letter
The purpose of this letter is to provide you with information required for you to make an informed decision regarding participation in this research.

Purpose of the Study
Currently, little is known about direct funding recipients’ experiences self-managing attendant services. This study will explore the work that direct funding recipients, and those who provide direct funding recipients with support, do to help manage attendant services. The goal of this study is to better understand the work of self-managing attendant services, and to inform the creation and maintenance of policy that is relevant, effective and accessible. It is anticipated that the research findings will provide critical insights to be used in the future development of self-managed support services.

Inclusion Criteria
To participate in this study, you must: be at least 21 years of age; be able to read, comprehend and communicate in English; have participated in the Ontario Direct Funding program for at least 2 years as (1) a self-manager, OR (2) as an attendant/primary support personnel to at least one self-manager, OR (3) in an administrative capacity for at least 1 year. Participants will be sought who have extensive and/or varied experience with the self-managed model of attendant services.

Exclusion Criteria
To protect privacy and confidentiality between support personnel and self-managers, individuals who currently support or have ever supported a self-manager who is already participating in the...
study are not eligible to participate in this study. Likewise, self-managers are not eligible to participate if anyone who they have ever employed as a support person is already participating.

**Study Procedures**
In order to understand the work you do, ODF recipients will be asked to take part in two interviews.

*Initial Interview*
The purpose of the initial interview is to explore your thoughts and feelings about the work that is involved in SMAS. The study investigator will guide the interview with pre-planned questions. You may choose to answer only those questions you feel comfortable with, and you will be invited to share any additional relevant information you wish to contribute. The initial interview will last approximately 2 hours and will be conducted in your current place of residence, or at a negotiated location of your choice that is suitable for a recorded interview. Demographic data, including your age, education, employment history, and length of time involved with the program will also be collected.

*Follow-up Interview*
The purpose of the follow-up interview is to discuss any topics that there was insufficient time to address in the initial interview, and to address any questions arising out of the first interview. As in the initial interview, the researcher will guide the interview with pre-planned questions. You may choose to answer only those questions you feel comfortable with, and you will be invited to share any additional relevant information you wish to contribute. The interview will last approximately 1 hour, and will take place in your current place of residence or at another negotiated location of your choice.

All interviews will be audio recorded to assist the researchers in accurately representing your perspectives. You may however request that the audio recording be stopped at any time.

**Possible Risks of Participation in the Study**
The anticipated risk to participants is extremely low. As in all research, it is possible that talking about your experiences may bring up thoughts and feelings that you find distressing. Should this occur, we would stop the interview until you feel comfortable continuing, cease the interview altogether, or re-book the interview for another time.

**Possible Benefits of Participation in the Study**
The information you share will be presented to policy makers and administrators who direct ODF programs, and to others through research briefings, presentations at conferences, and publications in scholarly journals. In this way, you may help to influence future development of services, programs and policy. The long-term benefits of the study are unknown, and it is possible that you will not experience any direct benefit from participation in this study.

**Compensation**
An honorarium of $50 will be provided to thank you for contributing your time and insights to this study. If you need to withdraw prior to completion of the study, 50% of the honorarium will be paid.

**Voluntary Participation**
Participation in this study is completely voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time. If you choose to withdraw, you
may choose if you would like the information you have provided so far to be destroyed, or if that information is okay to use in the final report.

**Privacy and Confidentiality**
All information is treated in a completely confidential manner. Your privacy and confidentiality are assured in this study, and an alias name will be assigned to everything you share with the researchers. If the results of the study are published or presented, no identifying information will be used.

Your information will never be shared with anyone who is not a part of the research team. This research is not affiliated with the Centre for Independent Living Toronto, the Independent Living Centre London & Area or the Ontario Direct Funding program. A decision to participate or decline to participate in this study will in no way affect your access to services offered by these organizations.

Representatives of The Western Non-Medical Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

**Contacts for Further Information**
Thank you for your consideration of participation in this study. If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Research Ethics [519] 661-3036, email: ethics@uwo.ca.

If you require any further information regarding this research project or your participation in the study you may contact Erika Katzman, the study investigator (ekatzma2@uwo.ca) or Dr. Elizabeth Anne Kinsella, the co-investigator and supervising researcher (akinsell@uwo.ca).
LETTER OF INFORMATION FOR ATTENDANTS AND PRIMARY SUPPORT PERSONNEL/PROGRAM ADMINISTRATORS

Study Title: Understanding the Work of Self-Managed Attendant Services

Study Investigator:
Erika Katzman, PhD Candidate, Health Professional Education Field, Health and Rehabilitation Sciences Graduate Program, Faculty of Health Sciences, Western University
Email: ekatzma2@uwo.ca; Phone: 519-719-0621

Co-Investigator and Supervisor:
Dr. Elizabeth Anne Kinsella, PhD, Associate Professor, School of Occupational Therapy, Health Professional Education Field, Health and Rehabilitation Sciences Graduate Program, Faculty of Health Sciences, Western University
Email: akinsell@uwo.ca; Phone: 519-661-2111 x81396

Invitation to Participate
Thank you for expressing interest in this study. You are being invited to participate in research on self-managed attendant services (SMAS) in Ontario. This research looks at the work that various people (direct funding recipients, attendants, friends, families, etc.) do to help manage attendant services. You are being invited to participate in this research project because of your first hand knowledge of self-managed attendant services and your experiences with the program. Your participation will help to advance knowledge about the work of SMAS.

Purpose of this Letter
The purpose of this letter is to provide you with information required for you to make an informed decision regarding participation in this research.

Purpose of the Study
Currently, little is known about direct funding recipients’ experiences self-managing attendant services. This study will explore the work that direct funding recipients, and those who provide direct funding recipients with support, do to help manage attendant services. The goal of this study is to better understand the work of self-managing attendant services, and to inform the creation and maintenance of policy that is relevant, effective and accessible. It is anticipated that the research findings will provide critical insights to be used in the future development of self-managed support services.

Inclusion Criteria
To participate in this study, you must: be at least 21 years of age; be able to read, comprehend and communicate in English; have participated in the Ontario Direct Funding program for at least 3 years as (1) a self-manager, OR (2) as an attendant/primary support personnel to at least one self-manager, OR (3) in an administrative capacity for at least 1 year. Participants will be sought who have extensive and/or varied experience with the self-managed model of attendant services.

Exclusion Criteria
To protect privacy and confidentiality between support personnel and self-managers, individuals who currently support or have ever supported a self-manager who is already participating in the
study are not eligible to participate in this study. Likewise, self-managers are not eligible to participate if anyone who they have ever employed as a support person is already participating.

**Study Procedures**

All study participants will take part in an audio-recorded individual interview. The purpose of this interview is to explore in detail your thoughts and feelings about the work that is involved in self-managed attendant services. The study investigator will guide the interview with a set of pre-planned questions. You may choose to answer only those questions you feel comfortable with, and you will be invited to share any additional relevant information you wish to contribute. All interviews will be audio recorded to assist the researchers in accurately representing your perspectives. You may however request that the audio recording be stopped at any time. The interview will last approximately 2 hours and will be conducted at a negotiated location of your choice that is suitable for a recorded interview. Demographic data, including your age, education, employment history, and length of time involved with the program will also be collected.

**Possible Risks of Participation in the Study**

The anticipated risk to participants is extremely low. As in all research, it is possible that talking about your experiences may bring up thoughts and feelings that you find distressing. Should this occur, we would stop the interview until you feel comfortable continuing, cease the interview all together, or re-book the interview for another time.

**Possible Benefits of Participation in the Study**

The information you share will be presented to policy makers and administrators, and to others through research briefings, presentations at conferences, and publications in scholarly journals. In this way, you may help to influence future development of services, programs and policy. The long-term benefits of the study are unknown, and it is possible that you will not experience any direct benefit from participation in this study.

**Compensation**

An honorarium of $25 will be provided to thank you for contributing your time and insights to this study.

**Voluntary Participation**

Participation in this study is completely voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time. If you choose to withdraw, you may choose if you would like the information you have provided so far to be destroyed, or if that information is okay to use in the final report.

**Privacy and Confidentiality**

All information is treated in a completely confidential manner. Your privacy and confidentiality are assured in this study, and an alias name will be assigned to everything you share with the researchers. If the results of the study are published or presented, no identifying information will be used.

Your information will never be shared with anyone who is not a part of the research team. This research is not affiliated with the Centre for Independent Living Toronto, the Independent Living Centre London & Area or the Ontario Direct Funding program. A decision to participate or decline to participate in this study will in no way affect your employment status as an attendant.

Representatives of The Western Non-Medical Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

**Contacts for Further Information**
Thank you for your consideration of participation in this study. If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Research Ethics, email: ethics@uwo.ca.

If you require any further information regarding this research project or your participation in the study you may contact Erika Katzman, the study investigator (ekatzma2@uwo.ca) or Dr. Elizabeth Anne Kinsella, the co-investigator and supervising researcher (akinsell@uwo.ca).
Appendix F: Consent form

PARTICIPANT CONSENT FORM

Title of Study: Understanding the Work of Self-Managed Attendant Services

CONSENT STATEMENT:

☐ I have read the Letter of Information and I agree to participate. All questions have been answered to my satisfaction. I will receive a signed copy of this form.

☐ I consent to be audio recorded during interviews.

☐ I understand that by signing this consent form I do not waive my legal rights.

________________________________________
Participant Name

________________________________________
Participant Signature

Date

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Curriculum Vitae

Erika Katzman

EDUCATION

**Doctor of Philosophy**, Health and Rehabilitation Sciences  
*Western University, London, Canada*  
Field of study: Health Professional Education  
Supervisor: Dr. Elizabeth Anne Kinsella  
Advisors: Dr. Pamela Cushing, Dr. Shanon Phelan, Dr. Jessica Polzer  
2011 – 2018

**Master of Science**, Occupational Therapy  
*Western University, London, Canada*  
Concurrent MScOT/PhD model, graduated with honours as class Valedictorian  
2013 – 2015

**Bachelor of Arts**, Honours Specialization in Critical Social Sciences  
*Trinity College, University of Toronto, Toronto, Canada*  
Majors: Social-Cultural Anthropology, Latin American Studies  
Minor: Sexual Diversity Studies  
2003-2007

SCHOLARSHIPS & AWARDS

Social Sciences and Humanities Research Council of Canada (SSHRC)  
Doctoral Award (2 years, $20,000 per year)  
2015 – 2017

Western University Graduate Research Scholarship  
(5 years, $19,000 per year)  
2011 – 2016

REFEREED PUBLICATIONS


**learning and education** (pp. 157-172). Dordrecht, NL: Springer.

**REFEREED CONFERENCE PRESENTATIONS**


TEACHING EXPERIENCE

**Instructor,** Disability Studies Undergraduate Program  
*King’s University College, London, Canada*  
DS 1010 – Exploring Disability  
DS 2201 – Rethinking Disability  
DS 3312 – Diverse Disability Studies Perspectives  
DS 3395 – Disability Studies and the Applied Health Fields  
2017 – Present

**Instructor,** Graduate Diploma in Applied Health Sciences  
*Western University, London, Canada*  
GRDIPAHS 9001 - Critical Thinking and Critical Analysis in Health Sciences  
2018 – Present

**Instructor,** Centre for Teaching and Learning  
*Western University, London, Canada*  
Teaching Assistant Training Program  
2018 – Present

**Instructor,** School of Occupational Therapy (MScOT Program)  
*Western University, London, Canada*  
OT 9642 – Practice in Context II (Community Development and Social Action Module)  
2017

**Teaching Assistant,** Faculty of Rehabilitation Medicine  
*University of Alberta, Edmonton, Canada*  
REHAB 599 – Qualitative Inquiry: Philosophical Foundations and Contemporary Approaches  
2017

**Teaching Assistant,** Disability Studies Undergraduate Program  
*King’s University College, London, Canada*  
DS 1010 – Exploring Disability  
2016

**Teaching Assistant,** School of Health Studies  
*Western University, London, Canada*  
HS 1002 – Introduction to the Social Determinants of Health  
2012

**Teaching Assistant,** School of Occupational Therapy (MScOT Program)  
*Western University, London, Canada*  
OT 9511 – Foundations of Occupational Science and Occupational Therapy  
2011

RESEARCH EXPERIENCE

**Qualitative Data Analyst,** School of Health Studies  
*Western University, London, Canada*  
2017 – Present

**Research Assistant,** School of Occupational Therapy  
*Western University, London, Canada*  
2014 – 2015
Research Assistant, Laboratory for the Investigation of Reflection in Everyday Occupation and Professional Life  
*Western University, London, Canada*  
2012 – 2013

**ADDITIONAL QUALIFICATIONS**

Registered Occupational Therapist – OT Reg (Ont.)  
*College of Occupational Therapists of Ontario*  
2016 – Present

**Western Certificate in University Teaching and Learning**  
*Centre for Teaching and Learning, Western University*  
2018

Graduate Studies 9500: The Theory and Practice of University Teaching  
*Centre for Teaching and Learning, Western University*  
2017

Teaching Assistant Training Program  
*Centre for Teaching and Learning, Western University*  
2015

**VOLUNTEER AND SERVICE WORK**

**Peer Review**  
Canadian Journal of Disability Studies  
2018

Occupational Therapy Journal of Research  
2016

**Abstract Review**  
Canadian Association of Occupational Therapists Annual Conference  
2017 – 2018

Council of Occupational Therapists for European Countries and European Network of Occupational Therapy in Higher Education Congress  
2016

Health and Rehabilitation Science Graduate Research Forum (Western University)  
2013

**Committee Membership**  
School of Occupational Therapy Curriculum Committee  
2013 – 2015