DISABLED YOUNG PEOPLE, SUPPORT AND THE DIALOGICAL WORK OF
ACCOMPLISHING CITIZENSHIP

by

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A thesis submitted in conformity with the requirements
for the degree of Doctor of Philosophy
Graduate Department of Public Health Sciences
University of Toronto

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ABSTRACT

Governments, human rights bodies and disability studies scholars all have suggested that disabled people’s citizenship – the legal status and lived practices that enable membership, participation and belonging in one’s community - depends on consistent, adequate and readily available home and personal supports. Yet, little theoretical or empirical work examines disabled young people’s citizenship or their use of support, particularly from their standpoints. Consequently, the ‘work’ disabled young people do to accomplish citizenship remains unrecognized, as are their unique requirements for support to do that work. Normative non-disabled citizenship assumptions remain unproblematized.

This study explores what disabled young people do to accomplish citizenship, using home and personal support as the empirical foci. I used a dialogic theoretical and methodological approach, drawing on Mikhail Bakhtin and Dorothy Smith. Both posit that our talk, consciousness and actions respond to and anticipate the voices of others. Through participatory media arts techniques with disabled young people, ethnographic observation and interviews with gatekeepers to formal and informal care, I describe the work that a group of disabled young people did to secure and maintain support and how this in turn shaped their opportunities for
specific citizenship practices: self-determination, community participation and social contribution.

I argue that disabled young people's work to secure and maintain support requires that they mobilize the authoritative discourse of 'the poster child': a set of objectified values and views encapsulated in utterances about disabled people as futureless, deficient and deferential, originating in images to promote charitable giving. I trace three sequences of activities in which participants assimilated, resisted or brought poster child utterances into ‘dialogue’.

The findings raise questions about the extent to which formal entitlements to supports influence how citizenship is lived. Drawing attention to the gaps and tensions in support provision, the findings illuminate the tremendous invisible, tacit work these participants do to strengthen fragile supports. This work, organized by philanthropic rather than rights discourses, leads to a qualified or fragile citizenship. Finally, the study raises questions about the normative and material demands that we may all experience with respect to achieving citizenship, regardless of disability or age.
Acknowledgements

As doctoral journeys go, mine has been long and circuitous. It has taken me many years to get here, but my travels have been easier in the company of generous mentors, colleagues, friends and family.

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CHAPTER 1
Introduction

Introduction

Situated in the heart of Toronto’s Fashion District, 401 Richmond West – a former garment factory turned grassroots community arts centre – has become the new home of the Poster Child Shoots Back Project. Moving through its ‘shabby chic’ halls, you can imagine the rows of immigrant women bent over their machines, producing Canadian women’s business attire. But these are only traces of the past, memorialized with gargantuan sculptures of sewing supplies – buttons, bobbins and spools of thread – on the street below. Production and consumption relations are still at work here – but material production has evolved into cultural production. Now, tucked in darkened corners are cultural workers – again immigrant women, but also aboriginal, racialized, queer peoples. They bend over computer screens, crafting images of exclusion, marginalization, resistance, subversion and transformation. Poorly remunerated, juggling creative work with contingent part-time service employment, cultural workers contribute to the appeal of the city – creating interesting oases for tourists and residents. They craft opportunities for people to feel at once adventurous, conscientious and worldly. Their work gets taken up by mainstream media, smoothed over and tamed for mainstream consumption.
‘I can’t believe I’m here’ breathed Douglas as he wheeled down the corridor. Kai, his support worker for the day, pushes the button for the elevator. Together we wait. (field notes)

The overarching narrative of this dissertation follows the path that took 18 disabled young people, their peers, a research team and me from Dream Town, an iconic recreation centre at the heart of Canada’s disability charity industry, to the galleries of 401 Richmond St. West, a sowing ground for Toronto’s arts and culture industry. Much of the content of this dissertation is based on the activities of the Poster Child Shoots Back project, a three-year media arts workshop in which a group of disabled young people conceptualized, created and disseminated artistic videos about support. This is not a dissertation about arts and culture however, but about the work these young people do to accomplish citizenship. The Poster Child project began through my interest in the relationship among young people, disability and citizenship and with my own experience with support.

The excerpt above comes from my field notes at about the halfway mark of the Poster Child project. I use it to open the dissertation because it is an instance of citizenship in practice. These notes captured a critical juncture within the project, in which participants moved from the academic research setting to a more public space. A group of young people were moving beyond their usual arenas of family, special programs and paediatric clinical settings. As the first disabled artists to find themselves in the halls of 401 Richmond, they seemed to fulfill the promise of citizenship: they were literally joining broader cultural life and were poised to autonomously, innovatively and publicly voice their concerns through their cultural contributions. But even at the threshold of citizenship, Douglas was not always able to fully grasp its promise. Like the immigrant workers before him, and other artists there now, Douglas worked hard to achieve what could only be understood as marginal, fragile citizenship.

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1 All participant names and names of support and agency staff are pseudonyms. The names of research team members, Nas Khan and Rita Chu, and the names of Trinity Square Video staff, Roy Mitchell and Aileen McBride, have not been changed.
2 Not the real agency name.
3 This is the actual name of the organization. The organization was aware that their name would be reported in this thesis.
4 As will become apparent throughout the dissertation, this project proceeded with a loose understanding of support as referring to formal and informal supports for the activities of daily living. However, the notion of support was deliberately kept open to be filled with the meanings and activities of participants.
In order to participate in this project, like any part of everyday life, disabled participants required considerable supports. Almost invisible in the vignette above is the presence of support workers. Douglas, who had only limited mobility (in one arm) as a result of Duchenne’s muscular dystrophy, required assistance for many aspects of his everyday life, including the project.

Personal support, also known in Canada as personal assistance and attendant care, is comprised of non-medical care that allows disabled people to take part in the activities of daily living. Unlike more broadly used social citizenship rights\(^5\) such as education or hospital-based care, support tends to be used by a ‘unique’ subset of civil society and thus “ideally serves as a social arena to observe how states, civil societies and individual particularity come together” (Werbner & Yuval-Davis, 1999:7). Examining the work of securing such rights provides insight into the tasks of becoming a citizen. Using support as an exemplar of social rights within the Canadian neoliberal welfare state, this dissertation broadens the conventional view of citizenship as a formal institutional status primarily concerned with redistribution of resources within civil society. As I will argue, citizenship is not simply bestowed upon someone; it is accomplished, through work that concerts with the work of others.

**The problem of support**

In Canada, disabled people receive support for daily living in a variety of ways. Most disabled people (approximately 78\%) receive some level of support through informal care provided by family, friends and volunteers (Galvin, 2004), which may or may not supplement formal publically funded home support. Many others live independently in the community through either a small number of agency-directed or consumer-directed publically funded personal support services. Others remain in long-term stay institutions or other forms of both public and private supported congregate living situations (e.g. group homes, nursing homes, etc.).

Despite the wide array of supports they use, Canadian and international research indicates that many Western disabled people continue to have unmet support needs (Clark et al., 2008; Hagglund et al., 2004a; Hagglund et al., 2004b; Krogh, 1999; Matthias & Benjamin, 2008; OCSA, 2008). Michael Prince (2004) has argued that current gaps within support services will

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\(^5\) From here on in, I will refer to social citizenship rights as social rights. These are defined in *Chapter 2*. 

widen with the demands wrought by several social changes in Western industrialized countries. Small families may be less able to provide informal support as in the past, while aging populations and further deinstitutionalization of disabled persons from facilities into communities will increase those requiring supports. Moreover, changes in the labour market brought about by the needs of an emerging high technology and knowledge economy create new demands for personal supports not previously encountered. At the same time, some disabled people are excluded from higher education and employment, have decreased capacity to acquire supports through alternate means, such as workplace accommodations or the private market. Furthermore, Canadian demands for a more flexible and responsive health care system will stretch health and social care dollars such that personal supports may not be a health or social policy priority.6

Disability rights groups continue to name these social and political responses to the support needs of disabled people as incursions into their citizenship (Kelly, 2010; Morris, 2005). In recent years those affected by the provision of support have organized for policy changes. Among disabled adults, the lack of consistent, adequate and universally available supports have been identified as a serious obstacle to the achievement of social rights of full citizenship (Beckett, 2007; Morris, 2005; Prince, 2004; 2009). Disabled adults organized and aligned their personal struggles within the larger socio-political discourse of welfare state retrenchment (Maxwell, 2001; Aronson, 2001). Similarly, informal caregivers, who provide unpaid support to disabled people on the basis of familial or voluntary ties, have viewed this work as located within changing notions of social citizenship. Like disabled adults, informal caregivers have articulated their experiences within a broader political economic context – as shaped by gender (Graham 1993; Kershaw 2010; Sevenhuijsen 1998), class (Ungerson, 1999; Armstrong et al., 1994) and race/migration relations (Anderson, 1998; Staslius 2008).

Young people with disabilities, however, have been unable to frame their experiences with personal support and social care policy in the same way, if at all. This absence reflects

6 In the wake of these social changes, some troubling responses and new forms of transinstitutionalization have appeared. Disabled people are being incarcerated within the criminal justice system in high numbers. The number of homeless people in both urban and rural areas have increased. A recent study indicated that the number of young and middle-aged disabled people in Canadian nursing homes remains high at approximately 8,500 (Priest, 2004). The OCSA (2008) reported that in Ontario, 20% or 1/5 of residents of hospital based continuing care facilities are under the age of 65.
young people’s doubly marginalized social locations as young and disabled. Until recently, all children and youth have been excluded from discussions of citizenship. Because of their discursive characterization within policy as dependent, vulnerable and less competent, young people have been viewed as “not-yet-citizens” (Wyness, 2000), “future citizens” (Lister, 2007a; Roche, 1999; O’Neill, 1994), and “citizens-in-the making” (Hall & Coffey, 2007; Armstrong, 1983). Many contemporary scholars have argued against this since the 1990s. Numerous efforts including youth councils, citizenship education, and youth engagement initiatives have attempted to foster the voice and participation of young people as citizens in the polity. Nevertheless, young people’s claims to and exercise of citizenship remain constrained on the basis of their young age. Disabled young people lack even this hope of future citizenship, traditionally regarded as unable to participate in paid production or social reproduction labour. Young people – particularly those with disabilities - have thus been embedded within the family (Makrinioto, 1997; Moosa-Mitha, 2005; Sgritta, 1997) – the major site of their socialization as young citizens. Social policy reform then, has rarely been seen as affecting them directly but remains committed to examining needs through the family or other adults, such as teachers, youth workers and so forth. In the past, their own views have been discounted as inexperienced and poorly informed. Furthermore, young people’s relatively powerless social status, among other factors, makes it difficult for them to organize around their own concerns (Lister et al., 2005; Hoikkala, 2009), a situation that is only exacerbated as they enter their teenage years. Any form of collective organizing among them is characterized as tantamount to ‘trouble-making’ (Valentine, 2001), potentially threatening to the social order and therefore is actively discouraged or regulated by adult authorities (Hart, 2009; Horgan et al., 2000).

As a result of young people’s disempowered social position, there is little research that focuses specifically on their experiences of support, and none that explores support and young people’s citizenship. Although the amount of data is small, young people with disabilities have spoken to their curtailed involvement in home, school and extra-curricular life, and to their difficulty securing and maintaining formalized support in carrying out “regular” activities (Lister et al., 2005; Morris, 2004; Priestley, 1999; Skar & Tham, 2001).

We are left with many questions about disabled young people’s use of supports. What supports do they use? What activities do they engage in, in order to negotiate, secure and manage supports as they garner greater formal citizenship status? Given that their families have been
largely responsible for managing and providing support as they moved through childhood and adolescent years, what knowledges and practices must young people acquire in order to get and keep support? Finally, how does the work of acquiring and managing support allow disabled young people to practice and accomplish citizenship?

**The research process and chapter overview**

This dissertation accomplishes several goals. First, it contributes to the empirical data about disabled people’s work of obtaining both formal and informal support to carry out their day-to-day activities. Second, personal support is used as an exemplar through which to empirically examine conventional notions of citizenship. Because support is interwoven with disabled young people’s everyday lives, in both formal and informal ways, I had many opportunities to observe young people articulate their needs and negotiate the organization of available support resources. Central to these practices is the concept of ‘dialogue’ – adapted from Mikhail Bakhtin’s (1981; 1986) theories of language. The dialogical nature of securing, negotiating and maintaining support is highlighted throughout the thesis – in order to map how requests for citizenship are made and re-made in everyday life.

“*The Poster Child Shoots Back Project*”: An overview

In 2001, I was approached by Dr. Kari Krogh, then a senior post-doctoral fellow in the newly formed School of Disability Studies at Ryerson University in Toronto. She had recently completed a video action research project ‘Beyond Four Walls’ (2001) addressing the impact of changes in British Columbia to home support provision to disabled people. Knowing my interest in disabled young people’s concerns in the same area, Dr. Krogh invited me to develop my thesis with an eye to future collaboration. After revising her video action method to fit with my theoretical orientation and substantive interests, I began to consider developing a set of media arts workshops in which disabled young people would produce a video documenting their concerns with home and community care. Dr. Krogh and I agreed that the final video(s) emerging from this project would ‘belong’ to her larger participatory policy review. The video documentary would be posted on a website, along with other visual images generated in different parts of her research. These videos would then be used to raise awareness and discussions among other disabled people. My project, “*The Poster Child Shoots Back*”, would guide and
I set out to develop two sets of networks which would eventually shape the direction of the project. Although I was not particularly artistic, nor well connected to the arts community in Toronto, I often frequented grassroots, community-based and alternative arts events. I began to approach artists whose work took up issues of the body, disability or youth. I was particularly interested in video and other forms of video art, but tried to remain open to the possibilities afforded by other genres.

Over the winter and spring of 2002, I made a number of strong connections with video artists in the queer, Asian, immigrant and labour arts communities. Within each of these communities, individuals shared their experiences of creating collective documentary work and working with young people in particular. I synthesized their experiences and strategies into a tentative workshop design. I had initially hoped to similarly bring together disabled young people to create a short documentary about support. But unlike the community projects I encountered, this workshop was also intended to be a forum for social investigation, critical education and potential social action around issues of home and community care.

By the late spring of 2002, I embarked on two lines of work. First, I hired Nas Khan, a video artist and teacher who had co-ordinated the Inside/Out Queer Youth Digital Video Project in Toronto, to help me lead the media arts workshops. I also hired an undergraduate student project assistant, Rita Chu, who helped me with participant recruitment and running the workshops.

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7 I found that most artists do not take up disability directly, but did reference ‘bodies’ in their work. As an audience for this work, I found numerous resonances with disability politics and culture.
At the same time, I began meeting with individuals who worked with disabled young people. These connections were fairly broad at first – I met with the directors of children’s treatment centres and a recreation centre serving primarily disabled members, the coaches of disabled sports teams, a host of ‘front-line’ workers – social workers, nurses, rehabilitation specialists – and leaders of grassroots disability and youth organizations. These meetings allowed me to promote the project to potential gatekeepers to disabled young people. They also provided valuable insight into the organization of community support services and allowed me to learn about the dominant primary organizing texts that are mobilized in institutional practices with young people. A discussion of these insights appears in Chapter 5.

Planning the workshop structure

Three groups of disabled young people were brought together over as many years, to take part in a series of media arts workshops. The first of these took place weekly for a three-month period from June to September 2002, and then met sporadically for the following 18 months. This ‘pilot workshop’ set out to explore the potential and feasibility of using participatory media-based techniques. The second workshop series incorporated some learnings from the pilot series and were designed to explore the research questions in greater depth. This second workshop series began in November 2002, meeting regularly for 18 months. As this second workshop series was underway, the participants began to raise concerns around the sustainability of the project. Many expressed an interest in pursuing new projects and more deeply exploring themes raised in their current videos. As well, disabled young people who were on the periphery of the project, mostly as actors and assistants to the participants in the second workshop series, were keen to try their hand at video art and persistently requested that Nas and I mount a third workshop series. At that point in the project, the workshops had moved from Ryerson University to Trinity Square Video (TSV). Nas and I made this move in order to use TSV’s editing equipment and to begin to connect workshop participants with other community artists. The executive director at Trinity Square Video, Roy Mitchell, also had concerns about how to support disabled participants within the organization. Together, Roy Mitchell and I decided to apply for funding for a third ‘transitional’ workshop series which I initially coordinated and

8 A fuller discussion of the sample and recruitment methods appears in Chapter 3.
gradually transferred responsibilities to participants and TSV staff. Consequently, the final workshop was less closely attached to the original goals of the project as young people moved to separate themselves from the academic research and assumed a working relationship with TSV.

Each workshop session was structured to provide both technical and artistic instruction and a space for dialogue and sharing stories. Work by other young and disabled artists was shown to the group and used as an opportunity to think about how to express one’s story through visual media and as a means to introduce the various ways to construct a video more generally. As much as possible, participants were given hands-on instruction with the camera equipment. Following Freirean principles of teaching, participants were encouraged to use their own experiences as material upon which to practice their newly acquired skills in video and media techniques. In the process, participants would be able to describe and document their experiences afresh, opening them up to renewed reflection.

Community Screenings

Over the three workshop series, participants created sixteen short videos. Participants organized two separate public screenings of their videos. Participants from the first and second workshops curated and presented their eleven videos to family, friends, members of the disability community and other human rights workers and academics. This event was attended by approximately 200 people and received coverage in the disability, alternative and mainstream press. The second screening was hosted by Trinity Square Video in late 2005 and was targeted to an audience composed primarily of artists and curators, in keeping with the curatorial practices of 401 Richmond St Cultural Arts Centre where TSV was housed. This screening was designed to promote individual works in order to be selected for gallery or film festival screenings. The videos from all three workshops have been screened singly and in combination in a number of settings including community agencies, university classrooms, conferences, curated gallery exhibitions and juried local and international film festivals. Three films have appeared regularly on cable television stations, including MuchMusic’s and Showcase’s Shameless Shorts.

In this section I have briefly sketched the Poster Child Shoots Back project in order to provide the reader with a context for the data and analysis that follows. I will discuss the

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9 Fifteen participants created individual videos. The sixteenth video was created as a collaboration between two friends.
methodological considerations related to this project in more detail in Chapter 3. I now move on to provide an overview of the dissertation.

Overview of the chapters

The dissertation is separated into 9 main chapters. In Chapter 1 I have provided a brief introduction to the empirical focus of the study and the media workshop design that provided much of the context for data ‘production’ and collection. Chapter 2 provides a rationale for studying the work of accomplishing citizenship. I begin with a rationale for situating the study in relation to the empirical and theoretical scholarship. I lay out the theoretical orientation of the study and the research design in Chapter 3. Because the interdisciplinary fields informing this study have no single theoretical basis, I drew upon materialist ontological strands from each. In the first part of Chapter 3, I outline the research question and objectives that guided the research followed by the methodological orientation of the study. Since this was part of a larger participatory policy analysis research project originally led by Dr. Kari Krogh, I outline the methodological considerations when carrying out any participatory work in which participants are considered expert-knowers and co-researchers. In this section, I also outline my position as a researcher both in relation to the study participants and to the substantive topic of the research. I then discuss the research methods – an amalgam of arts-informed techniques, participant observation and dialogical interviewing.

Chapter 4 provides a brief overview of the formal and informal supports available to the participants in this study. The focus in the chapter is on informal support provided by family members. I review what these supports consist of and how participants make use of these supports in their everyday lives. The chapter also points to how support enables three key practices integral to the accomplishment of citizenship (self-determination, participation and contribution). The chapter also gestures to the ambivalent character of support as it is currently organized. On one hand, participants cannot carry out the practices of citizenship without support. However, receiving support, places limits on the activities they might pursue, including those involved in accomplishing citizenship.

In Chapter 5 I introduce the persistent notion of the poster child as an authoritative discourse. Its ideological values and viewpoints form the substance of how workers and parents and ultimately participants themselves think about disability, young people and support. It is
these views and values: disabled people as futureless, deficient and deferential that young people mobilize or activate as they attempt to get and keep support.

Chapter 6, 7 and 8 deal directly with the work young people do to secure and maintain support. My argument across these chapters is that participants drew in the authoritative discourse of the poster child to carry out this work. The discourse of the poster child was available through the voices of parents and workers who were their gatekeepers to support.

In Chapter 6 I argue that participants assimilate the authoritative voices of parents and workers, reproducing the 'poster child' in their talk and actions. I focus the chapter on three main work activities - being spoiled, doing deference and doing deferral. Participants could not easily access supports that enable them to carry out the practices of citizenship. In other words, they could not exercise choice and control over their everyday lives, could not easily participate in/achieve a public presence and voice of their choosing or make publicly recognized contributions. I conclude the chapter by suggesting that by reproducing the poster child in their efforts to secure support, participants defer full adult citizenship.

In Chapter 7 I argue that the authoritative discourse of the poster child, available through the voices of parents and workers, continues to determine the work participants do to secure and maintain support. However, I suggest that disabled young people reject their voices, resisting the poster child. Again I focus on three sets of work activities: doing physical deference, positioning oneself as a future worker and pursuing normalcy. While resisting the poster child, participants strive for normative citizenship, in which citizens are independent, self-managing and normal. However, in doing so, they must defer their deficits/their disability and in turn, eschew support. Paradoxically, without support, they cannot carry out the practices of citizenship.

In Chapter 8, I examine how young people draw in the authoritative voices of parents and workers, bringing the poster child into dialogue with other voices, viewpoints and values. In this way they set the poster child discourse into a new intentional context in which its authority is de-centered. Much of this dialogizing of the poster child is aimed at drawing upon its authority to legitimize or mask their claims for support. In this way, participants can sometimes secure support for the practices of citizenship that they might not otherwise have had.

Finally in Chapter 9 I summarize the findings of the previous chapters and suggest some implications of the overall study. I note how the findings raise questions about the extent to which formal entitlements to supports influence the lived citizenship of the disabled young
people in this study. I draw attention to the gaps and tensions in current formal support provision. The findings illuminate the tremendous invisible, tacit dialogical work that these disabled young people must do in order to strengthen their fragile supports. This work, organized by philanthropic rather than rights discourses, ultimately leads to a marginal or fragile citizenship.
CHAPTER 2
Theorizing Disability, Citizenship and Support

In this chapter I have two goals. First, I wish to provide a conceptual rationale linking the work of negotiating and securing support with the work of accomplishing citizenship. Second, I begin to lay out the theoretical orientations for the research design. In the first section of this chapter, I present an overview of T.H. Marshall’s theory of citizenship as a universalizing status. Marshall’s ideas are foundational to contemporary re-workings and extensions of citizenship; his model can be understood as introducing the building blocks of contemporary notions of citizenship (Isin & Turner 2002). I demonstrate how Marshall’s ideas have underpinned many of the disability scholarly and activist approaches to rights and citizenship. I then look specifically at the Independent Living Movement’s (ILM) evocation of citizenship to argue for supports for daily living as a civil and social right. In my discussion I focus on how this potentially masks and deepens the inequities associated with disability difference. I present two alternative approaches for addressing these differences, feminist notions of cultural citizenship and lived citizenship. The first approach enables recognition of and accounting for the group-specific differences that always exist among citizens. While this approach acknowledges and attempts to account for difference in citizenship models, it does so in the public sphere. Yet disabled people’s lives, particularly as they relates to support, may mostly take place in the private intimate spheres. Ruth Lister’s notion of lived citizenship has the advantage of examining the dialectical relationship between formal citizenship and the substantive ways rights and responsibilities are put into practice in everyday life regardless of site. Lived citizenship focuses on the ways in which citizenship is comprised of an assemblage of practices or deeds that are answerable or in dialogue with the practices of others.

In the second part of this review I move to a discussion of Dorothy Smith’s theorized method of inquiry, institutional ethnography, and Mikhail Bakhtin’s notion of dialogue in order to provide a theoretical orientation for an empirical study about disability support and citizenship. Smith’s broad understanding of work as co-ordinated practices or doings and Bakhtin’s theory of dialogue are well-suited to ‘lived citizenship’ as a form of dialogical work. The chapter culminates in a brief discussion of my conception of ‘dialogical work’.

Citizenship has been reconfigured many times since its introduction in classical Greek literature, but its contemporary forms are commonly understood as comprising a legal status of
membership within a political community (Isin & Turner, 2002). For individuals, citizenship status confers rights, obligations and a sense of belonging to a political community. Citizenship offers increasingly diverse societies a sense of shared values, lending cohesion and unity to communities and the social groups within them. In response to the declining salience of class struggle in the West, citizenship has become the “panacea for all social ills” (Phillips, 1995: 12), a means of examining and arguing for the transformation of social relationships. At the same time, there has been widespread skepticism about universal claims about citizenship, particularly with the recognition that citizens live and experience belonging and membership differently based on class, race, gender, age, disability and so forth. To capture these differences, a panoply of citizenship forms have been proposed and described: intimate citizens (Plummer, 2003); sexual citizens (Davis, 2008); neoliberal citizens (Hindess, 2002); flexible citizens (Ong, 2001); safe citizens (Weber, 2008); networked citizens (Castells, 2007) and so forth. However, citizenship as legal status that marks membership, entitlement and obligations to a socially defined group have remained constant through its proliferating forms. In the following section I outline T.H. Marshall’s historical analysis of citizenship as a universal formal status. Marshall’s model heralded the contemporary thinking on citizenship particularly as it related to first the welfare and later the neoliberal state. Despite its limitations some of which will be discussed in this chapter, Marshall’s work continues to serve as a starting point for current thinking about citizenship.

Curing social ills: T. H. Marshall’s model of Citizenship

Marshall originally introduced his conceptualization of citizenship in his treatise Citizenship and Social Class in the post-war period of the 1940s. In his view, citizenship was a status bestowed upon those who were considered full members of a community. All citizens were to be equal with respect to the rights and duties endowed to this status, rather than their relative wealth or social position, thus representing a movement of societies towards a fuller measure of equality for all its members. Marshall believed that the growth of citizenship in the West was coincidental with the rise of capitalism and the system of class inequality it engendered. The status hierarchy associated with class was expressed in terms of legal rights and of established customs and values. While this form of social division was useful to capitalism in that it provided an incentive to effort and structured the distribution of power
within the capitalist system, it also introduced a number of problems. The most significant of these was that it gave rise to social tensions, manifested internationally during Marshall’s life in the rise of fascism, labour unrest and colonial revolt. Marshall suggested that citizenship was one means of abating what he termed ‘class’ tensions. To Marshall, citizenship was a mediating instrument – when the relationship between the state and its people was in crisis, citizenship became the device whereby such crises could be debated and mediated (Oliver, 1996; Marshall, 1950). Citizenship offered equality of opportunity for a basic standard of living. Examples of Marshall’s ideals abound in the extension of the vote to women in most parts of the world (Brodie, 1995; Armstrong & Connelly, 1999), the extension of the vote and other civil rights to blacks in the U.S. (Quadagno, 1984), the granting of civil citizenship with the end of apartheid in South Africa (Benetar, 1998); the establishment of the welfare state and the ensuing expansion of social rights in the latter half of the 20th century (Offe, 1984).

Marshall offered a tripartite model of citizenship: civil, political and social. Each of these forms evolved at different historical points, involving an elaborated extension of rights and reciprocal obligations or responsibilities to (ostensibly) all citizens. In his historical analysis, Marshall posited that societies first established civil citizenship, moving to more elaborated forms once its rights were established among the population. Civil citizens were afforded the rights necessary for individual freedom within a market system, including liberty of person, freedom of speech, thought and faith, the right to own property and to enter into economic contracts and the right to justice before the courts. Marshall argued that, in the past, class and status as a citizen were linked. Civil citizenship attempted to sever this link by ensuring that, in the economic field, the basic civil right would be the right to work (ideally in an occupation suited to one’s capacities rather than class status).

Next, Marshall argued that political rights were a secondary outgrowth of civil citizenship. Political rights were connected to civil rights in that a worker was free to enjoy whatever political rights were “attached to the economic achievements that civil rights entitled him and electoral reform increasingly enabled him to do” (1950:13). Political citizens had the right to participate in the exercise of political power both as a member of a body invested with political authority, such as elected governments or the judiciary, or as someone who could vote.

10 In the last decade, citizenship has retained its mediating purpose, but rather than merely mediating tensions between groups and the state, or between groups, citizenship, particularly ‘active citizenship’ attempts to mediate between individuals and their communities through enjoining people to mutual respect and benevolence.
for representatives on such bodies. In a sense political citizens had the right to representation in public debates about issues of concern to their political community - either directly or by being able to elect representatives on their own.

Marshall’s distinctive contribution to the conceptualization of citizenship lay in his introduction of social citizenship. Social citizenship encompassed a whole range of rights from a minimum standard of economic security, to the right to a “share of the social heritage” (e.g. education) and the ability to live within the standards of one’s community. Writing in an English context, Marshall argued that the original source of social rights was membership in local communities. Up until 1834, The Poor Law was a precursor to social citizenship. Attached to community membership, the law attempted to operate as a system which adjusted real income to the social needs and status of the citizen and not solely to the market value of his labour. However, after that date, the Poor Law:

renounced all claim to trespass on the territory of the wages system, or to interfere with the focus of the free market. It offered relief only to those who through age or sickness were incapable of continuing the battle, and to those other weaklings who gave up the struggle, admitted defeat and cried for mercy (Marshall, 1950: 37).

In his description of the revised Poor Law, Marshall demonstrates how social policy was directed at those who were not or no longer citizens. Individuals had to give up membership, and with the establishment of the poor house, participation in the community in order to qualify for the Poor Law’s benefits. Marshall points out that “like women and children” only those who were not citizens could be protected from the economic system. Social rights, largely associated with the development of the Keynesian welfare state, served as a way of bringing people back into the community as citizens regardless of their relationship to the economic system. Consistent with Marshall’s understanding of citizenship as a form of class abatement, social rights attempt to decommodify a person’s membership in community (Esping-Anderson, 1990; 2002), in other words ensuring a share in the common goods of a community, regardless of labour market participation or material needs.

Citizenship as a universal status

The goal of citizenship was the elimination and transcendence of class differences as a means to achieving equality (Phillips, 1993). Marshall hoped that through citizenship, individuals would ultimately transcend their own limited worries and insecurities to embrace
broader “general concerns” shared with fellow citizens. In the ideal, citizenship is a universal status, transcending the differences between us in terms of race, gender, class and disability because it speaks to the rights and responsibilities we all supposedly share. As citizens, we are called to abandon our local, sectional interests and look to the greater collective good.

However, Marshall’s notion of citizenship as a universal status has been thwarted from the start. At its very foundation, denial of citizenship and its concurrent rights to an individual or group of individuals becomes an overt articulation of ‘othering’ or marginalization. A key question confronting citizenship studies is if an active and egalitarian community is ever able to absorb everybody, since the very process of defining membership inevitably brings about exclusion (Bickford, 1997; Isin, 2002; Nash, 2005; Young, 1990b). Even Marshall acknowledged that citizenship could level a “skyscraper to a bungalow” and rebuild it once again. In his later work, Marshall (1963) acknowledged that citizenship could at best be expected to guard against absolute poverty – but that many divisions among citizens remained and detracted from his universalist ideals.

**Disability as a challenge to citizenship as a universalist status**

Marshall’s conceptualization of citizenship has been incorporated into disability scholarship with little attention to the ways in which it fails to account for the experience of disabled people and reiterates normativities. Disability scholars and activists (often overlapping groups) use citizenship as a tool to claim inclusion and integration of people with disabilities into mainstream society. There are many examples of when the disability rights movement has invoked citizenship in order to find a greater measure of freedom for disabled persons. Civil rights, particularly freedom from institutionalization and community care and freedom from discrimination, have figured prominently on the movement’s agenda. Disability rights proponents aspire to a liberal ideal of equality for all, an assimilation into a society that makes space for them. Once accommodated and in ownership of full citizenship rights, disabled people are assumed to be free to live ‘ordinary’ lives. However, such aspirations may be illusory; Marshall’s universalist, transcendent model of citizenship does not easily accommodate diversity. Citizenship, conceived as purely a formal status, may suppress, mask or even exacerbate social differences within a community.
Citizenship can cloak entrenched deep differences (Phillips, 1993). Citizenship traditionally is about public identity and the status and belonging that derives from participation in the public world of paid work. Its focus on transcendent public identity implies a split between public and private worlds and a valorization of the public over the private. Feminists have leveled a number of criticisms at Marshall’s theories of citizenship on this basis, many of which stem from the feminist recognition that women’s citizenship has been historically restricted in practice because of women’s family dependency (Fraser, 1987; Pateman, 1988; Brodie, 1995; Fraser, 1997; Fraser & Gordon, 1997; Daly & Lewis, 2000; Lister, 2005; Lanoix, 2007; Phillips, 1995). In their view, Marshall’s ideas failed to examine the impact of the family or the social reproduction work of the ‘private’ domestic sphere in terms of citizenship, in turn failing to account for how the lives of women, as well as young and disabled people, plays out in what we think of as the private sphere. Moreover, young and disabled people may confront obstacles that bar entry to the public sphere. For instance, disabled people have noted that without adequate personal assistance, they may be unable to take part in school (Pascall & Hendey, 2004), employment (Aronson, 2001; Barnes & Mercer, 2005) or simply leave their homes (Brooks et al., 2008). As a result, large parts of their lived experiences are overlooked in discussions of citizenship. In contrast to Marshall, Anne Phillips (1993) has argued that, rather than merely fighting for citizenship, we must take seriously the deep differences which thwart the ideals of equality.

Citizenship also functions normatively, suppressing the actual differences among members of a given community. Marshall’s conceptualization of citizenship was underpinned by an adult, able, male template in which the ideal citizen was employed and freely able to exercise rights and fulfill responsibilities. The intellectual and activist work informing the struggles for independent living for disabled people offers a useful illustration of how claims to citizenship status can suppress differences among citizens.

Perhaps the most effective invocation of citizenship has been the struggle for independent living. Motivated by UC Berkeley student protests during the late 1970s, the Canadian Independent Living Movement (ILM) positioned disabled people as consumers, with the right to exercise choice and control of the personal support services they require for everyday life (DeJong, 1979; Valentine, 1994) Largely developed and led by white educated, professional men with mobility impairments, the movement called for the deinstitutionalization of disabled people
and advocated their inclusion into all aspects of public life on the basis of civil citizenship rights (Fleischer & Zames, 2001). The ILM philosophy has at least three main tenets: first that disabled people have direct control over their personal support resources; second that they are able to identify, negotiate and secure personal supports based on their self-identified requirements and preferences and finally that they direct and manage supports (CILT, 2010). The ILM has argued for direct payment or funding arrangements in which disabled people would receive funds to hire personal support workers based on their own requirements and preferences. In practice, direct funding arrangements exist across Canada, but they are typically under-resourced, have long waiting lists and subject potential users to strict eligibility criteria. As such, the number of disabled people receiving direct-funding is low. Nevertheless, the ILM’s guiding philosophy of independent consumer-directed support has informed personal support services administered through agency directed arrangements as well.

The struggles and achievements of the ILM have undoubtedly brought about positive changes in the lives of disabled people. However, examined closely, the ILM’s efforts reveal the normative dimensions of civil citizenship status. The image of the citizen underpinning the ILM philosophy is of the self-managing and self-sufficient individual. The disabled person, with adequate instrumental personal support services, is posited as someone who can exercise the opportunities and carry out the obligations that citizenship rights afford any other individual. The citizen then is constructed as someone who is ‘whole’ of body and mind. Given that the ILM tends to emphasize utilitarian supports – assistance with hygiene, housekeeping, employment support – there is a sense that personal supports simply ‘remedy’ the individual’s functional impairment. The emphasis on the rational and informed person who can manage his or her own supports – including financial management highlights the cognitive and intellectual abilities assumed of bearers of citizenship status. Not only do these assumptions reinforce narrow medical/functional constructions of disability, they potentially leave the structural and cultural disadvantages of gender, race, age and other differences that shape people’s life conditions unexamined.

Disability Studies has tended to draw a straight line from disablement, to exclusion from the workforce to citizenship. Calls for inclusion and independence emphasize the economic contribution disabled people can make but are denied due to inadequate social rights (e.g. Oliver, 1990; 1994; 1996). Arguably this privileges a public identity that derives from participation in
the labour force. In many ways the ILM philosophy buys into the view that the ideal citizen is both a working contributor to the community and “accountable” both for his or her well-being and for those in his or her employ (Kendrick County, 2005), promoting an identity that contributes to the very basis for the exclusion of disabled people from full citizenship in the past. Gareth Williams (1983) noted that arguing for self-directed and self-managed resources for support fits with (neo)liberal, marketized notions of care that allow states to devolve responsibility for caring for oneself (and workers) to individuals themselves, while contributing to the individualized construction of the upstanding fully self-sufficient citizen. Moreover in North America, public funds increasingly devoted to self-managed care are used to pay family members and others in disabled individuals’ personal networks (Lord & Hutchison, 2008; Matthias and Benjamin, 2008), potentially reinforcing personal support requirements as a private concern, rather than a collective response to real social and material differences brought about through a disabling social order.

Finally, some critics have highlighted how social policies aimed at ensuring citizenship among the members of a community, may play on differences, if not exacerbating them to the extent that they become a source of inequality. As Williams’ (1983) concerns imply, an unproblematic claim to citizenship status may deepen existing social divisions. The neoliberal values consistent with consumer-directed/self-managed support services are most likely to be those that create new social divisions. For instance, many disabled people are barred from the paid labour force for reasons that cannot be addressed by support services. For instance, in an individual and focus group interview qualitative study of 56 disabled people in western Canada, respondents noted that their greatest barriers to labour force participation was workplace discrimination and labelling (Shier et al., 2009). Others may have impairments that preclude certain occupations. For example, people with visual impairments, seizure disorders or certain mobility impairments cannot be hired for jobs that require driving. Similarly, Deaf people are excluded from certain laboratory work for safety reasons. Among disabled people who do secure some labour market participation, their work is usually peripheral, marginally paid and unacknowledged or discounted as work (e.g. sheltered workshop activities, day programs, etc.) (Barnes & Mercer, 2005; Groce, 2004). Yet this work may not be easily associated with citizenship and may not be prioritized for scarce support resources. More troubling is that those who cannot independently manage their own supports or avail themselves of the opportunities of
citizenship status may be more likely to find themselves pushed into a form of peripheral citizenship, constructed as vulnerable, ‘incompetent’ citizens who are rightfully passive objects of social welfare benefits. For some, this peripheral or marginal status may leave them vulnerable to certain forms of re or trans-institutionalization\(^\text{11}\) (Priest, 2004), a fundamental withdrawal of citizenship rights. Even seeking citizenship status can widen differences. As Kate Nash (2005, 2009) recently observed, those who must continually turn to their civil and political rights are precisely those who lack the material and social resources to avail themselves of the opportunities citizenship is intended to provide. Those who must continually point out their exclusion are inadvertently, yet necessarily, engaged in a form of representational work in which they must continually reiterate their marginal status in public discourse and spaces.

In summary, I have introduced Marshall’s model of citizenship as a universalizing formal status that delineates a membership to a political community. While Marshall’s model brought together some of the basic building blocks of citizenship – rights, responsibilities, equality and belonging - it offers a ‘thin’ citizenship (Isin & Turner, 2002). Citizenship as a formal status paradoxically covers over and exacerbates differences among citizens, potentially creating new exclusions and marginalizations within citizenship itself. While some streams within Disability Studies have looked to citizenship to remedy disability disadvantage, notions of citizenship as a formal universalizing status may only provide cosmetic fixes, while reinforcing conditions of disablement.

There are a number of ways in which the differences among citizens can be critically surfaced. One strategy is to draw on feminist re-framings of difference that recognize the boundaries and categories that define difference as contingent, arbitrary and constructed, yet view the erasure of difference as increasingly problematic. The work of Iris Marion Young and other cultural citizenship theorists build upon citizenship status as a corrective, a tool to identify and remedy the inequitable distribution of benefits and burdens based on social difference. They propose a notion of citizenship involving processes whereby difference is recognized and accounted for (e.g. affirmed, accommodated, celebrated, deconstructed), such that citizenship may become a means to argue whether “rights and duties” should or even could be the same for all. A second way to understand citizenship is as lived (Isin, 2008; Lister, 2007a). Lived

\(^\text{11}\) Trans-institutionalization refers to the movement of disabled people from large residential institutions to new residential institutional settings. For instance, people have been relocated from large developmental centres to group homes, nursing homes, prisons and other congregate living situations.
citizenship is active and participatory. It goes beyond a formal status delineating membership in a polity to a social process through which individuals and social groups engage in claiming, enacting, expanding and losing rights (Lister, 2007a). These everyday practices have relevance as the “meaning citizenship actually has in people’s lives and the ways in which people’s social and cultural background and material circumstance affect their lives as citizens” (Hall, Williamson & Coffey, 1998: 2). In the following two sections I review these approaches.

Recognizing difference

Citizenship has the capacity to “transform the teacher, trader, corporate executive, child, sibling, worker, artist, friend or mother into a special sort of political being: a citizen among citizens” (Dietz, 1987: 14). Such a statement does not deny individual or group differences, but rather posits individuals as fragmented selves, capable of finding points of interconnection with other selves in the form of citizenship. Iris Young (1990a; 2000) developed this analysis further by emphasizing group identity and political representation. She argued that justice in a group differentiated society, demands social equality among and the mutual recognition and affirmation of all groups. Just and egalitarian societies attend to group specific needs and provide for group self-expression. Young valourizes difference, recognizing its potential as a liberating and empowering resource. Valuing difference, she argues, promotes social equality by undermining social and cultural imperialism, or the universalizing claims that mask diversity, such as those in Marshall’s model. Drawing on Habermasian ideal speech situations, Young claims citizens are active and reflexive, since they must hear and consider the claims of others, even as they assert their claims in the public sphere. Citizenship then both celebrates diversity and finds common space for mutual recognition.

Recognition of group specific differences also involves an analysis of current social inequities. Building on Young’s work, Nancy Fraser and others have called for a “multivalent” interpretation of needs of specific groups in relation to society (Bickford, 1997; Fraser, 1997; Moosa-Mitha, 2005; Yuval-Davis, 2006). In general, this view contends that citizenship must be situated in the various intersecting axes of ‘difference’. These ‘axes” locate individuals within both the political economy and the culture, and ultimately limit the extent to which interventions in either can foster the ideals of citizenship. Nancy Fraser (1997; 2005) for instance, suggests that citizenship cannot be achieved either through the affirmation of difference or the application
of formal social rights, but requires a multilayered strategy of socialist-inspired economic distribution and critical deconstruction and destabilization of normative categories of identity. Fraser urges western governments (particularly her own US government) to look for alternative strategies for redressing economic and cultural subordination through innovative strategies of recognition and redistribution. Fraser’s model provides space for the integration of multiple voices from different subject positions as related to citizenship. As such it demands the inclusion of the voices of disabled young people in debates about what constitutes their unique needs and capacities. It also affords us the opportunity to examine how disabled young people actively cope with or resist their construction as particular types of (non- or secondary) citizens.

Models that favour diversity, such as Young’s and Fraser’s, create the potential for the inclusion of individuals and social groups with ability, generational or age differences, and encourage us to look for points of connection across difference. However, recognition of group-specific differences holds some pitfalls for disabled young people with respect to support. These efforts to transform difference, locate citizenship in the public sphere, leaving aside the private sphere in which disabled young people spend so much of their lives and is one of the few places they may have a voice (Skar & Tham, 2001; Skar, 2003). Ruth Lister’s notion of ‘living citizenship’ may offer promise by looking at what people actually do as citizens that is, the local everyday settings of their lives, that are at once shaped by and shape the external social, material and cultural conditions.

**Living citizenship**

Citizenship can be understood as a dialectical relationship between formal status and the lived activities or doings of citizens in their everyday lives. That is, the formal rights and status of citizenship enable individuals to act or to be social actors in their communities. For example, civil rights upholding freedom of speech, become social when people speak out against political policies, engage in civil protest, create art or write a letter to the editor. All these activities are social in that they construct or reproduce shared meaning in interaction with others, they enact relationships between individuals and the state, they mobilize collective action and so on. Lived citizenship begins with a concern about formal status and its accompanying entitlements and obligations, but expands to consider how that status is interrelated with people’s activities and the social conditions that influence those activities. Here I outline at least two distinctive
dimensions of lived citizenship: its emphasis on deeds or practices and the ‘answerability’ of lived citizenship practices.\(^\text{12}\)

Typically within citizenship studies ‘practices’ are conceived as the enactment of neoliberal discourses – producing particular kinds of marginal citizens. Engin Isin (2008a) has claimed that this has led citizenship studies to focus on particular forms of subjects or the production of the citizen-subject. Isin queries this focus on the consequences of ‘deeds’, suggesting that a focus on deeds themselves may be instructive in understanding the conditions of possibility for citizenship. In a somewhat different vein, Ruth Lister (2005; 2007a) takes up the feminist critique of citizenship as a formal status, suggesting that it is the practices this status allows or restricts that is of most relevance in people’s lives. For Lister, a critical examination of these practices potentially illuminates the social, cultural and material conditions that shape how citizenship may be lived. Both Isin and Lister contend that lived citizenship goes beyond the practices of formal citizenship rights and responsibilities (voting, paying taxes, attending school, etc.), although neither denies that these have meaning in people’s lives. Rather, lived citizenship entails practices that make and re-make citizens’ relations with one another and to the political community to which they belong. Isin (2008a) points out that the lived practices of citizenship can be wide-ranging. They can involve highly public activities such as political protest, participation in cultural events or the articulation and claiming of new rights and responsibilities (e.g. same-sex marriage, environmental stewardship). But lived citizenship can also involve the practices typically excluded from discussions of citizenship, such as those in the private sphere. These can include practices of cultural and social reproduction that are typically associated with the home or friendship circles (e.g. childrearing, storytelling, faith practices, recycling and so forth). But it can also involve intimate, ostensibly private practices not generally viewed as supporting the political economy such as negotiations of safe sex between partners (Davis, 2008) or disabled persons and support workers’ negotiations of a transfer to a wheelchair. Lived citizenship crosses the boundaries between the public and private worlds and can originate in either site.

A second feature of lived citizenship is that practices are ‘answerable’. In other words, practices or deeds are two-sided. They respond to the given situations in which citizens find

\(^{12}\) I use practices, doings, deeds and activities interchangeably in this section. Depending on the ordering of different sections in this chapter I may narrow my use to one term. My preference is to use ‘doings’ as Smith does.
themselves. They also anticipate and will respond to one another’s citizenship deeds. Lived citizenship practices are almost like lines in a dialogue responding to and anticipating the acts of others. As such, people’s activities connect, one to another. Together, citizens may act reflexively or critically, to expose exclusion (and exclusionary practices) and articulate (through their answerable acts) new-shared ideals or citizenship horizons. Perhaps more cynically, the answerability of citizenship allows us to identify differences in authority and social material resources among citizens: we can examine how resources facilitate or restrict rejoinders or even deeds themselves. We can see what practices are authoritative, conditioning the responses of others.

As a cursory illustration, we might think about the recent practice of ‘kettling’ of young protesters by the police during political demonstrations. Kettling is a relatively non-violent act of crowd control, whereby police block roads, sidewalks and other exits such that protesters are forced into a smaller and smaller space. In theory, the kettled crowd gets tired and bored of simply standing around and the protest eventually loses momentum such that police may more easily detain protesters or allow them to return home. Some might argue that for protesters, ‘the kettle’ represents the climax of the demonstration. The fall-out after ‘the kettle’ becomes the means by which protesters can continue to articulate their political concerns. In other words a dialogue is initiated between protesters, the police, state officials and the public. All of this is made possible through formal and lived citizenship. Protesters may gather to demonstrate their disagreement with the issue at hand (often global economic and governance policies), but they demonstrate in ways they know will elicit a particular response or answer from others. The protest itself is an exercise of civil and political rights (the right to gather, the right to express one’s political views). However, these citizenship rights are lived by young people in ways that communicates a particular identity, establishes a specific relationship with the police and the broader community.

Both Isin and Lister suggest that the lived practices of citizenship can be creative or even emancipatory, shifting the very rules and norms of citizenship itself. If we think of lived citizenship as a set of practices that responds to and anticipates the deeds of others, then it is possible to think about citizens as responding to normative practices in ways that distinctly

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13 However I believe one could also argue that kettling distracts the public and protesters from the issues that initially mobilized the demonstration.
emerge from their own cultural, social or material circumstances. Their responses, must take into account what came before them, but also with how they might wish others to answer. Seen in this light, these practices have the potential to keep citizenship in flux. Practices may deepen (or wear away at) the thickness of people’s citizenship (the degree to which people’s unique identities can be understood or accounted for) (Isin & Turner, 2002), subtly alter the (re)distribution of resources, or widen the ways in which people can make claims for these resources.

To study lived citizenship we might pay attention to social and cultural practices that are affected by formal citizenship status. Therefore, as I indicated above lived citizenship can range from the stories parents tell their children (Kershaw, 2010) to wearing a hijab to our participation in civil disobedience and political protest (Saunders, 2008) to the career aspirations we might hold as young people (Lister, 2007a). The expansive character of lived citizenship makes it necessary to determine some practices of particular interest to this study. Jenny Morris (2005) identifies three key broad citizenship practices that have salience in the lives of disabled people: self-determination, public participation and contribution.

**Self determination**

Self-determination involves making and acting upon one’s choices and exercising control over one’s person and everyday life conditions (Antelius, 2009; Boyle, 2009; Stainton, 2000; 2005). It includes activities that preserve bodily integrity and personhood, such as how one may be touched and by whom (Saxton, 2005). In speaking of women’s citizenship, Ruth Lister closely relates self-determination to autonomy, “the ability to determine the conditions of one’s life and to pursue one’s life projects” (Lister, 1995: 72). In other words, self-determination means people are in charge of their own lives: they may formulate and follow their own plans, desires and dreams.

Within the disability rights movement, self-determination has been positioned as a central practical expression of citizenship. It has only been within the last few decades that in the West, disabled people have secured the opportunity to exercise choice and control over their lives. Indeed the most dramatic incursion into self-determination was segregation (through specialized schools, sheltered workplaces, exclusion from the paid work force). Disabled people have had a long history of being told where to live, what they will and will not do for a living, how to
pattern their everyday lives, even what they eat, when they should get up in the morning and go to sleep at night. The challenge has been to translate self-determination into practice, for taking back this control has been central to accomplishing citizenship.

**Participation**

Participation involves active engagement in various public and private spaces, such as the workplace, school, the creation of families or in political life. It involves a civic and political presence and voice(s) of disabled people (Morris, 2005) in all areas of life, but particularly in those arenas in which decisions that affect their lives are being made. There are a number of ways participation among the general population is encouraged, particularly when decision-makers are seeking the voices of marginalized people. For instance, opportunities for public participation include community-based research, think tanks, public consultation processes, community boards and advisory committees, community partnerships and even activist initiatives, such as street or digital protests (Hoikkala, 2009). These activities not only allow individuals and social groups to accomplish a public presence and visibility, but also can allow people to play a part in naming and changing their social conditions, ultimately reshaping the communities in which they live.

**Contribution**

Contribution may be the most contested sphere of practices with respect to disabled people’s citizenship. In short, contribution refers to activities that fulfill responsibilities through work, family and community (e.g. Nussbaum, 2006; Lister, 1995; Turner, 2001). Paid employment, domestic labour, military service, childrearing and volunteerism are the key ways many of us fulfill our citizenship obligations. In policy and even academic work, disabled people are often viewed as having fulfilled citizenship contributions when they move from receiving benefits to earning a living (see for instance, Oliver, 1990; Canada Health and Welfare, 1981; Shakespeare, 2006). The reality for some disabled people, including most of the participants in this study, is they will remain on income transfers and other state supports much of their lives. Under contemporary notions of active citizenship, acts of contribution and welfare receipt are often incommensurate, and as such disabled people are sometimes seen to be passive recipients of other people’s responsibilities – whether through direct care or indirect financial support.
Another tension arises from the characterization of disabled people as dependent, which can obscure the many contributions they have and will continue to make. Gail Fawcett (2009), Hilary Graham (1993) and others have pointed out that the informal care provided by disabled people is rarely recognized as a public contribution. Similarly, user involvement in community organizations has typically been viewed as a way to enhance disabled people’s participation activities, but less often acknowledged as a valuable contribution to the very fabric of their families, communities and broader society (Hutchison, Lord et al., 2008; McLaughlin, 2004). When disabled people do marginally paid work under supported conditions or within institutional contexts (e.g. sheltered workshops, psychiatric institutions, prisons), their work is not counted as part of the general economy. Instead non-traditional forms of labour are institutionally classified as ‘recreation’ (e.g. Groce, 2004), therapy (Reaume, 2009) or community and social support (Butcher & Wilton, 2008).

So far in this chapter I have reviewed Marshall’s foundational theory of citizenship. Marshall’s intention that citizenship be a universalizing status that transcends difference underpins the claims of the ILM and other parts of the disabled people’s movements. I go on to point out the limitations of Marshall’s approach for many disabled people, as it may only exacerbate disability difference. In order to address this limitation I turned next to feminist understandings of cultural and lived citizenship. These allow us to both acknowledged the differences among citizens, regardless of their shared formal status and the ways these differences play out in their everyday lives.

**Theoretical orientation**

My dissertation is grounded in Dorothy Smith’s work on the social organization of knowledge and ruling relations in contemporary capitalism. I use her work as an epistemological and ontological map, orienting my exploration of different bodies of scholarship. In most instances, the intellectual terrain is similar or intersecting, such as my use of Mikhail Bakhtin’s theory of dialogue and language, which shares a materialist ontology. Similarly, I draw upon the materialist strands of the interdisciplinary fields of disability and childhood/youth studies (Oliver, 1990; Thomas, 2007; Morris, 2001; Abberley, 1999; Oldman, 1994; Oakley, 1994). However, at the close of this chapter I apply Smith’s work to the idea of ‘lived citizenship’, which has more diverse theoretical roots (post-structuralist, feminist, critical theory). I use Smith’s emphasis on ‘doings’ and ‘texts’ to bring these diverse bodies of scholarship together.
Dorothy Smith (1987; 1990b; 1999; 2005) refers to her project of inquiry as a step in a corrective social science, one that goes about remaking the conceptual, theoretical frameworks of sociology and its methods. Her work is a challenge to mainstream sociology’s commitment to abstracted concepts and nominalist conceptual categories. Smith follows the Marxist rejection of Hegelian idealism that posits only ideas or conscious thoughts are real. Idealism holds that apart from what we conceive nothing has substance; as such the only way to understand human existence is through philosophical concepts (Morrison, 1995). For Smith, mainstream sociology erases the textual presence of people as subjects and agents, while preserving the presence of what they have done (Smith, 2001). In her view, we are left with a sociology that is abstracted from the very people whose activities make up the social world. Following Marx, Smith argues that when the real existence of individuals is understood as merely ideas or philosophical categories, then the real and practical problems of individual lives are overlooked.

Smith proposes an alternative sociology, institutional ethnography, that begins “on the ground” (Smith, 2009: 651) in the actualities of people’s everyday experiences. Institutional ethnography is committed to a materialist ontology that looks at human problems by studying the real conditions of human existence, and takes as its starting place the view that, before anything else, human beings must satisfy their everyday economic needs through their practical productive activities (Morrison, 1995: 32). People and their subjective meanings are not the focus of investigation and analysis; instead, institutional ethnography begins with the actual work of real people, engaging in their local ongoing activities (Smith, 1992:123). It is through the standpoint of people as they do this work, that we come to investigate ‘the social’. The social world posited by practitioners of institutional ethnography comes into being through people’s actions with one another; thus ‘the social’ can be discovered through any person’s standpoint as it is experienced and recounted.

Smith’s analysis extends beyond its starting point with individual standpoint. While institutional ethnography is grounded in the sensuous, embodied activities of people, it ultimately moves to explicate to the social relations that are present in, yet extend beyond the local site of these activities. Social relations are sequences of activities that together form courses of action. For Smith, people’s everyday activities or doings are understood to be coordinated with those of others making up social relations of which they are generally only marginally, if at all, aware. Smith understands our everyday lives as deeply “penetrated, organized, shaped by social
relations that coordinate people’s local doings with those of others, both those immediately present and others elsewhere or elsewhen.” (Smith, 2009: 420). In institutional ethnography, social relations serve as an analytical device. We observe how they are made through people’s actions, and how they extend from one occasion to all past and future occasions (Smith, 1987: 94-95; Smith, 1990b).

A focus on social relations provides a way for us to begin our inquiry in the local, the specific or the particular and move to the more general: the complex of ruling relations that organize our local settings and those beyond. Ruling relations are “conceived as “emerging historically as an objectified order of relations differentiated from the local and the particular” (Smith, 2001: 161). There are many features of these objectified and translocal relations that do not reside in any one particular spot or with particular individuals. For instance, Smith gives the example of ‘the university’. She notes that the ruling relations that organize what happens in ‘the institution’ do not come from any one site. Instead, universities are governed by governments, but also academic and professional discourse, corporations – coming together in a hub to shape the workings of those lives implicated with the institution.

Another distinguishing feature of institutional ethnography is that it does not proceed from a set of presuppositions; nor is it part of a theory-building exercise. Rather it is an open-ended process of discovery that will bump up against, substruct and possibly dislodge some of our preconceived ideas. As such institutional ethnography seeks to produce explicative accounts of our world.

Smith’s ethnographic project is interested in discerning the ruling relations that coordinate and concert the activities involved in both the local setting of participants’ lives and beyond. This differs from conventional forms of ethnography which aim to develop a rich description of what takes place in the research setting (Spradley, 1979; Hammersley, 1981). Instead, the goal is to start to explicate, or map, the social organization or the replicated network of interconnected everyday/everynight talk and action that make up, and sustain particular social relations “in which each knowing subject is located. In other words, institutional ethnography inquiry is directed towards exploring and explicating how the social is put together.

Another way institutional ethnography departs from traditional sociology (and ethnography) is in its analytic focus on the materiality of texts; it draws attention to what has been ignored in traditional sociological inquiry – the organizing capacities of textual processes.
In institutional ethnography, texts are not simply repositories of meaning and information, but an active constituent of ruling relations. Texts are any word, document, standardized form of discourse or image that can be read, written, or heard. While we are interested in the content of texts, we are equally interested in ‘texts-in-use’ (Devault, 1999).

Smith argues that texts mediate, regulate and authorize people’s activities. Texts allow actual people’s doings or actions to be coordinated, as their standardized forms are activated in different places by different people over time (Smith, 1999:7). They enter people’s local practices of writing, speaking reading, looking, video-making and so forth. They coordinate actual people’s doings or actions as their standardized form is activated in different places by different people over time (Smith, 1999:7). Texts can be easily replicated through print or electronic communication, such that similar or the same words can be easily disseminated in many different places to many different groups of people. It is this feature of texts, their ability to transmit objectified, standardized discourses/ideology across time and place that forms the basis of ruling relations.

Texts also make it possible for us to generate explicative accounts of the complex of ruling relations. The social – our interactions and actions situated in a particular time and space - degrades in the moment of their doings. We live our lives moment to moment, waiting for the bus in one moment, sitting in class in another, negotiating intimate care with a support worker in yet another. In a sense the social is ephemeral, slipping out of our ability to know it even as it happens. However, texts hold some aspect of our interactions constant, to be replicated in different times and places. We can trace texts through sequences of action and through institutional paths that produce standardized controls on people’s work activities. As we begin to map these textual paths, we can discover how it is that the social, beginning in the organized configuration of the local doings, is put together.

If we consider then how the “world is a series of factual accounts” (Jackson, 2004), then we can begin to understand language itself as a social relation. Talk, dialogue and the sharing of stories, creates opportunities for connection, mutuality and the co-ordination and concerting of people’s activities. These opportunities rely on the “two-sided character of words and the production of an interindividual space between speakers (Volosinov, 1986/1929: 12-13). Words rest in the interchange between speaker and hearer, and as words come into being for the pair, their consciousnesses are coordinated in language. Language organizes how we understand our
experiences and perceptions. For instance, Smith (2005) refers to consciousness-raising activities. Such activities entail naming and describing experiences that previously remained hidden or silent. A first step in organizing as disenfranchised people is to develop an organizing language. Telling stories, creating slogans, articulating resistance are all tasks in finding an interindividual territory where one’s experiences of exploitation can be ‘perceived’, recognized and collectively challenged.

Language brings people together within a sensory community – since it allows us to communicate our particular “experiences and perspectives in a world known and named in common” through our embodied activities (Smith, 2005: 78). Take the more mundane example of the shopping list handed from disabled person to personal support worker. Both (for the most part) understand the activities that lead to and emerge from the list. The actual items on the list are organized by the everyday knowledge the disabled person has of her household. The list is a reflection of personal tastes, health needs, cooking skills and so forth that she and other household members possess. The list, locally produced, is also organized by extra-local relations. The disabled person may write or dictate her list in the kitchen, alternately checking the fridge and cupboards, taking stock of her grocery needs. But this practical set of embodied activities, situated within the heart of her home, is influenced by social, economic and political forces emanating from far outside her home and frequently outside her immediate consciousness. Time constraints due to her school, work or volunteer obligations lead her to select easily prepared, convenience items; while avoiding ingredients required for more complicated recipes. Similarly, time pressures on personal support workers, their work schedules, workloads, agency policy and practice guidelines, and other labour conditions, may similarly influence what is added or deleted from the list. Availability of out-of-season produce in grocery stores greatly expands what we might include on the list. In turn, discourses of ‘independence and self-sufficiency’, ‘work-life balance’, new health risks or other food contamination may also shape what she writes. As the support worker reads the list and picks up the specified items off the shelf, he or she unknowingly activates all the influences. Although as disabled person and support worker, writer and reader, probably are only marginally aware of the network of ruling relations in which they are enmeshed and which they maintain, the list reveals how unique experiences and perspectives intersect with forces far outside writing and reading the list.
Texts, both mundane and official, that reproduce interindividual territory proliferate in our everyday lives – and surface repeatedly in our communities. Schedules, time-tables, maps, directions, instructions, email trails, to-do lists, shopping receipts are texts that create interindividual territory – bringing together various members of the community by drawing on everyday shared knowledge which we use to negotiate our common world.

Although Smith focuses on material texts, many such texts are largely available through talk\textsuperscript{14}. Certain pithy phrases, stereotypes, popular sayings and so forth have a material origin or presence, but are largely only available through talk. For instance, the phrase ‘innocent little lamb’ surfaced repeatedly throughout the research. Although this utterance can be traced to material texts and images – largely associated with Christianity – in recent years, particularly with the decline of church attendance, we could speculate that young people are most likely to encounter the phrase through utterances in conversation. An utterance is a basic unit of language, usually spoken that arises with a certain form and theme (Bakhtin, 1986; Volosinov, 1986/1929). I now turn to Mikhail Bakhtin’s work, reviewing his theory of language, with a focus on dialogue. I suggest that Bakhtin’s ideas enable us to see how we hold utterances in common as we speak to one another. In this way utterances are a certain spoken or written micro-text that may shape and co-ordinate social relations in the way Smith’s material texts do.

**Language, utterance and dialogue**

In *The Dialogic Imagination* (1981/1935), Mikhail Bakhtin adopts a broad conceptualization of language as “any communication system employing signs that are ordered in a particular manner”. There are several key elements to his theory: its inherent traces of struggle, heteroglossia and dialogue.

Bakhtin believed that language possesses both centripetal and centrifugal properties. In the former, language brings groups of individuals (communities, classes, professions, nations)

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\textsuperscript{14} For instance, in the context of this study, ‘bookings’, a scheduled appointment with a personal support worker in which a disabled person received assistance with a task, commonly arose in conversation. ‘Bookings’ were generally made when a disabled person contacted the administrative offices of a support provider agency or a support worker directly to prearrange a set time and period during which the worker would provide support around specified activities. Making a booking consisted of recording the appointment in a schedule. The actual activities that took place during ‘a booking’ were often far broader than appeared in the material text of the schedule. However, through listening and observing dialogue, the work of ‘doing a booking’ could be ascertained.
together, striving to make everyday life coherent. In this sense language has unifying forces. However, language also keeps these same groups of individuals apart. Bakhtin contended that language is always stratified into various dialects or ideolects – ways of speaking that are peculiar to a particular social group. Dialects/ideolects create and maintain meanings within localized spheres of activity associated with these groups. Each of these dialects always contains traces of values, standpoints and experience that emerge from the social group’s history and is articulated to its imagined future. We might think about how the dialects employed by young people and personal support workers will both overlap and differ in meaning and ideological content. The two groups will understand each other to some degree, particularly as they use common language. For instance, the two groups will understand what is meant by ‘a booking’ or ‘a transfer’. Yet the ways in which they talk about the everyday experience of providing or receiving support will differ. Struggles around dialects within language are fights between these perspectives and values or viewpoints. Language also exhibits signs of struggle between its two competing but interdependent, centripetal and centrifugal forces. Bakhtin argues that these forces function at every level that language operates: within and between individuals, social groups and societies. Language does not simply reflect this struggle, it is formed through the struggle of these forces; thus language is constantly in flux.

The centralizing forces of language are less powerful, but essential to the function of language. The forces that work to unify language can best be thought of as ideals, much like justice, peace, equality or health. These are political and social imaginaries that serve as driving forces of society, but are never fully within our grasp. Indeed part of what contributes to the struggles within language, is the effort to reach these ideals. Bakhtin seems to view these centripetal or unifying forces as setting a boundary, albeit somewhat permeable, on the struggles within language, preventing communication and meaning –making from falling into chaos, or ‘babel’. However, Bakhtin contends that the centrifugal or disunifying forces are more powerful, operating all the time in the product of texts, speech utterances and everyday conversation. The views, values, standpoints that permeate language are constantly shifting as different speakers speak in different historical, social and material positions.

The emphasis on struggle leads to the second fundamental concept of Bakthin’s theory of language: heteroglossia. Heteroglossia refers to any utterance of any kind. Whenever we say something (in writing or through speech), the meaning of the utterance is always in context.
Therefore, the same text uttered in a different time and place will always mean something different. It is in this contextualized utterance that the collision between the centralizing and separating forces can be revealed.

Bakhtin argues that any individual might not be able to recognize all the ideological positions inherent within our speech. Part of how we come to be conscious of the ideological content of language is through ‘parody’. We quote, re-write and reframe other dialects/ideolects, integrating alien dialects into our own. By placing the speech of others against one another in our utterances, we draw attention to the tensions between their values or standpoints, illuminating the social relations between the different positions. This parody is essential to the dialogization of languages: the mixing of two or more linguistic consciousnesses. Heteroglossia then is the mixing of various languages, revealing the various ideologies at play in any text or utterance.

Any ideolect, however, has the possibility of constraining understanding or imagination. Without contestation between dialects we would not be able to think or imagine beyond the boundaries of our ideolects. Bakhtin introduces the notion of monoglossia, as evident in authoritative discourse, such as the policies of totalitarian or fundamentalist regimes that squash opportunities for hearing the voices of others. Closer to home, we might think, as Dorothy Smith (1999; 2005) does, of institutional documents that obscure the varied and inarticulatable work of individuals, by providing no opportunity to enter into dialogue with the text. For Bakhtin (1984), monologue was “fatal” to language, closing off utterances and texts from one another such that they became static and irrelevant to people’s everyday lives. In order for language to be enlivened, to grow, change and remain immediately relevant to people, texts and utterances needed to be dialogized. They needed to be brought into dialogical interaction between speakers. As utterances were brought into dialogue, their original values, views and standpoints were brought forward lending a linkage with their social and material origins. Dialogized utterance took on intent and tone in the immediate context of their articulation and anticipated future rejoinders and responses. It is through dialogue that speakers could respond to, evaluate and shift the ideological content of utterances and the interindividual territory between speakers.
Dialogical work

It is here that I bring together Bakhtin’s notion of dialogue with Smith’s definitions of work to consider how citizenship is accomplished through disabled young people’s dialogical labours. Following Isin (2008a) I suggest that deeds/activities or practices are worthy of study in their own right. I argue that citizenship can be understood as comprised of sequences of activities that connect with the activities of other individuals in other places and times. In this sense, citizenship can be understood as a social relation grounded in people’s everyday concerted activities that are enabled by formal rights.

As I contended in the previous chapter, support can be viewed as an arena in which we can examine citizenship; stated differently, support is an exemplar of citizenship. It rests in the dialectic of formal and lived citizenship, going beyond the possession and exercise of a social entitlement to an assemblage of everyday/everynight practices that people do and connects with the practice of other people in other places and times.

I understand these practices, doings or activities as work in a Smithian sense. Work, in Smith’s view, extends to anything “done by people that takes time and effort, that they mean to do, that is done under definite conditions and with whatever means and tools and that they may have to think about” (Smith, 2005:151-2). Work includes the silent, unpaid and often invisible ‘doings’ or everyday activities which sustain and coordinate with the activities of others in different places and times.

Further, as I mentioned above, Lister and Isin view the activities, doings or ‘work’ of lived citizenship as answerable: responding to and anticipating the doings or activities of others. Lived citizenship is comprised of the everyday activities that are enabled by our formal entitlements. These activities must always be co-ordinated or concerted with another’s. Therefore in this study, I was interested in how the formal citizenship entitlement to support enabled disabled young people’s work of lived citizenship. I imagined that young people’s work is always ‘in dialogue’ with the work of others responding to the demands made of them, articulating their concerns and claims and anticipating how others might respond to them.

In order to begin to consider how this work was organized or ordered, I employed Bakhtin’s notion of dialogue. Specifically, I treat the utterance as a ‘co-ordinating micro-text’. I contend that as utterances are activated in dialogue they shape young people’s consciousness,
activities and relations. I believed that if I could identify key utterances in disabled young people’s talk related to support, I would be able to begin 1) to identify the work young people did to secure support and to accomplish citizenship (and challenge the notion of disabled young people as passive recipients of assistance); and 2) to understand the extent to which support made full citizenship possible. In the next chapter I explain how I began to trace utterances through dialogue to see how these shape the work young people do to secure support.

Summary In the present study I am interested in two intimately connected forms of work: the work of securing, negotiating and maintaining support, and the work of doing citizenship. The shift to independent living throughout the West with its drive to autonomy and self-determination has given rise to a whole body of disability-work that entails the acquisition and management of support. To explore the character of this work I begin with the experience of disabled people as they engaged in purposeful day-to-day activities to negotiate, secure and maintain support. As I have outlined in Chapter 1, the activities that comprise negotiating, securing and maintaining support are implicated in ‘doing citizenship’ in two ways. Support enables disabled people to carry out the practices of lived citizenship and getting and keeping support is the exercise and actual doing of citizenship.
CHAPTER 3
Research Design

Study Questions

This study sought to “write the social” (Smith, 1999) into citizenship through the exemplar of home support provision to disabled young people. The inquiry begins from the standpoint of young disabled people as embodied knowers who are active participants in their own support.

• What work do disabled young people do to accomplish citizenship?
• What is the role of support in disabled young people’s work of accomplishing citizenship?
• What knowledges and activities do disabled young people pursue to secure and maintain supports?
• How are these support-related knowledges and activities socially organized?

Methodological approach

This research drew upon multiple methods including participant observation, interviews, arts-informed inquiry and critical pedagogical methods, interwoven into a participatory action research design. Participatory action research (PAR) is consistent with the political and theoretical orientations of disability studies which call for a transformation of the relations of knowledge production, such that disabled people are included in the production, analysis and dissemination of research about their lives (Barnes, 2003; Finkelstein, 1991; Oliver, 1992; Woodill, 2006). As described in Chapter 1, I undertook this research as part of a larger project examining disabled people’s experiences with home support conducted by Dr. Kari Krogh at Ryerson University. The broader study included key informant interviews, video action research and participatory policy analyses, to facilitate disabled people’s participation in home and social care reform. My research was intended to insert a youth-stream into the overall project, and was deliberately constructed to produce visual data for a planned website dissemination strategy.15 While I shared the larger project’s substantive focus on support and used participatory methods as part of my research design, my own project followed a unique direction in that I was more

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15 Dr. Kari Krogh became seriously ill in the latter part of 2003 and throughout 2004. In 2005, she disbanded the overall project due to her continued health concerns.
interested in support (and making claims to support entitlements) it related to citizenship.

The participatory action research process followed a three-step trajectory – social investigation, consciousness-raising and social action. The researcher meets with the community to jointly identify researchable questions, embark upon collaborative data collection and analysis. Storytelling is integral to the research process; community members share their experiences rendering them public, analyzable and potentially transformable (Maguire, 2000). PAR methods rely on the assumption that given information, the tools of analysis and the space to safely use those tools, people will be able to critically reflect upon their storied experience (Park, 1993). Finally, PAR is a dialectical research process– social investigation and consciousness are used to uncover new problems for investigation, alongside potential solutions. Social change can take place even within the research process (Williams, Labonte and O’Brien, 2003), since PAR may foster a sense of solidarity among participants, and may facilitate the inclusion of submerged community knowledge in the broader political and cultural horizons of meaning (Lara, 2002).

Among the ‘tools’ to facilitate PAR are methods of data collection that visually document everyday conditions. Visual methods (e.g. photography, film-making, drawing, cartography) enable more and diverse participants to be involved in knowledge production. Many marginalized groups - children (Morrow, 2001), indigenous people (Casteldan et al., 2008), homeless people (Crowe, 2007), the queer community (Holliday, 2000; Ta-Young, 2008), psychiatrized people (Parr, 2008) and disabled people (Booth & Booth, 2003; Goodley and Moore, 2000; Ignagni & Church, 2008) have adopted participatory visual methods to document, explain or story their life circumstances. In part this is practical; visual methods ostensibly circumvent the written text in research, thereby opening the research process to people with varying verbal or written literacy. Moreover, visual arts informed methods can surface and represent experiences that cannot be easily articulated in words. Visual methods also may lead to alternative research products such as exhibits, documentaries, or photojournals, broadening the audience and its engagement with research analysis.

Participatory visual methods may also enhance participants’ political capital. Limited and negative portrayals of disability in policy and mass media communication have been and are instrumental in the continued social and political marginalization of disabled people (Barnes, 1999; Hevey, 1992; McRuer, 2006; Siebers, 2008; Titchkosky, 2007). Eager to transform and
broaden these restrictive images, the disability rights movement has undertaken new efforts to re-model its activities into a politics of visibility. Taking control over one’s representation, making one’s case for equitable treatment, is seen to be critical to altering the social and material conditions of disabled people everywhere. (Berube, 2003; Davis, 2002; McRuer, 2006; Monks, 1999). Thus visual participatory methods not only allow participants to air their concerns, but also may renew the representation and response to those concerns.

My project design integrated the principles of two different participatory visual methods: photo-voice and video action research. Photovoice was developed initially by Carolyn Wang, for use in international health research and education (Wang, 1999; 2003). A participatory research strategy, founded in Freirian principles of education for critical consciousness and empowerment (Freire, 1970; 1976), photovoice draws on the democratizing potential of new media (Kahn & Kellner, 2004). Marginalized groups are equipped with cameras and other image technology to document, represent and produce new knowledge about their social conditions from their own perspectives. Facilitated group discussions about produced images aim to delve into critical analyses of their social conditions and their root causes. Even the practice of taking photographs itself can illuminate social conditions. For example, in Pole and his colleagues’ (2001) investigation of their labour force participation, young people were not permitted, by their employers, to photograph their job sites, for fear their poor working conditions would be exposed (Pole, Mizen & Boulton, 2001). In another project, young sex trade workers were questioned and their cameras confiscated when adults assumed that they had obtained the equipment illicitly (Young & Barrett, 2000). These challenges highlight how generational or adult – child/young people power relations intersect with those of class, race and gender to constrain and otherwise organize young people’s everyday activities in local settings.

The present research design also drew from a second form of image-based research - video action research (VAR). VAR, developed by Canadian social scientists, allows participants to analyze qualitative research (Krogh, 2001). Participants are videotaped by researchers as they are interviewed or go about their daily activities. Participants are then given their tapes and asked to identify themes or ideas they feel are salient to the research goals. Eventually all participants collectively review the tapes and choose common themes. Participants work with an editor, to identify and organize video clips that exemplify themes to create a documentary of their findings. In VAR, analysis is less contingent on the analyst's verbal literacy skills,
addressing criticism that participatory research projects limit community involvement through to the analytic phases (CRIAW, 1996; David, 2002; Maguire, 2000).

I integrated photovoice and video-action methods into the research design for several reasons. In Krogh’s earlier work, ethical review boards suggested that the use of participants’ images associated with their narratives would compromise their anonymity, in ways that the REBs deemed negative. Also, in my view, videotaping young people as they were interviewed evoked images of youth surveillance associated with the technological turn to video testimony and counselling, an image that was not consistent with the emancipatory basis of the project. Photovoice techniques placed the camera in the hands of participants, ostensibly removing their identities (name, visual image) from the frame. Also, photovoice allowed me to literally see the world from participants’ standpoint – I would be able to ‘see’ their work routines and everyday practices as they documented them in images. Finally, the relatively low costs associated with photovoice meant participants could take the camera with them as they went through their day-to-day routines, and thus direct the ‘investigative gaze’ away from the immediate research context. In Krogh's (1999) earlier work with a disability rights advocacy group, participants had their own pre-existing research problematic to guide the investigation that complemented those of the university-based researchers. However, I suspected that this would unlikely be the case in this research as disabled youth typically have few opportunities to organize collectively around their concerns. While participants may not have come into the project with their own political agenda, photovoice methods would allow them to explore their communities and then identify key concerns outside the immediate research setting, such that they could autonomously shape a small part of the research agenda.

The relationship between researcher and participants in PAR is conceived within the critical mode of qualitative inquiry (DeVault, 1999). Participants, who themselves were not the ‘subject’ of the research, are treated as ‘competent knowers’ (Mykhalovskiy, McCoy & Bresalier, 2004) of their daily work activities in which they were engaged. Campbell and Gregor (2002) note that any research we initiate immediately “commits us to a certain kind of social relation” (15). The researcher cannot step outside her body, the social situation or the particular

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16 However, deeper markers of identity are likely impossible to bracket from images. A simple example would be the angle from which a photograph is shot communicates information about the image-maker’s ‘height’ in the world. For instance, travel photographer, Kevin Connelly, who is a double amputee, uses a ‘skateboard’ for mobility in his travels through different parts of the globe. His photographs are therefore taken from a distinctively low angle, such that all people (and animals appear to be staring ‘down’ at him.
point of time of the actual research process. We stand (or sit) alongside participants as they are located in a particular spatial and temporal site and a particular configuration of their everyday/everynight world. In taking the standpoint of young disabled people, I ‘sat’ with them as they were actually located to create their videos: as they talked to one another, waited for the bus, read, watched movies, ate lunch and so forth. To paraphrase Smith (2005; 2009), these activities hook them (and me alongside them) into extended social relations linking these activities to those of other people in ways beyond their immediate knowing. This was ideally suited to PAR design, in which the participants and researchers are co-learners (Freire, 1976), both parties discovering and explicating together the invisible social relations interpenetrating the immediate context.

Questions of insider and outsider knowledge that frame the qualitative researcher’s role do not typically arise in institutional ethnography, since in taking the standpoint of participants, the researcher participates in the organized and organizing social relations under investigation. However, I would argue my own ontological positioning as a disabled person was key to understanding the disabling practices that characterized the everyday lives of participants (Tregaskis & Goodley, 2005). In some ways, my own positioning and subjectivity as disabled with respect to this project brought me into more intimate contact with participants. I, like many of the participants, require support, although in no way did my requirements approach theirs. While my disability and experiences in securing and using support services helped me assume the standpoint of participants, in that it was sometimes easier to recognize sequences of work activities in the research setting, in other instances, some features of the prevailing social relations of support have likely remained invisible to me. Moreover my social location as a disabled woman sometimes seemed to create awkwardness, especially among artists. They would ask, only after many meetings spanning several months why, as a person with a visual impairment, I was interested in such a visual medium. In contrast, those within disability agencies were overly familiar – often treating me in a manner that I perceived as condescending. I learned, like the young people in the project, to use my disability to its best advantage, always in anticipation of my audiences’ response.

Another dimension of PAR is the researcher’s obligation to bring analytical resources to the participants in the research project. In Freire’s (1976: 99-103) work, researchers practice a form of critical pedagogy, teaching participants to read, write, map their communities, account
for their labour or otherwise resource them with tools to reconsider and transform their lives. In this project, I also brought what I came to see as representational and literacy resources to the project, in the form of video-instruction, equipment and materials and access to community arts resources. In the discussion of the research design below, I describe my role as facilitator/teacher in more detail. However, this role as facilitator reproduced pedagogical relations occasionally within the project. For instance, the language used within the workshop, such as ‘homework’, ‘assignments’, ‘exercises’, placed the workshop artist/facilitator and me in a teacher relationship with participants. I draw attention to these moments, when relevant, throughout my analysis.

My positioning through this project thus reaffirmed my status as the researcher, not the researched. Pierre Bourdieu has asserted that all social science is based on some form of “participant objectivation”, in that the research participant is always objectified in order to participate within the researcher’s objectives and ambitions (Bourdieu & Wacquant, 1992: 259). While participatory research and institutional ethnography position participants as the ‘expert knowers of their worlds’ (Smith, 1990a; see also Maguire, 2000; DeVault, 2006; Friere, 1979)\(^\text{17}\). Kevin Walby (2006) notes that we cannot avoid the intersection of our research and social lives. The literature we read, the questions we ask, the data we attend to and our analytic choices have as much to do with our own social positioning in relation to participants as it does to any theoretical or methodological orientations. Where possible, where my positioning came to consciousness, I will lay bare how this occurred throughout the course of this project.

**A focus on dialogue**

Of the various methods used in the research, dialogical data, collected through participant observation and interviews, have been the most significant, grounding much of what I say in subsequent chapters. I also made a methodological commitment to dialogue within the research design. Dialogue is central to the development of critical consciousness in PAR. As people talk together about their world, they “disassemble” their understandings of the world into so many different problems. Through creative and collaborative discussion, people consider and reconsider these problems such that they may be reassembled into a new understanding of the world. For this reason, I was intentional in creating opportunities for dialogue within the research design.

\(^\text{17}\) Working with institutional ethnography was an attempt to avoid such objectification, since the method of inquiry takes the organization of social and ruling relations as its focus, not individuals.
A second way in which I used dialogue was informed by Bakhtin’s work. Following Bakhtin, dialogue entails a moral demand that each speaker “grant equal authority to the other’s voice” (Frank, 2004: 614). Although this is largely a ‘non-fictional imaginary’ (Isin, 2008a), each speaker must be willing to let the other’s voice count as much as his or her own, striving always for balance among voices. As we incorporate the voice or utterances of others into our own, we enrich, expand and shift our individual consciousness, while at the same time assimilating ideological authoritative content of other’s speech utterances to establish new unifying boundaries or limits to our own. Such mixing of languages continues from the past active contexts in which utterances were last used and anticipate future articulation. When we do not approach a balance of voices, or when the voices we incorporate are so authoritative that they allow no ‘play’ or mixing with our own, dialogue disappears and we are left with a closed and rigid monologue. Consequently, our chances of arriving at new understandings of our world, or making claims that benefit ourselves and others are foreclosed. Methodologically, I attended to the dialogical character of participants’ talk, noting when participants actively brought the utterances of others into their own, or when utterances shift into monologue. In tracing dialogue, I have a way of discovering the ideological context of certain utterances and consider how these coordinating the activities involved with securing and managing support. I describe this in greater detail in the section on analytic technique below.

**Research Design**

The research design shifted throughout the course of the project. This is not unusual, for most qualitative research projects are not hypothesis driven and tend to rely on iterative paths of investigation. Evolving designs have become a standard feature of much qualitative research. However, the turn in the Poster Child Shoots Back project altered the artistic products emerging from the research and held significance for the interpretation of the findings. Rather than create a collective documentary based on participatory policy analysis, participants elected to create individual videos. For me, this turn was a moment of discovery, a point at which the direction of...

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18 Some theorists, such Zizek (2003) argue that dialogue is always fraught with power imbalances, and the dominant voices will prevail. Bakhtin acknowledged that social and material power differences exist between speakers. However, he believed that dialogue could expose and begin to re-create these differences. For Bakhtin, balance itself is unimportant; rather the struggle for balance is what keeps language alive and allows us to be continuously re-examining and re-creating our worlds.

19 Consciousness being much like alternating utterances (Volosinov, 1929/1986, pg. 38).

20 Including my own.
my research was re-oriented. A different kind of turn then, an ‘investigative turn.’ The following discussion of the design outlines the events leading up to and around these turns.

**Negotiating Access to Disabled Young People**

Through the process of gaining access to potential participants, I had to partially negotiate and thus learn the social organization of the “social and community care of young people with disabilities”. For instance, throughout the recruitment process I learned a specific language of working with disabled youth. I learned how, when speaking to professionals, to speak in terms of skills – how to highlight the potential skill deficits among the young people and how to posit their involvement in the project as offering them new skills (e.g. writing, communication, interpersonal). In keeping with participatory methods, I initially sought out an organized group of young people already interested in support and personal assistance issues. After little success, I connected with several receptive organizations serving young individuals. Although I had personal knowledge that these organizations served young people who were HIV positive or who were mental health or developmental service users, staff were unable to identify disabled clients. Although it is not clear whether these young people would have self-identified as disabled, the fact that workers did not make that connection, suggests that workers themselves were operating with a pre-conceived image of disability and possibly who qualifies for support. In some respects, these contacts with workers proved helpful, since they agreed to promote the project, suggested artists who might be willing to mentor participants, volunteered other resource planning workshops and eventually screened the videos within their organizations.21 As I realized no groups of organized disabled young people existed outside of traditional clinical settings, I considered bringing together a group of young people for the express purpose of developing some action around support.

I began to engage in a form of ‘purposive sampling’, searching for young individuals whose standpoints could provide insight into how the institutionalized practices of community and social care penetrated their experiences.22 Given my interest in the intersection between young people's need for home support and their participation in community life, I approached

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21 It was through this initial set of contacts that I was able to meet Nas Khan, the workshop facilitator. I also met artist members of Trinity Square Video who facilitated participants’ use of its resources.
22 The term ‘purposive sampling’ is not wholly accurate. In institutional ethnography, social relations or courses of action, not ‘populations’, are the research problematic. See Smith (1987, pgs. 186-187)
community-based organizations and clinical services for disabled young people. I contacted each organization by telephone, briefly explained the project and asked for a contact within the organization with whom I could continue discussions. I then sent a letter outlining the project and requested permission to promote the project among the organization’s families. I followed up the letter with a telephone call to the contact person within the organization.

These contact people, often professionals providing direct service within the agency, initially expressed scepticism regarding young people’s ability to participate meaningfully in the project. I arranged to meet with these individuals in order to explain the project in greater detail and initially to ask for help in recruiting participants. After the first four meetings, I came to view these meetings as proving me with valuable insight into the context in which young people received and utilized home support services. Gatekeepers’ talk and their description of their work with young people also brought into relief their perceptions of which participants exemplified ‘young disability’. This latter point suggested that gatekeepers were mobilizing a discourse of young people that emanated beyond my recruitment needs for the project. I wondered if I was beginning to discern the objectified concepts that might somehow be shaping young people’s access to support. I decided to interview gatekeepers in a more systematic way in order to more fully discover the constituent conventions that shaped their work with young people.

**Gatekeeper interviews**

Seven gatekeepers were invited to participate in individual semi-structured interviews. I met with these individuals for 1½ to 2 hours at their workplaces. These gatekeepers were all members of health or disability related organizations and were responsible for programs that integrated ‘disabled youth’ into the larger community. The purpose of these audio-taped, focused interviews was to obtain information about the activities and experiences of gatekeepers related to support provision to disabled young people. Within this group were two child and youth workers, two social workers, one nurse, one occupational therapist and one speech therapist. All who were invited agreed to participate.²³

I began my interviews as focused conversations. I began the interview by asking gatekeepers to tell me what they believed were the key concerns facing disabled young people

²³All gave informed written consent, approved though University of Toronto’s Ethics Review Board.
with respect to home support. Although this is not the way IE generally begins, my purpose was to obtain an understanding of the 'official' and naturalized discourses about support that were forefront in workers' consciousness. I then adopted a more conventional interviewing approach, asking gatekeepers about the activities that comprised their everyday work. As much as possible, I asked questions to obtain detailed accounts of everyday activities and experiences that were oriented to connecting young people with support for independent living. Two interviews were with disabled workers who had been raised within the same system in which they now worked. These two informants were uniquely able to speak from two different standpoints - as a disabled individual and as a front-line worker in the state's efforts to prepare young people for citizenship. I also asked these disabled gatekeepers about their own experiences with support - and whether they saw or heard about similar experiences with other disabled individuals - particularly disabled young people. Texts and artefacts that were presented by the informant during the interview were documented in field notes.

Building networks

The interviews with gatekeepers eventually allowed me greater direct contact with the young people they served. Gatekeepers, eager that I witness their work in action, invited me to discuss the project directly with the young users of their services. At this point, Rita, the research assistant, accompanied me on my excursions. She and I dedicated weekend afternoons and many weekday evenings to picnics, BBQs, arts workshops, day camp activities, social networking meetings, disability dances, sex education workshops, teenager make-up application sessions...any activity that put us face-to-face with young people. We had only planned on bringing flyers promoting the media arts workshops to young people and their parents. In practice however, we were extra sets of hands; we were constantly enlisted into service. For example, one afternoon we worked with a group of 17 to 21 year old young people with intellectual impairments making macaroni jewellery. Another time we found ourselves holding up various fabrics against young women’s faces so they could decide on lipstick shades. One hot late spring day I transplanted a patch of rhubarb in an arts-garden project. After one afternoon playing soccer in strappy sandals, Rita ruefully acknowledged that she would have to re-think her clothing during this project. When she showed up the following weekend at a dance dressed
in runners, an old T-shirt and shorts, we were scornfully sent off by the organizers to haul cases of soft drinks from the walk-in fridge located in the basement.

Sometimes we observed more than we participated. Rita and I jokingly dubbed this period ‘the summer of love’. We had attended many sessions on ‘how to find a date’, ‘sexual mechanics 101’, ‘adapting your sex toys’ and sexually transmitted infection (STI) prevention. From disabled young people, we heard about boyfriends and girlfriends, first dates, proms, burning crushes and tragic break-ups. As we hung out at dances, meetings and other community events we noticed, overheard and interrupted many a tender love tryst and sometimes more passionate encounters. We began to recognize some other interpersonal relationships as well – who volunteered where, whose parents came along to events, who was friends with whom, who were sworn enemies and so forth\textsuperscript{24}.

These outings allowed me to witness support in action – indeed, our physical and intellectual abilities meant we were quickly woven into the network of supports around young people. In other instances, my eyesight meant I quickly became one of the people to be supported, placing me as a sort of novice participant in the activities of community and social care\textsuperscript{25}. I also came to recognize the community of young people and their families who were involved with these organizations – I learned ‘back stories’ to many of the young people who would eventually be involved in the project even tangentially. I learned about young people’s priorities and concerns and how these differed from or echoed what workers themselves expressed. Most crucially for the project, I directly met eight of the young people who later agreed to participate in the research.

Whenever Rita and I went to an outing, we distributed flyers about the media arts workshop series (see Appendix A). The flyer briefly described the project and directed interested young people to contact me by telephone or email. I often spoke with young people and their families about the project as we distributed the flyers. Six young people contacted me directly after reading the flyer once, but only two of these ended up participating in the workshops. The other four were under 16 years and did not receive parental consent for participation. This is where my participation in community events and programs was useful. I

\textsuperscript{24} Throughout this period of recruitment, people knew we were researchers since we were distributing recruitment flyers. We were also given consent by the organizations to recruit in these sites.

\textsuperscript{25} Of course I was not a novice to some form of ‘care’, but I was certainly unfamiliar with the supports offered in research contexts.
encountered the remaining participants and their families several times during various outings. I met some participants as many as six times before they approached Rita or me about participating in the project. Of the 18 core young participants in the research, 16 met me at least three times before asking to speak with me about potential participation. Of these, ten participants had a parent or worker who was also interested and invested in the young person’s participation. Indeed, 43 young people eventually expressed an interest in the project, but most could not make the requisite transportation or personal support scheduling accommodation. Without the investment of non-disabled adults (charged with their care), participation was impossible.

It is noteworthy that my participation in these activities also sensitized me to the place of participant observation in the research. Because these outings took place in an array of settings that were mostly unfamiliar to me and almost always involved activities I rarely performed, I often sought support – both formal and informal, while simultaneously cast as an ad hoc support worker. This sort of ambivalent positioning sensitized me to the work of receiving support. For instance, on one occasion I was helping at an arts and crafts activity in an outdoor setting. The craft ‘stations’ were set up under a complicated tent system that meant, as someone who was supposed to be ‘fetching’ supplies, I had to negotiate around tent ropes. I did not do well. After having tripped many times I tried switching tasks with Rita, but was sharply rebuked by the program manager. She suggested that I consider refreshing my mobility training at the CNIB. I was surprised by how her comment paralleled those of gatekeepers described in Chapter 5: she clearly framed ‘my problem’ as one of poor skills. It also seemed to be a moment of disjuncture (Smith, 1987) in which one’s actual experience does not fit with the assumptive order. I was in a setting that promoted the inclusion and personhood of disabled children and young people – indeed the program was open to both disabled and non-disabled children. The program thoughtfully created arts experiences that would be open to all young people; and yet there was a way in which support for that inclusion was only available in officially sanctioned forms – in my case through skills training. Beholden as I was to the manager for access to participants, I felt I had little choice but to meekly concur with her suggestion and resume ‘my duties’, slowly and poorly. For days afterwards, I alternated between waves of embarrassment and self-reassurances that I had misread the exchange. It brings to mind Tim Diamond’s description of participant observations, based on his ethnographic work in a US nursing home:
… invitation to the researcher to incorporate physicality, bodies in motion, the author’s and others. Putting one’s body on the line as part of a research project seems to give rise to discovery in one’s body of relevant data. Its specific aches and pains, its emotions, the messiness of the flesh and blood events – these provide a corporeal, incarnate base in which to ground the author’s and others’ bodies in action and coordination (Diamond, 2006: 59).

Through this and similar experiences, I became attuned to the ‘little gestures’ and comments that took place in the research setting. My experience during these outings helped me become aware of how even cursory interactions and practices could indicate and entrench an objectified course of action.

Core participants

A core group of eighteen young people participated in the project; of these, six took part in each of the three workshop series over 36 months. At the beginning of the project, the six young men and twelve young women ranged in age from 17 to 25 years. Participants had mobility, fine motor, intellectual, affective, visual and/or oral-motor impairments affecting speech. Fourteen of these participants had complex care needs and required assistance with many activities of daily living. Two participants did not participate long enough in the workshops to complete their videos. Two others participated in two workshop series. The first had been part of the pilot workshop series and decided to continue into the second series. The second participated in the second workshop series and continued into the third series. He eventually withdrew from these workshops after his parents refused to transport him.

Table 1: Participant Table

<table>
<thead>
<tr>
<th>Name</th>
<th>Workshop</th>
<th>Supports</th>
<th>Age</th>
<th>Disability</th>
<th>Primary activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cynthia</td>
<td>Workshop Series 1 (pilot)</td>
<td>Family Day program Unspecified</td>
<td>21</td>
<td>Quadriplegic Cerebral Palsy Severe seizures</td>
<td>Day program attendance</td>
</tr>
</tbody>
</table>

As I mentioned in Chapter 1, the project was divided into three different workshop series. I described this in greater detail below.

All but one lived at home or in a transitional living program at the time of recruitment. Over the course of the project, only four remained living with parents while the rest lived in group homes, transitional living programs or were living independently. Only one participant received direct funding for personal/home support, the remaining participants secured supports through CCACs, SSLUs and informal means. All participants except one received ODSP upon turning eighteen.
<table>
<thead>
<tr>
<th>Name</th>
<th>Workshop Series</th>
<th>Supports</th>
<th>Age</th>
<th>Disability</th>
<th>Primary activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rosalyn</td>
<td>1</td>
<td>SSLU</td>
<td>19</td>
<td>Spina bifida</td>
<td>High school student</td>
</tr>
<tr>
<td>Bernard</td>
<td>1</td>
<td>Family Day program</td>
<td>25</td>
<td>Intellectual disability</td>
<td>Day program attendance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Developmental support worker 4 hours/week (shared with mother)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Joanne</td>
<td>1</td>
<td>Family Day program</td>
<td>19</td>
<td>Intellectual and affective disability</td>
<td>Day program attendance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Developmental support worker 3 hours/week</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gerry</td>
<td>1</td>
<td>Family Day program</td>
<td>21</td>
<td>Down’s Syndrome</td>
<td>Day program attendance Supported employment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>support Private support workers – 3 half days/week</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anna</td>
<td>1 &amp; 2</td>
<td>SSLU Attendant care</td>
<td>19</td>
<td>CP</td>
<td>High school student</td>
</tr>
<tr>
<td></td>
<td></td>
<td>provided at school</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Douglas</td>
<td>2</td>
<td>SSLU</td>
<td>25</td>
<td>Duchenne’s muscular dystrophy</td>
<td>Volunteer and recreation activities</td>
</tr>
<tr>
<td>Caterina</td>
<td>2</td>
<td>Family</td>
<td>20</td>
<td>CP with cognitive involvement</td>
<td>Volunteer and recreation activities</td>
</tr>
<tr>
<td>Therese</td>
<td>2</td>
<td>Family (mother only)</td>
<td>20</td>
<td>Brain tumour with motor, cognitive and affective involvement</td>
<td>Community college student</td>
</tr>
<tr>
<td>Graham</td>
<td>2 &amp; 3</td>
<td>Family Education assistance at school</td>
<td>19</td>
<td>CP and other neurological conditions</td>
<td>High School Student</td>
</tr>
<tr>
<td>Isabella</td>
<td>2</td>
<td>SSLU</td>
<td>22</td>
<td>CP</td>
<td>University Student</td>
</tr>
<tr>
<td>Zachary</td>
<td>3</td>
<td>SSLU</td>
<td>20</td>
<td>CP</td>
<td>Volunteer and artist</td>
</tr>
<tr>
<td>Name</td>
<td>Workshop</td>
<td>Supports</td>
<td>Age</td>
<td>Disability</td>
<td>Primary activities</td>
</tr>
<tr>
<td>----------</td>
<td>----------</td>
<td>----------------------------------------------------</td>
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<td>--------------------------------------</td>
</tr>
<tr>
<td>Ainsley</td>
<td>Workshop 3</td>
<td>Family Attendant care 1-2 hours/day</td>
<td>17</td>
<td>CP</td>
<td>High school student</td>
</tr>
<tr>
<td>Melanie</td>
<td>Workshop 3</td>
<td>½ hour/day attendant care at home. 1 hour/day attendant care at school Workplace accommodation attendant care</td>
<td>19</td>
<td>CP</td>
<td>University student Part time employment</td>
</tr>
<tr>
<td>Joshua</td>
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<td>SSLU</td>
<td>25</td>
<td>Spina bifida</td>
<td>Volunteer and recreation activities</td>
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<tr>
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<td>Workshop 2</td>
<td>Case management</td>
<td>20</td>
<td>Schizophrenia</td>
<td>University student</td>
</tr>
</tbody>
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I would like to emphasize that the sampling of participants in this study was not intended to represent the population of disabled people in Canada. For instance, the sample does not include participants living with sensory impairments, who identify primarily as being consumers of the psychiatric system or who live with profound physical, cognitive and communication impairments. The research goal and methodological design of the project do not aim to characterize particular disabled individuals or populations, but to conceptualize, document and explicate textually mediated and coordinated doings related to the acquisition and maintenance of support. It could be argued that individuals with impairments not represented among the participants of the present study are nonetheless caught up in translocal relations coordinated by the poster child utterances. The ways in which they may have participated in dialogical work or the forms of support they sought and used may have reflected individual particularities or the nature of their disabilities, but their doings were still constituents of generalizing courses of activities related to support.
Media arts workshops

Overview

Three media arts workshop series were conducted between July 2002 and September 2005. The first workshop was planned as a methodological pilot, exploring the potential of using participatory media-based methods to create new and meaningful forms of participation within the research process, and to explore the feasibility of using this method to answer the research questions. Meetings took place weekly for a three-month period from July to September 2002, and then met sporadically for the following 18 months. The second workshop series, comprised of seven people, beginning in November 2002, incorporated some of my learnings from the pilot and was designed to explore the research questions in depth. This series was much longer than the first, ending in March 2004 with a community screening of eleven videos created to that point in the project. Workshop meetings were held on weekend days alternating weeks to accommodate participants’ schedules and support requirements. A significant learning from the pilot was how much I had underestimated the time to conduct the workshops. In the pilot workshop series, weekly meetings were 3 ½ hours long, but it was often difficult for participants to first manage a weekly commitment and second, to practice video making techniques in the short duration of the workshop session, given the demands with negotiating and waiting for support. During the second and third workshop series, I changed the meeting schedule to full day sessions, twice a month. The most significant change to take place in the first workshop series was the decision to create individual works rather than a collective documentary. I used the same model throughout the second and third workshop series.

The third and final workshop series, extending from May 2004 to September 2005, was less closely attached to the research goals of the project. This third group of young people assumed a working relationship with Trinity Square Video (TSV), a grassroots community arts organization and the barrier-free program at Anne Johnson Health Station. Participants were selected through a ‘call for proposals’ system in keeping with the funding body for this phase of the project and TSV practices. All those who submitted a proposal had already contacted me in regard to participation in one of the previous workshops. Participants were most keenly

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28 The third workshop series was funded by a Canada Council for the Arts’ Community Grant which I prepared in conjunction with Trinity Square Video.
interested in establishing themselves within the video arts community, while TSV hoped to learn how to make their organization inclusive to a more diverse membership. This final stage of the project was consistent with PAR principles, in which community members avail themselves of their new knowledge, developing infrastructure for its application as they part ways with the researchers (Maguire, 2000).

The first two workshop series were led by a video artist, Nas Khan, who was experienced in working with young people in similar digital video projects. I attended all the workshops and, although I clearly identified myself as a researcher, I took on the role of a workshop co-facilitator or assistant as needed. There were also two undergraduate research assistants involved with the project, Rita Chu and Terry Poirier. Rita was closely involved in both the pilot and second workshop series, Terry was only involved in the pilot series. When the workshops moved to Trinity Square Video for editing and the third workshop series, two members Aileen McBride, an editor, and Roy Mitchell, the executive director assumed facilitator roles, particularly in the latter days of the workshop. One to three personal support workers also attended the workshops to meet the support requirements of the participants29.

Finally, a number of disabled young people participated in the project peripherally. They came into contact with the project when they helped participants shoot and edit their videos. Because they were often part of the conversations that took place in the workshop setting, data from their interactions are included in this dissertation. All core and ‘peripheral’ participants, workers and workshop ‘staff” provided written informed consent (see Appendix C).

Each workshop session was structured to provide both technical/artistic instruction and a space for dialogue and sharing stories. Young people learned all aspects of video logistics and narrative development; they were introduced and carried out all steps of video creation – from conceptualization to final editing and dissemination. As much as possible, participants were given hands-on instruction with the camera and editing equipment. Following Freirean principles of teaching, participants were encouraged to use their own experiences as material upon which to practice their newly acquired video and media techniques. In the process, participants would be able to describe and document their experiences afresh, opening them up to renewed reflection with each step of the video making process.

Opportunities for discussion and feedback were built into the design, in order to

29 Workers and artists were paid through a Canada Council for the Arts’ Grant.
encourage dialogue and critical reflection among participants. As well, Nas argued that feedback was integral to the artistic process; audience interpretation and response was central to how participants crafted and conveyed their stories. In order to create engaging work, Nas instructed the group to offer one another constructive reflection and criticism. She posed the following questions to the group:

- How did that story make you feel?
- What did that story make you think about?
- The part that really captured my attention was…
- The part I didn’t understand was…
- Something I might like to see in this story was…

Sometimes the responses to these questions yielded data relevant to the research topic, however, not consistently.  

Work by other young and disabled artists was shown to the group to demonstrate alternative narrative and artistic expressions; however, we also used these artworks as a way to hear more from participants about their experiences of support. Images, either those created by participants expressly for the project, or those already in their possession that they planned to incorporate into their videos were also used to promote discussion. We also tried to structure conversations through exercises involving the various instructional components of the workshop.

Piloting the workshop

Initially, participants were asked to develop a single documentary about support. In the pilot workshop series, largely in response to participant requests and practical considerations, we decided that each participant would create his or her individual video.

In order to provide each participant with adequate support, Nas and I stipulated that each video could be no longer than five minutes and should focus on support. Final videos ranged in presentation from Disney-esque fantasy to cinema-verité attempts to provide a ‘video-camera’s eye view’ of a particular participant’s world. Some used simple shots of old family photographs, while others adopted ‘filme-noir’ or ‘Soviet-montage’ techniques.

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30 Some data related to the responses to these questions has been presented and published in other places.
31 Filme-noire is a cinematic style characteristic of Hollywood crime dramas spanning from the 1940s to the 1950s. Alfred Hitchcock films are an example. Soviet-montage refers to an avant-garde cinematic technique of the 1920s and 30s that relies heavily on editing different shots together to shape audience response.
While each work took up the theme of support in a unique way there was not a consistent claim made across the 15 videos. Nevertheless, taken together, the videos provide insight into the multifaceted and diverse ways in which these young people understood support. More significantly, the process of creating the videos offered insight into the work of securing support, beginning with the move to individual narratives. In many ways there were advantages to moving to individual short videos. Like the difficulty in finding an organized group of disabled young people to mobilize around support issues, the move to individual videos provides insight into the social organization of young disabled people’s lives.

Data Sources and Management

Data collection took place over a period of approximately three years from May 2002 to September 2005.

Entry and exit meeting data

Initial meetings with disabled young participants took place individually in a variety of locations including participants’ homes, recreation centres, participants’ health care institutions and local coffee shops. They were audio-taped. In the initial meeting I asked each participant what he or she expected of the workshop, why they were interested and if they had a story of support they wanted to tell. I also explained the overall project to participants, outlining Kari’s participatory policy review and my interest in support and citizenship and the relationship between the two. Some initial discussion of the details around stories took place at that time, but these interviews were intended to establish a sense of how young people understood support and of their expectations for the workshop. I also used these entry meetings to work out their specific accommodations with respect to the workshop procedures.

Through these meetings I became aware of the amorphous definitions of support that existed among young people and their reluctance to define support narrowly. I attempted to encourage each person to elaborate his or her own understanding and practices with regard to support, following the unfolding nature of their accounts. I began to develop a list of prompts from the first meetings, adding to them as new dimensions (work practices, problems, problems,

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32 Informed written consent was obtained at the beginning of these initial meetings. Informed consent forms were sent to participants via email and discussed over the telephone prior to the initial meeting. They were represented to participants in the initial meeting and signed.
knowledges) of support were raised by each participant. I used these prompts when they were warranted - for instance, when similar issues had been raised by another participant. This was particularly the case in initial meetings with the second and third workshop participants. By that time, I had a strong impression that young people were not able to articulate their experience of support easily, so my strategy was to ask them about a typical day, focusing on school, home and work and then ask questions about how they went about acquiring support for the activities they mentioned.

I also conducted exit interviews with participants after each of the two community screenings. In these meetings, I asked participants for their general impressions about the workshop and if they had any recommendations for future workshops. I returned to the issue of support once again, asking young people about the supports they were currently using, how they received those supports and the tasks related to managing these supports. Unlike the entry meetings, participants seemed to easily discuss several key forms of support they received including home/personal support. These audio-taped, personally transcribed meetings lasted from 30 minutes to 2 hours.

Workshop data

Workshop data were collected through various means. Each workshop was audio taped; two or more tape recorders were used in order to record discussions when we broke into small groups. I reviewed all tapes after each session, taking field notes and memos as I listened to the workshop's discussions. I tried to keep track of the various discussions within each workshop and then transcribed specific discussions from each tape. Occasionally, as my analysis developed, I reviewed the tapes again - sometimes transcribing new sections.

Audio-taping workshop sessions had several drawbacks. Two participants had respiratory impairments and spoke so softly that it was not always possible to discern their voices. Two other participants had speech impairments so it was often difficult to clearly make out what they were saying on the tape. This was a significant problem when I had not been in the room or present when they had spoken in small groups. I had no cues, no memories of their physical communication or the emotional content of their discussion to help me piece together what they were saying. When this occurred, I asked the research team member who had been

33 I elaborate further on this difference in Chapter 4.
with them to clarify certain segments of the discussion. In this way I was able to piece together what had been said.\textsuperscript{34} Another significant problem was that some participants stopped speaking whenever they became 'newly aware' of the tape-recorder. I also found that participants spoke in a somewhat more unrestrained manner when the tape-recorder was not present, as did the research team members. Consequently, I chose not to audio-tape all interactions. In editing sessions, I sensed participants were able to direct the process if they were not orienting themselves towards the tape-recorder.\textsuperscript{35} On other occasions, using audio-tape was simply impractical. This was true for the video shoots, which involved a lot of movement, cross-talk and management of other technology. Whenever audio-taping was impractical or impossible, I made field notes of what had occurred. Sometimes I jotted down quick notes when there was a break in the workshop (e.g. when participants were eating and could not speak) and then flesh these out once I was in my private office. Other times I waited until after the workshop session had ended. Similarly I included other discussions that related to the workshop and the larger project in field notes. Field notes mostly included telephone conversations and conversations that took place while I waited with participants for Wheeltrans\textsuperscript{36}. These were often closely related to the project or to support provision generally, but occurred at times when audio-taping was impossible.

I audio-taped research team de-briefing meetings after workshop sessions. We held these sessions after almost every meeting. We discussed what we thought had gone well in the session and what we thought needed improvement before the next session. Early in the project, these discussions dealt more with the actual structure of the workshop sessions, but as the research progressed, discussions took on a more analytical form. We debated what we thought was possible to accomplish in the workshops, the degree to which we should direct participants along their narratives, and so forth. Textual materials from workshops were also gathered as data. These included instructional materials distributed to the participants in each workshop, written work completed by participants throughout the workshop, email messages that were sent back and forth throughout the course of the workshop, rough drafts of individual narratives, storyboards and shot sheets. Many of these data were used together with tapes, transcripts and field notes to trace the re-working of final videos and the various influences in their creation.

\textsuperscript{34} Very little of the data produced when I was not present are used in this dissertation.  
\textsuperscript{35} Lomax and Casey.  
\textsuperscript{36} Wheeltrans is a public accessible transportation service that is part of the Toronto Transit Commission.
Finally, images by participants (photographs, drawings, practice tapes and raw and final videos) generated from the workshop were collected. As mentioned above, participants were given the opportunity to review and remove any images they did not want included in their projects. Participants were given one set of the photos, the negatives, raw video footage and various rough cuts and with participants’ consent, I kept a second set of those that were to be included in the project. These materials were used in conjunction with other data to track participants’ evolving stories.

Analytic techniques

Participant Analysis

The opportunity for participants to direct the analysis of ‘data’ departed somewhat from that described in the Krogh (2001) or Wang (1999; 2003) projects. As I stated earlier, the intent had been for participants to direct a thematic analysis of video-taped data of their experiences of support. However, the shift to individual short videos created different opportunities, although far less explicitly or consciously ‘analytical’. I would argue that analyses among participants emerged through conversations and interactions among all the workshop participants. In the chapters that follow, I highlight dialogue where participants worked out competing understandings of support – and other issues related to citizenship. While participants obviously were not reflexively analyzing ‘data’ in these instances, they were committing themselves to ‘an analysis’, or in keeping with Freirian methods, a critical consciousness. In my own analysis of the data, I have taken special effort to present these to the reader much as they occurred in the workshop. I have then added a second ‘layer’ of analysis, attempting to highlight the sequence of work activities directed at securing support.

Another illustration of participant analysis is related to their efforts to revise and edit their videos. Although these activities were primarily directed towards developing the artistry of the video, I began to see how revision and editing both indicated and informed participants’ analysis of the social and material conditions of support (along with other aspects of their lives). During revision and editing, participants identified and reflected upon the interpretive frames and responses different audiences might bring to their work. Participants also considered the different consequences of disclosing the conditions under which they received and used support.
Both forms of analytic work were pivotal to the knowledges young people acquired and practiced in order to secure support. Again, I present data in which this critical consciousness surfaced in participants’ talk and actions, making them available to the reader. While in some instances these are presented as ‘stand-alone’ excerpts in the larger text of the dissertation, such as longer passages of dialogue in which participants reflect upon and debate shared concerns. In other instances, I use participants’ analyses as a foundation for my own. For instance in Chapter 4, I present participants’ categorizations of their supports; I go on in subsequent chapters to examine the sorts of dialogical work participants would need to carry out in order to secure those supports. Finally, where participants’ analyses diverged from my own, I approached these as a ‘dialogical opportunity’, moments in which different voices are juxtaposed, brought together in mutual evaluation. I try to signal these moments of agreement and dissent in my writing.

**Researcher analysis**

I began my analysis through listening to audiotapes and electronic texts of the transcripts. My first review was to identify the ways in which participants raised support. I listened for ‘what’ participants understood as support, even if it did not closely relate to home support as it appears in the literature. Throughout my review of the data, I also paid special attention to moments during which participants spoke freely and easily and those during which they appeared 'at a loss' for words or seemed to have had difficulty expressing their thoughts clearly. I took articulate accounts or talk analytically as 'better rehearsed', most familiar and therefore dominant accounts of their work routines and likely to be those that most closely reflected the ideological objectified knowledge of support. By contrast, moments of inarticulateness, may signal moments of everyday experience which are commonly subsumed by textually mediated relations that organize participants’ routine activities. It is those moments that signal where people's embodied everyday, everynight work is out of sync with the social organization - these are precisely the moments in which the invisible ruling relations which organize participants’ everyday talk and action can be made explicit and explicated (Devault, 1999; Smith, 1987). It is in these moments that the actualities of creating the account become visible - for the virtual or textual reality has slipped away. In the absence of a clear institutional narrative, by default participants must resort to accounts of ‘what they actually do’.
This approach to analysis was most useful when I was reviewing comments made by gatekeepers, parents or other workers. Young disabled individuals – both the core members of the workshops and the peripheral members of the group – tended to have more difficulty articulating their ideas. So many aspects of their lives were unfamiliar or new\textsuperscript{37} (creating a video, living independently, using personal support workers, receiving ODSP, looking for a job, attending post-secondary school); they may have lacked the language and interpretive frames to speak all that they were experiencing. I took Marjorie DeVault’s (1999) suggestion “to develop an analysis through close readings of coherent narratives” for the insight into the “particular dynamics of institutional practices” of community and social care. I was interested in how young people were making sense of this unfamiliar social organization; I listened to how they shared and interpreted stories. I listened to the stories they told in the larger group and in one to one conversations, stories that were related in some way to support. Sometimes a story was only tangentially related to support, but as I examined its larger dialogical context, it was sometimes clear that the story illuminated the work practices or knowledges young people required in order to participate in support.

A good deal of my analysis focused on participants’ work practices and knowledge. Following Smith (1987; 2005), Mykhalovskiy, McCoy and Bresalier (2004) and Church, Diamond and Voronka (2004), I approached ‘support’ and ‘work’ as empirically empty terms, ones that wait to be filled with what young people said about their practice and experience. This notion of work is an extension in common use in institutional ethnography research, deriving from Alfred Schutz “as purposive, embodied action that gears into the social, physical world surrounding any one individual” (Schutz, 1962, cf Smith, 1999). By focusing on people’s embodied actions, Smith contends we pull ethnography out of the discursive and textual terrain that renders (young disabled) people’s activities understandable and explainable within the institutional order. In other words, I focused on what participants were doing in the ethnographic setting rather than bringing intact concepts of ‘youth’, ‘support’ or ‘work’ I previously encountered in the academic literature, media or policy to shape my observations and analysis. Work, as I use it in this dissertation, is not part of a theory-building exercise. Rather I viewed young people’s work coordinating an ethnographic project that commits analysis to exploring how their experience, in this case their experience of securing support, is organized.

\textsuperscript{37} This finding is discussed further in Chapter 4.
I also employed analytic techniques grounded in Bakhtin’s (1981) theory of language. Bakhtin argues that as individuals, we constantly struggle between authoritative discourse and discourses we find internally persuasive. Internally persuasive utterances are those that we can readily infuse with our own intentions, respond to, selectively assimilate and otherwise stylize (ibid, 341). How people work out this struggle is evident in our talk; therefore analysis involves looking for:

**Socially typifying language:** the language of social groups such as that used by gatekeepers, personal support workers, teenagers and so forth. An example might include contemporary ‘youth language’ that incorporates texting and other social media written text into verbal speech such as “It was so funny, I lol’d (laughed out loud)” or “What you sayin’ this weekend” (what are your plans for this weekend?). These phrases are typical of the contemporary young generations of the English-speaking North. This involved tracing the use of jargon or common short-forms that were used by participants within a particular context.

**Intersecting languages:** the languages that typify different social circles or specific contexts that come into dialogue or interaction with one another.

**Monologic languages:** languages that depersonalize, and intensify the differences between languages and their speakers. These languages leave no room at the edges for dialogue, instead they are unchanging across contexts, rigid, unyielding to the intentions of the speaker. Poetry, metaphors, schedules and scripted language work this way.

**Fixed terms:** words that are deeply authoritative, invested with authority, linked with power historically. Their meaning remains constant despite different contexts. Bakhtin likens these utterances to sclerotic deposits, words whose past meanings and context endure into the present and future.

Initially I focused primarily on words and utterances that related to support, particularly participants’ stories of support. As I describe in Chapter 5, my analytic interest shifted to an analysis of talk about the ‘poster child’. I began to examine what participants did discursively with utterances related to both support and ‘the poster child’. Again my analysis was informed by Bakhtin’s theoretical concepts with respect to dialogue. Among the dialogical activities I examined were:

**Intentional context:** Here I traced certain utterances through different conversations. In each context I asked what is the utterance meant to do? What response is the speaker
anticipating from the addressee? How is the speaker making the utterance do something that was not initially intended?

In order to answer these questions, I also examined how different utterances, particularly those that seemed to be used in different contexts, were combined or juxtaposed. I also paid attention to the tone and intonation which participants brought to an utterance. For instance, sometimes when participants repeated an utterance in a particular tone or with a specific intonation, they could shift its meaning to one that suited their unique intentions. Play, parody and mimicry were examples of bringing new tone or intonation to an utterance. I looked for examples of when participants used these dialogical strategies in their conversation, paying attention to whether or not they shifted the meaning of an utterance slightly or were able to expose some of its authoritative quality.

Decisions about writing

In the analysis of the data, I began to experiment with my writing in an attempt to capture some of the creative spirit of the workshops. I wanted the spontaneous and surprising ways in which I was learning about support to emerge in the text of the dissertation. While much of this dissertation is written in a conventional style of qualitative research – quotations or observations followed by explication and analysis - I inserted three distinct forms of experimental writing: mundane texts, vignettes and dialogue.

Mundane texts

I draw on mundane texts to illuminate and represent my analysis and findings. At the close of Chapter 7, I present a schedule of morning preparation tasks that a disabled young woman and her personal assistant accomplished within a half-hour period. The schedule is in large part based on a conversation with the young woman, but in other ways is a composite, synthesizing data from many conversations, observations and interviews; it communicated participants’ work knowledges and activities, resulting in social and body-based compromises, to accommodate institutional ‘time-tables’. These and other mundane texts (segments of scripts, sections of a letter exchange, a sample daytimer page) are intended as a textual bridge, allowing

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38 Mimicry and intonation give the words uttered their ‘real meaning’ (Bakhtin, 341).
readers to enter into the world of participants. These mundane texts communicate an analysis rather than serving as an example of something found in the research process. Each of these texts creates an interindividual territory with the reader, participant and researcher. While readers may have their own perspective and experiences of the text in question, its very ordinariness means that each reader can apprehend certain aspects of the text in common, and coordinated his or her everyday activities similarly. Returning to the example of the schedule presented in Chapter 7, we regard pacing, number of tasks, type of tasks, time constraints and other features of the text similarly.

Vignettes

I also introduce vignettes throughout my writing. Vignettes are short literary sketches of small occasions or incidents that occurred or were relayed within the larger project. Together, vignettes form the larger narrative of the dissertation. They work as ‘moments’ or breaks in the text which allow us to see the hidden work of securing support – they allow me to make this hidden work visible to the reader for explication. Vignettes also replicate the way in which support work was communicated to me. Although it was not until the latter stages of the project in which young people could articulate their experience of support, I often had access to their work through small, seemingly unrelated vignettes. In a sense, vignettes reflect ‘moments of discovery’ for both participants and myself, during which an experience or occasion, was reconsidered for its implications about young people’s activities.

Dialogue

Finally, I inserted extended passages of conversation or dialogue throughout the text. These allow some of the coordinating function of the poster child discourse to become visible to the reader as they were to me in the moment of their utterance. Representing longer dialogues offers the chance to show different voices both directly and indirectly. For instance, a conversation about accepting unsolicited donations from strangers demonstrates the ways in which different ideas and value systems may emerge from common experiences yet coordinate competing courses of action.

A second way in which I use extended dialogue is to ensure that the voice of participants with intellectual impairments were included in the larger dissertation. Developmentally disabled young people generally spoke in short phrases or single words. Often, I needed to ask many
close-ended questions or I would paraphrase and repeat what participants had said in order to comprehend what they were trying to communicate. By including these long tracts of conversation, I hope to make visible disabled young people as speaking subjects.

Several of the vignettes (and longer narratives) presented in this dissertation are in wide circulation among the ‘disability community’ in Toronto. I have encountered these stories many times since initially hearing them in the workshop. Isabella’s story about visiting Rosie O’Donnell, Elena’s concerns about looking for a partner, or Zachary’s efforts to video-tape the women’s march are stories that I would argue approach objectification in a Smithian sense. Stories circulated from one setting to another mediating relations of young age, heteronormativity and other social relations across the various circles of its articulation. I draw attention to the instances in which this occurs, proposing how the vignette may have shaped the activities of those in the immediate circle of its utterance and those who would be similarly influenced by it in other places and other times.

Ethical concerns

In total I submitted six separate ethics protocols to five academic institutions and organizations at the University of Toronto ethics review boards. Each of these was approved (Appendix C). Throughout the research process and writing, I have made every attempt to protect the privacy and confidentiality of the participants and the organizations involved in the project. Dr. Kari Krogh and I received written informed consent from all workers, project staff and participants. Whenever possible, I let participants know when I was going to use their dialogue or a particular story in presentations or in the writing of this dissertation. I paid special attention to this when I used an incident or an experience that could be easily traced to particular participants. In situations in which I did not or could not get this permission\(^\text{39}\), I have taken steps to combine similar details taken from different stories. Most information gathered through the course of the research was kept confidential. Each participant, except for project staff was given a pseudonym and I tried to minimize details that would reveal a person’s identity.

Despite these efforts, participant anonymity and confidentiality remains challenging. Participants were open about their involvement in the project and for obvious reasons wish to be

\(^{39}\) For instance, one participant passed away immediately after the project completed and I lost contact with two other participants.
associated with their videos. Several participants received media attention based on their work and have discussed the process of workshop participation publicly. I have found that although I had not planned to work with participants’ final videos, in some instances it has been impossible not to raise the video topic in discussion. I have recognized situations and stories discussed in the workshop setting, in other researchers’ publications and presentations. This suggests that some of what appears in this dissertation could be easily traced back to participants. I am most uncomfortable around confidentiality with regard to developmentally disabled participants. Consequently, fewer data from these participants appear in this dissertation in an effort to protect their privacy. In the end, while I would contest the existence of a bounded ‘disability community’, there are cohorts of disabled people who frequent the same few accessible places of recreation, education, transportation or employment, who use similar social services, visit the same doctors, attend the same rallies, political events, arts exhibits and so forth. Our lives are entangled through circumstance – and it becomes difficult to seek, let alone protect, privacy.

Another issue is that much of the visual data included images of participants and their friends and family that could not be anonymized. Again, participants were asked if they consented to my use of these images in reports of the project. Unlike their response to textual data, participants were more reluctant to allow these images to be used. Several took back their images from me or asked that they not be used.

Data files were stored on my password-protected computer. Transcribed data and research notes were stored in a locked filing cabinet in my office and only I had access to this cabinet. I removed all identifiers from written data; however, I have not removed identifiers from visual data.
CHAPTER 4
The role of support in accomplishing citizenship

Introduction

In this chapter I provide an overview of the supports used by participants and the implications of these supports for citizenship. I begin in the standpoint of young disabled people, taking their descriptions of their activities surrounding support as an empirical entry point into citizenship. As I described in Chapter 3, the data came from my participant observations in media workshop settings and from interviews and conversations with young disabled people, gatekeepers, and other workers and family members who I encountered in the course of the research. Although I began the project with a basic, personal understanding of the organization of home and personal support services to disabled people, I knew little about the everyday world of getting and using support services, the activities those supports enabled or how formal services were complemented or supplemented by a much broader array of informal supports. I was aware, as I have outlined in the background to the present study that, in using supports, disabled people opened themselves up to being viewed as passive recipients of welfare services. In my view, this obscured disabled people’s activities to secure and manage supports, erroneously casting them as wholly dependent on the caring work of others.

Because I was interested in young people’s work of accomplishing citizenship, I paid attention to how support enabled certain key ‘practices’ that arguably have particular salience to disabled people’s citizenship: self-determination, participation and contribution (e.g. Lister, 2003: Morris, 2005). I looked beyond actions typically linked to citizenship, such as self-advocacy, voting, rights-education, social security receipt) to include activities people adopt, resist and ultimately transform in order to achieve citizenship (Isin, 2009: 372; Isin & Nielsen, 2008). I was especially interested in tracing how supports enabled young people to carry out these ‘acts of citizenship’.

This chapter sets the stage for understanding the connection between receiving support and enacting citizenship. In the following sections I provide an overview of the extent and range of supports needed and used by participants. Throughout I try to signal how these contribute to and enable participants’ everyday lives, with a focus on citizenship practices of self-determination, participation and contribution. In order to offer the fullest illustration of the
potential links between citizenship and support, I limit my discussion in this chapter to assistance provided by family members, a decision I examine more closely in the next section of this chapter.

Support requirements for disabled participants

To review from Chapter 3, all disabled participants and two gatekeeper participants required supports for at least some aspects of everyday life. At one extreme, Cynthia, who had cognitive, speech and physical impairments and frequent seizures, needed assistance with all aspects of daily living including assistance with communication, fine and gross motor activities, memory and learning. In practical terms this meant she required support for everything from drinking a glass of water, to making herself understood when she spoke, to re-orientation after a seizure. Therese, an 18 year old college student had a benign, inoperable, brain tumour. She walked with a cane and had impaired mobility in one arm; she could perform most tasks of daily living. However, she also had learning disabilities that affected her memory and information processing. She also had frequent episodes of what one worker described as ‘altered affect’, in which her mood shifted abruptly. While Therese provided communication and physical supports to her fellow participants in the workshop, they often reciprocated by offering her memory prompts or reassurance when her anxieties rose. Other young people required some financial and physical supports in one or two areas of everyday life in order to live independently. For instance, Joshua and Melanie carved out an existence that minimized their use of physical or even social supports, preferring to perform as many activities of everyday life on their own.

My observations of support initially significantly diverged from what I was told about disabled young people. As I was initially planning the research, I was informed by family members, workers and other professionals that young disabled people would not be able to identify nor adequately explain the assistance they used. At first, as I reported in Chapter 3, this seemed to be an accurate assessment. Young participants were not initially forthcoming about the supports they secured and used. However, my early observations suggested that disabled young people possessed a much broader understanding of support than older non-disabled carers.

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40 Immediately following a seizure, Cynthia was disoriented. She had trouble remembering where she was, who was with her and what she had been doing prior to the seizure. On several occasions I observed workers reassure and re-orient Cynthia to her immediate surroundings. In this way Cynthia could gradually integrate herself back into her activities.
had imagined. That is, my findings belied what I was told by adult caregivers. Young people
could comment on supports, but in ways that did not neatly fit with taken-for-granted and
administrative categories.

At the project’s outset, participants’ descriptions encompassed a wide and
undifferentiated array of supports, often blurring the distinctions between its formal and informal
forms. Personal assistance, family, community services, clinicians, friends, financial supports
(ODSP and other forms of welfare benefits, charitable monies, gifts from family) and social and
specialized services all figured into their understandings. They did not readily employ public
policy terminology or academic conceptual categories to distinguish among its various forms.
Instead, they talked about “home support”, “personal assistance”, “home care”, or “attendant
care”, using these and other policy and labour market related terms interchangeably, with little
discernable intent. Similarly, participants never clearly articulated academic and activist
distinctions among support, assistance, help and care. Instead they seemed to simply use specific
terminology as befit conversational contexts.

It is not surprising that young people blurred conceptual and administrative support
categories. These objectified categories did not reflect the actualities of securing and using
support. Most participants had felt little prior cause to differentiate among forms of support.
Only two participants had been living independently for any length of time: Joshua was living in
a Support Service Living Unit (SSLU) for approximately three years when he joined the third
workshop session and Melanie was living in student housing on her university campus. The
remaining participants had either very recently entered transition to independent living programs
or they were still living with parents. Consequently, most were entering a period in which their
everyday activities and their support requirements were changing in tandem. Participants were
learning new activities, in new and sometimes unfamiliar sites, with an expanded scale of roles
and responsibilities. Moreover, most participants were just beginning to assume control for
meeting their support requirements. As children and young teens, they had relied on informal
supports based on personal, intimate relationships. For the first time, many were entering an
expanded network of formal support relations and were only beginning to learn how to articulate
clear distinctions between various forms of support. By the close of the project, most participants
were using some type of formal supports, and their descriptions and understandings had
correspondingly become more sophisticated and nuanced, probably reflecting their expanding
and increasingly complicated knowledges, practices and critiques of scarce and restricted support resources.

All participants also had support requirements that exceeded formal administrative/policy classifications, and they seemed unable to easily articulate discrete requirements. As described below, supports could exclude fairly conventional tasks (assistance with bathing, housekeeping, school work completion, etc.). However, many other activities involved intimacy, familiarity and trust. For instance, assistance with eating, or personal hygiene matters tend to be intimate activities in which each of us has our unique preferences and boundaries. However, official language and practices rarely account for these unique dimensions of everyday intimate support, instead seem to be fairly generic. Similarly, in order to get at this kind of complexity in supports young people used fluid and ambiguous and often quite personal language.

In the next section I follow participants’ emphasis on the informal supports received from family members, primarily parents. Particularly at the beginning of the research, young people spoke readily about assistance they received from parents. This emphasis is not surprising, since in the movement from family to independent living, participants gained critical insights into the supports they had previously held. Deficiencies and limits on the supports families provided were revealed as participants either ‘outgrew’ or developed requirements that exceeded what family members had provided previously. Yet as young people sought out new options for fulfilling support requirements, they gained an appreciation that the depth and complexity of family-based care was impossible to replicate in other ways. As supports were in flux, their nature and role in allowing young people to pursue and engage in the practices of citizenship came into relief. My overall focus remains on personal support in home, school and work settings; however, I have also noted the way these interconnect with other forms of organizational, welfare and charitable assistance. In the following sections I have organized participants’ understandings of support under the broad descriptive headings or ‘topics’ they used in their conversations. Although I try to use participants’ language, over the course the project their words eventually mapped onto formal administrative terms. For instance, I first encountered the term ‘environmental support’ in an interview with a disabled gatekeeper. However, as the project continued, disabled young people themselves also began to use this language, so while indigenous, the classification system is a hybrid of local and authoritative voices.
I begin with physical care/support. My discussion of this set of activities is divided into several sections: basic support, environmental assistance, prompting supports, ‘little luxuries’ and protest supports. I then discuss clinical or medically related supports, educational supports and financial supports.

**Physical care/support**

As several participants explicitly stated, family members “do it all”. According to participants, parents provided assistance with routine tasks of personal care (hygiene, eating, transfers), medical technologies and complex care needs, education, financial and in-kind supports. Ainsley described how her mother, a single parent, fulfilled most of her personal support requirements.

She can do everything for me of course. She’s there when I need to shower or get dressed or when I need extra help in the bathroom. Like if I’m going out, I can’t really fix my hair or do my make-up on my own, so she’ll help. (…) And school things too. Like she helps me with preparing assignments for school. I wouldn’t say she spoils me or anything (laughs). But she’s always right there for the stuff I need help with.

Ainsley’s sentiments were echoed by others. While young people could gesture to the array of supports provided by family members, the most fundamental were basic physical care supports in which they functioned as young people’s “hands and feet” (Murphy, 1987; Meyer, Donnelly et al., 2007). Physical assistance meant that family members acted as an extension of the young person’s physical body. Ostensibly those providing this sort of support, do so at the will and direction of the disabled person (Murphy, 1987); but as I will discuss later, this was not consistently the case when family members provided support.

While all participants accepted physical support from family members, Rochelle did so most extensively. Rochelle, a 19-year-old university student, had developed a neurological condition as a toddler. At the time of the project, she used a power wheelchair which she operated via a joystick. For limited periods she could move her hands and one arm in a restricted range. In order to write by hand, she positioned one elbow on the table, slowly, gradually lowered her forearm, until her hand met the table surface. From there, her fingers would ‘crawl’ spiderlike across the table to the pen. Grasping the pen, she balanced her hand into position so she could write a few words slowly into her notebook. On a good day, Rochelle could grasp and
raise a drinking glass close enough to her face to drink from a long straw; sometimes she could eat by herself. Most days though, someone helped her with these and other personal tasks. Other participants had less range of motion with their arms and hands, such as Zachary who always required assistance for these activities, or Douglas, who required assistance to place his hand back on his wheelchair controls if it slipped off. Yet, observing Rochelle provided me the best insight into the breadth of physical support disabled participants received from family members.

Rochelle and her mother intertwined their days such that Rochelle could count on her mother being at her side at a moment’s notice. Whenever we held a workshop, Rochelle’s mother drove her downtown from the apartment they shared with her younger brother miles away. She accompanied Rochelle into the building, pushed the elevator button and brought her to the TSV offices. Then she removed her daughter’s coat and other outerwear. Then Rochelle issued instructions about notes and other items to remove from her bag and place in specific locations around her. In sparse sharp orders, Rochelle specified the exact arrangement of items. Then she asked her mother to prepare her a drink, turn off her cell phone and suggest a time she could return. Sometimes, Rochelle asked her mother to assist her to adjust her clothing and/or to remove or put on an item of clothing such as a sweater or a scarf. Other times she asked for her hair to be redone, pulled off her face or an ill-positioned hair clip to be readjusted. Finally, she would ask her mother to return at a particular time in order to provide bathroom assistance. Generally, at 45-minute intervals, Rochelle’s mother returned to check on her daughter, and assist her with whatever concerns had arisen. This level of assistance continued until Rochelle and her mother were confident in my ability to find appropriate workers, at which time these tasks were slowly assumed by workshop staff for the six hour duration of the workshop.

Rochelle’s experiences illuminate the potential for physical support to foster self-determination. She was, for the most part in control of the support her mother provided. Moreover, her experience mirrored the immediacy in the support participants received from family members. Someone was always ‘right there’, as Ainsley stated at the opening, to facilitate their movement through their worlds. With her mother at hand, Rochelle never waited until someone came along to push the elevator button for her. Nor did she wait until a workshop staff arranged her papers for her. She never waited for public transit. She could fluidly pass through much of her day, as she directed her mother. Moreover, she could respond to her environment much like most non-disabled persons. Establishing little creature comforts, adjusting an
uncomfortable item of clothing or brushing away loose strands of hair, meant she could focus on the workshop activities rather than trying to suppress or transcend physical annoyances.

In addition to my direct observations, participants detailed assistance regularly provided by parents in their homes. Although she had just moved to a transitional independent living program at the start of the project, Isabella described the hour and a half routine that had previously started the day for her and her mother. Her mother woke up each morning at 5:45 am, 15 minutes before Isabella’s alarm went off.

She usually fixes herself a coffee first – the machine is on a timer, so it’s ready when she wakes up. She brings it in and it keeps her going. Then she disconnects the night ventilator. Then she sets up the hoist and transfers me to the wheelchair or sometimes a commode – but usually I just wait. Then she helps me shower, fix my hair – you know blow-dry, style it and stuff. Usually she gets me dressed for the day. Oh and that’s not easy since I put on so much weight!! Anyway then she and my little sister do this tag-team thing. My mom goes to make sure my brother and step-dad are up and makes my brother’s lunch. My sister finishes dressing me and fixes my make-up. Maybe she helps me get my bag ready for school. Uh – of yeah, she helps me brush my teeth – and yes, yes I know it should be AFTER breakfast – but the timing doesn’t work. Then my mom has breakfast ready for me in the kitchen and I just try to eat quickly and make my Wheeltrans for 7:30. It’s kind of a rush, but we get it done.

There are at least three noteworthy elements in Isabella’s account of her previous morning routine. First, physical support fits within, and was in part dictated by Wheeltrans transit schedules. For many participants, the physical assistance they received was structured more by external institutional regimes than by their individual or family/worker’s requirements. The influence of institutional routines and schedules only became more restrictive as young people moved to using formal supports. Second, her morning routine spanned a generous time period, with family-members ‘tag-teaming’ their efforts to complete her preparatory tasks. Finally, Isabella was able to extract many assistance tasks from her mother and sister. While not all were to her preference, it was evident from this and other comments that these supports were of her choosing. However, none of this – the extended time, the extra effort for ‘hair and make-up’ or a ‘team’ of support providers – were institutionally possible when Isabella eventually left her family home.

Such physical support allowed disabled young people to literally get out of their homes and to engage in the broader social world. But family members provided physical care that was
more nuanced than ‘getting out of bed’. Physical supports provided by parents went well beyond ‘basic’ requirements (eating, toileting, cleaning) to include those that might contribute to the construction and maintenance of a public identity. For instance, putting on make-up or hair styling lets young women be recognized as feminine, youthful, and fashionable. Social networks, friendships, volunteer and semi-employment opportunities came to them more easily, than with others who had less thorough, consistent and immediate supports.

Environmental assistance

Care-providers maintained the ‘physical environment’, tasks we had to quickly master within the workshop settings. Family members accompanying their young adult children to the workshop, like Rochelle’s mother, would ensure that their children’s physical environment was literally within ‘easy reach’. On the occasions when we accompanied someone to their home to work on parts of their video, I observed how care-providers organized household items in certain locations according to the young person’s direction. Anna’s aunt, who we ran into on one visit, quickly set up a book, re-positioned the television converter and set up a CD for her niece before clearing out of the apartment. These little steps enabled participants like Anna, who had some mobility, but within a limited range, to ‘take control’ of some activities without further assistance. As Isabella noted:

I LOVE my laptop – it’s just opened up the world to me. It used to be if I woke up before someone came to get me out of bed, I would just lie there. You know, like alone with my thoughts. Now I make sure that my mom or the worker or whoever, leaves the laptop on my swing table. That way I reach it on my own and I can email or msn or whatever. It’s like amazing! I don’t have to wait around if I want to do those things.

Isabella’s comments illustrate how citizenship and support are intertwined. When disabled young people, receive help in organizing even small aspects of their environments, their subsequent control over their lives can be greatly enhanced. Here, Isabella can autonomously begin her day, make some choices about how to use her time, rather than remain beholden on the availability of others. With more control over her time, she is freed up to do homework, network with others, write and otherwise participate and contribute to the larger community.

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41 With technological support as well.
Prompting (Thinking) supports

Some participants described themselves as relatively physically able, and therefore felt they did not need very much physical support. Rather than acting primarily as their ‘hands and feet’, family members (and others) provided, what Therese referred to as “prompting” and guidance to enable them to assume their own physical self-care. As several workers quipped, “what these guys need is an external brain”. Young people assessed themselves similarly, as Cynthia did

I have problems with my head. My head. Can’t think. My dad helps me think. My sister helps me with my head, remembering, thinking.

Or as did Bernard

Me? I have trouble to understand. To spell. To remember. You know – how things happen? The right to do. Everytime you should do the right thing. It’s my brain…in my brain. My mom remembers for me. She reminds me what to do.

The supports these young people received from others were not precisely physical, but did facilitate their physical self-care and movement in the social world. Joanne and Gerry were also both quite physically mobile but their developmental impairments meant they required help with the fine motor and cognitive work that often accompanies physical activities. Bathroom routines offered a window into the sort of supports they used. Joanne was quite capable of walking unaided to the washroom, to physically perform the minute tasks of self-care, however, she seemed to have difficulty translating these abilities into the actual ‘washroom experience’. She needed help to sequence the required tasks – everything from recognizing physical cues, finding the washroom, keeping the washroom door shut, unfastening and fastening clothing and hand-washing. Sometimes the assistance was cognitive, such as reminders and prompting. Other tasks, such as clothing adjustments or fastenings required more conventional physical support.

In a similar vein, Gerry seemed able to perform many activities independently – but always required physical supervision and sometimes more assertive intervention. During one of the first workshop sessions, Nas asked participants to display their photographs by sticking them on the wall with ‘sticky-tack’. Sticky-tack, a blue thick adhesive substance, looks like chewing gum, a similarity not lost on Gerry. Gerry promptly popped the substance into his mouth, much to the chagrin of the research assistant working with him. When we later shared the incident with his day-program manager, she noted how his family and workers continuously reminded
him about items that were and were not edible, since he loved to eat and would consume everything in sight. The manager went on to explain how he was never without the company of a parent or sibling, when not under staff supervision, in order to provide this ‘guidance’.

Prompting supports are in part pragmatic; they are basic efforts to maintain the public health/safety standards for young people as well as those with whom they interact. But these supports also have social and moral impacts. They facilitate the dignity and personhood – indeed the citizenship of these young people. Hygiene supports, like Joanne’s needed washroom assistance were aimed at keeping young people within the boundaries of bodily care and presentation (Twigg, 2006). While our social inhibitions around certain forms of bodily display and dirt may be built upon non-disabled/able-bodied (and minded) ideals, upholding these norms indubitably strip off some layers of stigma. Community participation and membership may come more easily; and certainly within the context of this research, participants who received this sort of support consistently through informal or informal channels were ultimately able to secure volunteer and paid work.

**Support for accessing “little luxuries”**

Sometime physical supports enabled what participants referred to as “little luxuries”: attendance at a special event, travel to another country, participation in recreational activities or hobbies. These activities could be difficult to support because they were outside young people’s typical routine. Melanie recounted a ‘black tie event at which she needed to wear formal attire. Usually able to handle her own clothing, Melanie described how her mother’s assistance made her attendance at the event possible.

Melanie: Thank god for my mum. I couldn’t hitch that dress up on my own! There’s all these times I think – man, I could use an attendant. This was one of those times – I couldn’t get the dress up. I kept losing my balance in the stall. I thought I was going to fall right into the can!

Ainsley: Woah, talk about fashion crisis.

Melanie: My poor mom. My dad was the designated driver… so she didn’t know she was going to end up doing that - so both of us were kinda wobbly! After a while she said, hey hold back on the drinks!

Isabella shared a slightly different story.
There was this one time, one of my best friends got married and her wedding was all the way out in mid-town Toronto. But you know at the time we were living in Scarborough. The church, the reception hall, nothing, nowhere did they have an accessible washroom. And my friend is like ‘you got to come to the wedding, you’re not allowed to miss this. Our friendship will be in jeopardy if you do that’. And then I say “Yeah, where will I pee?” And you know what she says “Well can’t you hold it?” Uhh, no I don’t think so.

… Anyway, here’s the thing. I DID hold it. I went at the church. Then my sister had to drive me all the way home – an hour away. My mother has to stay home on a Saturday waiting for me so I can go to the toilet! Then I pee. And then my sister drives me all the way back to the wedding. I didn’t even have the satisfaction of raiding the open bar. My mom says ‘listen, I’m here waiting for you if you need to go to the washroom’.

Caterina: That’s really nice of her.

Isabella: Yeah but it wasn’t right. I wish people would think about it, it’s not just me that’s inconvenienced; it’s my family or whoever else too.

In both scenarios, mothers not only provide physical help to their daughters, but in doing so, facilitate their daughters’ effort to participate in their communities. Support enables both young women to maintain a public presence: to enter public spaces, maintain and build social networks, to be seen and recognized as friend, daughter and member of the community at a significant social event. Participation and public presence moved citizenship from a legislated status, to an accomplishment connected to disabled young people’s activities in the cultural life of their communities.

It is noteworthy that both young women, like their peers throughout the research, characterized these supports as luxuries. In fact both Melanie and Isabella expressed frustration in the poor accommodations at their respective events and with the organization of formal support arrangements that did not allow for a personal support worker to be available to them. However, by referring to family supports as a luxury, they cast these as privileges, not as basic citizenship entitlements. And as privileges these supports may only be available to those who are deserving. It may not be coincidental then that both Melanie and Isabella reference their part in making parental support arrangements possible. By not drinking or eating, Melanie, Isabella and other participants managed and manipulated their physiological needs to fit the constraints of particular situations. I discuss these activities more fully in Chapter 7.

42 Neighbourhood names have been altered.
In other instances, family members provided physical support for recreational activities. Joshua’s and Zachary’s fathers each supported their camera work, performing the physical labour of setting up equipment for a shoot. Joshua in particular might have been able to perform many of these activities if he had obtained accessible equipment – but the cost was prohibitive. As an alternative, he asked his father or other non-disabled family members to accompany him and set up equipment at his direction. These supports were not necessities for survival or even a standard of basic dignity. These supports allowed young people to fulfill personal desires, easily overlooked practices of self-determination. In turn, by pursuing their interests and talents young people could develop their unique public presence in the community, in this case as emerging artists. These activities might also be linked to future contributions, since it is through their pursuit that young people develop the skills and work ethic necessary for future labour force participation (Groce, 2004; Morrow, 1994). It is noteworthy that the supports provided by family members to Isabella, Melanie, Zachary and Joshua, were contingent on their interests and availability, especially after young people moved into independent living situations. None of these participants had access to direct funding dollars and therefore were constrained by the supports they could access through their SSLU, or receive through employment. Although workers in their respective SSLUs were eager to do this work, there was simply not enough funding.

Supports for overcoming obstacles

As an additional dimension to physical supports, participants explained how family members sometimes went to extraordinary lengths to negotiate or overcome inaccessible physical environments. For instance, Graham described how family members carried him in his wheelchair up a set of stairs at the local hockey arena so he could join them to watch his younger relatives’ games. Claire, a peripheral participant in the workshops, recounted how her father interrupted his workday, drove to her school and carried her into an inaccessible theatre arts class. Sometimes these physical barriers were closer to home; according to Seth his parents “bumped my chair up the front stairs” to enter their home until they finally built a stair-lift in the garage when they could no longer physically manage his weight. All participants shared examples of how family members carried, pulled, pushed or dragged them over and around

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43 Melanie held a student government position which covered attendant care costs for her tenure in office.
obstacles in the built environment. These efforts are significant for several reasons. First, these efforts allowed young people to both participate in and contribute to their communities, even if it was only to assist a young person over a single step. Assistance overcoming obstacles allowed them to enter spaces in which they could work, learn, pursue their interests, consume and so forth. Yet, young people found these supports distasteful and humiliating. In a sense these supports undermined their self-determination, because they had little choice but to grudgingly accept them, even long after they had moved to independent living. As well, this sort of support could only ever be provided on an informal basis since paid attendant and personal workers were often not allowed by their agencies to perform activities that put their clients or themselves at risk of injury.

Finally, these supports were at odds with a disability rights analysis that eschews individual efforts to surmount barriers (e.g. Morris, 2004; Shakespeare, 2006). As I elaborate in later chapters, efforts to overcome barriers in this way may feed into to young people’s future stance towards securing and maintaining support. In order to secure membership and belonging in one’s community, disabled young people learn they must sometimes be prepared to come up with individual solutions, even if they involve risk to their psychic and physical integrity.

**Support for activism**

Another form of physical support provided by family and friends was practical assistance with activism. On occasion, family members’ willingness to help disabled young people confront environmental barriers nurtured political protest. Joshua recounted how he got ‘stuck’ on an escalator in a subway station. Like some other manual wheelchair users, he occasionally wheeled backwards onto the escalator, jamming on the brakes for stability. Precariously balanced in this way, he like other ‘extreme’ wheelchair users could access otherwise inaccessible subway stations, allowing them to travel between floors. While obviously quite dangerous, this practice was in part an act of protest against an inaccessible transit system⁴⁴, a transgressive strategy of self-determination. On one occasion, however, the escalator stopped moving when he was mid-flight. ‘Stuck’, Joshua demanded that the transit employee call his father for help. Upon hearing the story, workshop participants could barely contain their amusement.

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⁴⁴ Since the time that he told this story, the transit system in Toronto has progressed towards greater accessibility.
Melanie: Get out! You called your dad?
Josh: Yes. He used to balance me on the escalators when I was younger. He knew what to do to get me down.
Melanie: Wouldn’t the EMS guys know that too? You called your daddy?
Josh: No. I knew my dad would get me down and that they (TTC personnel) would listen to me if he was there. They would take me more seriously like (clip) He obviously would take me seriously, so you know, the officials would think – like okay, maybe this guy knows what’s what.

Although Joshua never directly framed his actions as political, I believe they can be interpreted as such. They clearly draw attention to the ways in which the built space of the subway station reinforces unequal movement around the city. Although it is difficult to assess how successful his actions were in contributing to better access, his father’s support is integral to his project. First his father ensures his safety and well being, ‘rescuing’ Joshua when his plan goes awry. This sort of support allows Joshua to take the risk of political protest. Second, Joshua’s comments suggest that by recognizing and validating his son’s presence, his father paves the way for relatively powerful others to do the same. If nothing else, his father’s support seems to give Joshua the confidence to make his political claims.

Support for this sort of transgressive activity was again never sanctioned for disabled young people through formal support channels. While this form of support was uncommon among participants, it most directly and consciously promoted citizenship. Both young people and their families co-operated in voicing (or acting out) their discontent about some disabling aspect of the environment. Unlike Melanie and Isabella’s description of supports as little luxuries, support in Joshua’s story was an extension of his claim for equitable entitlements to community resources – in this instance public transit.

Clinical support

All participants reported using unpaid family support to manage their clinical self-care. In Ontario, medically-related care provided in the community is restricted through legislation. Personal support workers are only permitted to provide clinical interventions in a person’s home. In other settings, such as schools, work, on public transportation and so forth, only legislated health care professionals (RNs, RPNs) may carry out ventilation, physiotherapy suctioning, gastrostomy tube feeding or administering prescription medications (Lilly, 2008). Unfortunately,

45 Only Joshua, Melanie and Therese used this support.
funding constraints meant that most participants could not access these qualified personnel easily. Since all required some clinical intervention from time to time, participants used informal supports, frequently parents who were legally sanctioned to do so, to carry out these functions.

Unlike physical support, young people’s descriptions of clinical support seemed emotionally intense. Many participants had been and still were considered medically fragile; they credited their survival to the clinical support provided to them by parents. For instance, Therese poignantly credited her mother for her survival after two operations to remove her brain tumour.

She is my hero. I believe she saved my life. After my surgery I couldn’t do anything. I couldn’t talk or get out of bed. But I knew everything that was going on you know. Everything...(The hospital staff) didn’t know that (…) But my mother knew. She was my advocate, my voice when I couldn’t speak. It was her, the bond we have, it’s the spirit that helped me. She’s the reason I’m here today.

In her final video, Therese described how her mother helped her re-learn how to “do everything” including how to talk, walk and think clearly. She, like other participants, appreciated that these actions did not solely stem from parental obligations, but reflected her mother’s valuing of her as a person. As Ainsley noted,

You know we’re lucky our parents are willing to look after us. If they weren’t, we’d have been left behind in some NICU (neonatal intensive care unit) somewhere... I hate to say it, but left to die. Throw away people.

Support then, to participants, secured the most fundamental form of self-determination: the right to “entry into being” (Frazee, 2003). Participants had health care support needs that often exceeded what they could publicly and easily access, but were provided by those who had an emotional stake in their well being. Participants found that formal support workers did not share in this stake. As the study progressed, disabled young people were increasingly in situations in which no informal, family-based supports existed. When this occurred, they had little choice but to retrench their movements and living arrangements to the few places where they could obtain regulated care – or simply do without this care. I examine this in greater detail in Chapter 6.
Educational Support

Another form of support participants named and described was educational support. Disabled young people, their parents, personal support workers and professionals distinguished support provided in schools from supports provided in homes and in communities. Educational supports seemed to overlap with the supports presented above, but may also refer to activities that were directed to a different site of public presence. These supports involved physical supports related to the completion of schoolwork, but were imbued with a commitment to the young person’s capacity for legitimate academic accomplishments and the benefits that derive to others from those accomplishments.

Throughout the workshops, participants casually referred to the ways parents or siblings organized their work areas, retrieved and set up their reading materials, typed revisions for essays, read texts aloud, helped them memorize material for tests, and otherwise facilitated schoolwork.

All the participants had received additional supports while in elementary school. This usually meant they had access to an educational assistant to help them with physical care, personal support and completion of in-class work. All participants complained that allotted educational assistance hours had been inadequate; they rarely completed schoolwork on time, missed out on classroom instruction during personal care assistance, ate lunch segregated with other disabled students rather than friends in order to share a personal assistant, and so forth. However, participants who received ample one-on-one assistance had other complaints. They had been constantly accompanied by a formal educational assistant and found private time with peers impossible. In order to escape constant adult supervision, they ‘opted out’ of consistent education support to gain some “normal kid time.” The upshot was that, in either situation, young people had to seek out extra assistance from family and friends outside of regular school hours to complete or catch up on schoolwork.

Unfortunately, drawing upon family members for help with schoolwork carried unique challenges. Participants acknowledged that sometimes help from others around schoolwork crossed “ethical boundaries”. As Anna recalled:

My mom used to help me with my schoolwork, but then it got a little weird. She wouldn’t write down stuff I said. She’d write down what she thought I should be saying. So then, I’m always worried that it might seem like my mum…is maybe
like plagiarizing or something? I made her stop that – but then there were these other times I would make mistakes in my work. Like big mistakes and I’d come home and yell at my mom. You know, like why did you let me hand it in like that. When I started college I thought, alright, that’s it, I do it by myself now.

Here, Anna grapples with a problem of legitimacy as she accepts support from parents. Many participants recognized that when family members supported them in school, their academic integrity, independence and competence became suspect. Participants expressed exasperation at how support providers were assumed to have had actually accomplished the work. I address this issue more thoroughly in *Chapter 6*, but here I will point out that young people responded to these allegations in several ways. Some internalized them and lost confidence in their abilities. More often, they sought out the most ‘neutral’ form of assistance, as Anna eventually did. Anna obtained technological aids, a modified keyboard and voice recognition software that allowed her to attempt work without assistance. But, like other participants who needed scribing support, she complained that the technical aids did not produce the same results as working with a ‘live person’. Computer viruses, printer jams, technical glitches with the voice recognition software were just some of the problems that participants could not resolve without human assistance. Yet once technological supports were in place, most found justifying human supports difficult. Ironically, they ended up relying on family and friends for support once again.

Educational support, then, is in an ambivalent relation with citizenship, raising questions about the legitimacy of disabled young people’s achievements. Particularly when supported by parents, young people’s work was not seen as entirely their own, but was attributed to those who were providing assistance. As a result, their contributions and accomplishments as emerging citizens were disqualified. One way participants addressed this was to adopt a utilitarian approach to support, replacing one-on-one personal supports with technology, or by workers who the outside world would perceive as disinterested and unlikely to do the young person’s work. However, in order to make significant achievements at school (and in later life), young people needed workers willing to invest in their accomplishments.

Young people described other ways parents offered support to their educational pursuits. As some participants had begun post-secondary education, studying and completing assignments became more demanding. They found they needed to dedicate more and extended time to schoolwork, in turn affecting their support requirements – especially around scheduling.
Rochelle: I try not to pull all-nighters if I can. Well, to be honest I just can’t. Because if I do, someone’s got to stay up with me till I go to bed and that’s always my mom. So, let’s say I decide to stay up to three in the morning to finish a paper. Then my mom’s staying up until three too, otherwise how would I get into bed?

E: I remember you mentioned you stayed up editing until quite early in the morning – so who was your assistant then?

Rochelle: Oh for the film projects? Yeah that’s right. Oh, yes my mom did stay up with me those times.

Esther: She stayed up?

Rochelle: Oh yes, I needed her help with paper and reading and stuff. Yes see that’s what I mean. But the film project…that couldn’t be helped.

The supports Rochelle’s mother provided for ‘all-nighters’ were essentially physical care: maintaining the work environment and acting as Rochelle’s ‘hands and feet’. However, there is a commitment in providing this form of support that seems to go beyond everyday personal care. In providing support, her mother actively enabled Rochelle to make artistic and scholarly contributions not otherwise possible. Through making these contributions, Rochelle could establish herself as an active citizen in several different ways. First the films created through her ‘all-nighters’ were the realization of Rochelle’s potential to be productive. The film also served as a vehicle through which to showcase the work of other artists – dancers, musicians, actors, technicians. As Rochelle’s films traveled the film and video festival circuit, she secured further funding, hired others, creating small yet highly coveted employment opportunities in the culture industry. Her success helped TSV secure further public grants to fund the work of other marginalized artists. These contributions emerged from Rochelle’s artistic vision and endeavours – but without the exceptional support from her mother, it is unlikely she would have realized them.

**Financial Support**

Many participants indicated that families provided them with financial support, either through cash or gifts-in-kind, sometimes regularly. As Isabella described:

My mom just deposits money right into my account. She knows how much I get from ODSP and OSAP and how much it costs for me for rent, food and other stuff. She deposits it about a week and half before the ODSP cheque comes in. It’s a big help. I couldn’t do it really on my own.
Isabella’s mention about the timing of her mother’s bank deposit is suggestive; she like many others could not stretch limited ODSP payments to meet her costs. Unlike gifts-in-kind, participants positioned money from family as a consistent form of financial support that, when consolidated with state income redistribution, allowed them to meet their basic needs.

In general, participants seemed to be cautious consumers. Joshua, Zachary and Douglas each wanted specific video and computer technologies, but complained about not having enough money to buy these items. Rosalyn, who received supplements from her parents, talked about clothing she could not afford. With the exception of participants from more well-resourced families (e.g. Caterina, Gerry, Melanie) all participants were cautious about spending their money – even small decisions like buying a soft drink were carefully considered. This hesitation and prioritizing around spending, together with comments about lack of money, suggested that cash received from parents must have been directed towards covering their basic expenses.

Participants also described having received gifts-in-kind from family members. Upon moving out on their own they were given furniture and other household items by their families, usually their parents. Although many of these items were not to their preference, young people appreciated the immense cost-savings. They also relied on their families for food, toiletries, household cleaners and so forth. All of this seems consistent with the supports financially secure middle and working class parents offer their children when they first leave home (Coles, 1995; Jones, 2009). However, as I will describe in Chapter 7, these financial and in-kind supports were critical to young people’s efforts to secure extra personal supports, consequently enabling greater control and choice in their everyday lives.

In the preceding sections I provided an overview of the forms of support identified by participants. As I indicated at the outset of the chapter, I have narrowed my presentation to the informal support provided by family members that substituted for or complemented the formal supports offered by paid workers. In what follows I focus on the unique dimensions of supports from family members and suggest how these could both enable and limit young people’s efforts to accomplish citizenship.

*I never directly asked young people to report details of their parents’ income, occupation or living situation. However, over the course of the project, I learned many of these details. For instance, I dropped off one participant to his family’s home in an affluent neighbourhood; I could see what cars the family drove and I knew the father worked as an executive at a bank. In contrast, when we shot footage for other participants, I found myself going to their homes, located in social housing.*
Support from families as enabling citizenship

Relying on family members for support had significant advantages for participants. First, relying on parents lessened the work young people had to devote to managing supports. Participants described how their parents anticipated their needs in tandem with their own awareness. Several participants described how their parents provided support without their “even” having to ask. As Rochelle elaborated:

My mother looks after all my support needs. We have a deep connection, I suppose deeper than most mother and daughters. No one ever does transfers or bathroom support like her. It’s intuitive now, we don’t even have to speak.

This rapport and connection freed up participants’ time (but took up their parents’); they did not have to provide instruction or direction for the support. Indeed they did not even need to take the time to ask; an especially prized benefit for those who had speech impairments and were not easily or quickly understood by others. After about a year in the project, Rita, the research assistant found herself developing this innate sense of participants’ support needs.

It’s like a rhythmic thing isn’t it? I just get to know, ‘oh she wants that now’. So I just push (what she wants) closer to her so she can get it without asking. Or you know with Douglas, with drinking… it’s like I can just feel… I don’t know maybe he breathes differently or something…I just know, it’s time to lift the glass. Like it’s better for us now right? He doesn’t have to ask, I don’t have to figure out what he’s asking for... we just stay in the rhythm of whatever we’re doing.

Rita illuminates how familiarity moves support into an intuitive even anticipatory relation. As she notes, this relation “made things better” since support tasks could be performed quite quickly, leaving participants with more time for other activities. Participants themselves also noted time-savings….

As much as I hate asking my parents for help, it’s about a million times better than asking a worker I don’t know well. My parents get it, they know how it all works, everything goes faster. (Douglas)

One sad thing about moving out (of my family home) is that everything is going to take sooo much longer. Like my mom and sister are superfast – you know I don’t have to waste time telling them how to position the showerhead or how to put on my make-up. Or whatever. (Isabella)

I feel I’m really busy with school. Not overly busy, just everything takes so long. Like getting to class, I have to go way, way out of my way to get to the accessible entrance. That’s part of why I still live with my mother. I have to save time.
wherever I can. I don’t need to direct her. She’s figured it all out what works best for her. For me, it’s more efficient this way. I can manage my time efficiently.

(Ainsley)

In these comments participants invoke a neoliberal sensibility of efficiency and productivity – often at odds with the receipt of social benefits. Spending extended time in mundane support activities\textsuperscript{47} left little time to accomplish other activities typically associated with citizenship. Given that no participant received more than two hours of formal personal assistance per day, the speed and efficiency of the work performed in each support interaction took on a greater importance.

Another benefit is that participants were assured a fairly high and consistent quality of support from family members. Young people described their parents as skilled and experienced in providing complex and ‘risky’ supports. Often participants made reference to their family members’ acknowledgement of their limits when providing supports, in striking contrast to strangers, friends, teachers or even personal support workers whose skills and self-awareness they regarded with more scepticism. At no point did participants ever share an incident in which they felt their parent had put them at physical risk, even during lifts and transfers in contrast to their accounts of PSWs and friends.

Finally, parents allowed a form of ‘one-stop-shopping’ – providing an array of supports that were otherwise impossible to access simultaneously or in co-ordination. Traditional supports tend to be divided into separate and particularized spheres of everyday life and associated with specific institutional contexts. As I have already noted, participants could get educational assistance while at school, but not at home where they completed homework and studied. Similarly, participants could access basic clinical supports such as suctioning, ventilation support or administration of medications by personal support workers while at home. However, SSLU, health and/or educational policies precluded workers providing these supports while participants were out in the community, at work or at school. Parents’ capacity and willingness to be available at different times in a variety of contexts mitigated the gaps among poorly co-ordinated and patchy resource services.

\textsuperscript{47} All through this, of course, parents found themselves in a similar situation to their children in that they were providing this mundane support.
Support from parents as limiting citizenship

Up to this point, participants’ descriptions positioned support from family members as almost a ‘gold standard’. Compared to residential care, help from parents enabled young people to control and follow their own life paths, to participate in the operation and future of their communities and to make a range of contributions commensurate with their young age. In the next section, I present some complications to this depiction. First, changes in the lives of both participants and their family members often meant that informal support was no longer feasible. A second complication was that informal supports from family could limit the ways in which participants engaged in those very activities aimed at accomplishing citizenship. In some instances, the support received from parents almost shunted young people towards peripheral forms of citizenship.

Participants often had insider knowledge of the time and energy their family members invested in their care. For instance, parents’ consistent presence or ability to be “right there” to provide ongoing support meant they would forego vacations, full-time employment or other life decisions. As Therese speculates

I think my mother would have left my dad a long time ago. They’re relationship is pretty loveless. I know she’s stayed for me. She’s spent all her time looking after me…like helping me with everything. School, my medical issues, doing my rehab with me, feeding me, getting me to the toilet…everything. She’s made a lot of sacrifices. It’s like she’s put her life, her happiness on hold so she could look after me – be there for me, you know what I mean?

These perceived sacrifices seemed to impose a sense of obligation on young disabled people, infusing future support interactions. Later their awareness of such “sacrifices” served to motivate young participants to either acknowledge or redress them in their interactions with paid support providers. As I discuss in Chapters 6, 7 and 8, young people’s attempts to mitigate the hardships for their workers’ led to their constraining their own choice and control over their everyday lives.

Familiarity also brought its problems. Within our workshops, I was troubled by how routines made it easy to over-ride participants’ ‘voice’. We all slipped into comfortable routines that took for granted what participants wanted. Assuming we already knew people’s preferences meant we might not take the time – often extended time - to listen. I cannot think of occasions when this may have happened within the workshop, but there were suggestions that just as
familiarity, routine and efficiency may have fostered community participation, it was as likely to limit self-determination. As a gatekeeper noted:

I had this one kid I was working with and he had the best shirts. One day he comes in wearing this great purple number, really funky. And I said that’s a great shirt. I love that shirt. He looks at me and says (adopting a sullen tone) “I don’t. Purple is for girls. My mom put this on me this morning”. And I’m like ‘hold on, hold on! Your mom picks your clothes? Why’s that happening? Now your mom has good taste, but then we’re both middle-aged women, so that’s probably why I like it.” This kid is seventeen and his mom is picking out his clothes. That’s just wrong. How’s that kid ever going to make a decision for himself? (Gatekeeper 1)

Participants echoed these comments. Although they clearly valued the benefits familiarity brought to the support interactions, young people found it difficult to challenge established practices. Rosalyn had never been able to purchase her own clothing. Graham had never been allowed to set his own bedtime. Joanne participated in swimming competitions for a charitable agency at her parents’ direction. Almost none of the participants had ever been able to prepare (let alone direct the preparation) of a meal. None reported having spent an evening alone until they had moved to a transitional housing program. Most young people talked about reverting to patterns of eating, hygiene, dressing or other everyday routines that no longer suited their schedules, preferences or needs but were too difficult to change. Graham explained:

Well there’s no point telling her (mother) now. She’ll just feel bad. And I dunno, I don’t want to deal with that you know. It’s no big deal. I’ll cope.

Or as Melanie quipped about her brother.

M: Oh yeah, like after all this time I’m going to say anything. No way! I don’t want him starting to second guess his every move. I want him feeling as if everything he does is special, perfect. I figure he’ll just keep doing those things.
E: Even the things that aren’t helpful?
M: Gotta take the sweet with the sour right?

In this way familiarity undermined self-determination, often at the intimate level of the body. Worries that parents and other carers would withdraw supports seemed to cloud support interactions, so young people rarely challenged established practices. As young people moved into formal support arrangements, they carried forward a reluctance to challenge or re-direct established practices.
Participants faced other limitations with respect to citizenship as new questions around support arose. What supports could family members provide? Which family member should provide supports? What supports could young people accept from family members? How should participants respond to, or reciprocate family supports? Participants faced these questions as they encountered new pressures to revise the organization of caring labour provided by parents and other family members. Those who had grown up in heterosexual two parent families identified recent shifts in the gendered division of support labour in their home, especially related to cross-gender intimate supports\textsuperscript{48}. For instance, Zachary described the changes in his family as he got older.

My dad and uncle always did most of the personal things when I got older. I came to Toronto for surgery when I was in grade seven. I spent most of the year here. When I went back home that was it, my mom didn’t do any of that personal sort of you know...
E: Personal?
Z: Showering, getting dressed, shaving... well my mom could shave me, but I got to...I wanted my dad.

Douglas also described how his father and older brother took over these various aspects of intimate support gradually. He explained that as his impairment became more involved and he could perform fewer “personal” activities unaided, his mother “sort of went into the background about those things” and his father and older brother played a more central care-giving role. Others, however, resolved tensions around cross-gender care by moving to paid formal care providers to provide intimate support (eg. Showering and shaving).

As well, over time, participants found social sanctions against the requests they could make to family members, particularly parents. Isabella poignantly recalled a high school health class:

The teacher is showing us all these diagrams and we’re sitting in a circle and it was like very kumbayah, you know? And she says to us, like, we should become familiar with our bodies as women. Like she tells us that when we go home that night to stand over a mirror and take a look at our genitals. And I just started killing myself laughing. I couldn’t stop – the whole class is looking at me, and just there laughing hysterically. I completely lost control. They never knew why I was laughing. I’m sure they thought it was about the word genitals or something...But I had this image when in my head of going home and asking my mother to put a mirror between my legs so I could look at myself. That teacher had no clue about what she was saying. Believe me, I got home and I wasn’t

\textsuperscript{48} For example, bathing, toileting, sexual, etc.
laughing anymore. I was down, really, really down. I thought, my god, I don’t even know what I look like in the nude. I don’t know what my body looks like. I couldn’t even talk about that with my mother, let alone ask her to put me in front of a mirror…you know, to let me see.

Similarly, Claire, a young disabled woman who helped with shooting several videos, spoke at length about negotiating support with parents and partners. As part of a larger explanation about the excessive support needs that would emerge if she were to date or marry a disabled man, Claire recounted a recent date with someone who was also a wheelchair user.

He comes to pick me up for my date – and then my dad has to bring me to the cab, gets me into the cab. Whose parents do that? I thought – wow, is this going to happen with all my dates from now on? When’s this going to end?

Both Claire and Isabella were keen to find alternatives as their support requirements began to tread on more intimate ground. While relationships with parents often involved bodily and personal contact that many non-disabled young people do not share with anyone, including parents, it seemed some intimate spheres were socially awkward if not taboo. In both these and other instances, receiving support from parents stood in the way of young people’s autonomy around their sexual and intimate exploration and expression – certainly a key part of adult citizenship. For instance, knowledge and control over one’s body and sexuality are central to maintaining one’s safety and being able to recognize potential violence (an argument Isabella tried to make in the creation of her final video). As well, dating and forming relationships are precursors to forming longer lasting partnerships and eventually families. However, most participants were clear that these activities could not be supported by their parents or other family members49.

Sometimes participants ceased using family members as supports as they developed other parts of their lives. Douglas and Zachary for instance, decided to move from their remote rural homes into the city in order to be part of a wider, more accessible community. Obviously this dramatically narrowed the nature of support they received from their family members outside visits. Other participants began relying on parents far less as they moved into post-secondary education. Although they were clear that receiving support from parents at university or college seemed to exceed the boundaries of typical parent/child relationships, other reasons made

49 It is noteworthy that few supports currently exist for intimate or more accurately sexual supports, although viable models exist elsewhere (Shildrick, 2004; Tepper, 2000).
parental support impossible. The irregular nature of post-secondary student schedules (long hours, stretches of time outside of class) and more sophisticated academic work meant that parents were no longer a practical form of support. However, some participants did continue to rely on parents extensively. As I describe in a subsequent chapter, Rochelle’s mother provided unique and complicated personal assistance that most workers were unwilling to perform. However, eventually most participants found that their opportunities for community participation, self-determination and various forms of citizenship contributions were constrained if they continued to rely on family members for support. With this, they began to more purposefully enter the sphere of formal supports.

Towards The Next Chapter: Moving from family to formal support

In this past chapter I looked at the various forms of support used by participants. These supports seemed to have an implicit ‘chronology’ for lack of a better expression. As participants grew older, they required new supports, while other supports were no longer needed. Young people began to use supports in new sites such as school, college and universities, day programs and sometimes workplaces. New complications, tensions, limitations, obligations and reciprocities arose through the provision of support. While I am not interested in explicating this chronology per se, its underlying presence created a ‘temporal’ opportunity in the larger research project.

Once the Poster Child Shoots Back project was underway, participants started in earnest to move away from parents as their primary support providers. This meant they needed to negotiate the world of more formal supports. Several had experience with formal supports since their parents had used Special Services at Home to fund attendant care, in home therapy and respite care. Others had spent time in institutional settings for up to three years at a stretch. However, most entered the unfamiliar social organization of home and personal support as novices.

As young people moved outside of the home and away from their family members as providers of care, they encountered the unfamiliar organization of support services. In the face of such uncharted terrain, young people looked for guidance through the network of services, providers, institutional protocols, scripts and so forth. I argue in the following chapters, that all participants seemed to find this guidance in the authoritative discourse of the poster child.
CHAPTER 5
The authoritative voice of the poster child

Vignette: Seeing the poster child

Anna's apartment was stifling now. We had turned off the air conditioner so its hum wouldn't interfere with the shoot of her voice-over, Two and half hours later and we still had to go upstairs to shoot Rosalyn's footage. Nas’ tone had a sharp edge:

"What's next?"

Anna studied her apartment, searching for the next thing to shoot. Rita and I looked at each other. "Why hadn't she prepared?" Later we resolved never to allow any of the other participants to stray from their shot list\textsuperscript{50} - a promise we weren't really able to keep.

Anna had decided.

"Oh I know. My poster. I can't believe that I forgot that". Nas moved the camera, setting up the tripod in front of a large poster hung over Anna's bed. A photograph of Anna and Silken Lauman, hugging and both smiling into the camera. The caption read "Dreams are possible." I thought to myself: "Neat. The poster child shooting herself. The poster child shoots back."

(excerpt from fieldnotes, August 2002)

Introduction: The poster child appears

In the previous chapter I presented the informal supports provided by the families of disabled participants. At the time that participants were entering the Poster Child Shoots Back project, assistance from families was beginning to be replaced by an unfamiliar system of formal supports. These publically funded formal supports differed in many respects from those provided by families. For instance, they entailed fewer practical assistance activities, were narrow and utilitarian in scope, were subject to any number of policies, protocols, and tacit expectations. In order to secure supports from this unfamiliar system, participants sought a map to guide their efforts. In this chapter I present a kind of map that was available to both those providing and receiving support: the poster child. Also, at the start of the previous chapter, I noted that disabled people are often assumed to be passive recipients of welfare services. My findings and analysis

\textsuperscript{50}A list of shots that will later be used to construct the video. The shot list includes the substance of the shot and the camera angles.
in this and the following chapters challenge this assumption. I argue that disabled young people in this study actively work to secure and maintain support. This work involves articulating, embodying and enlivening several views and values of disability. I suggest these views and values are key dimensions of an authoritative poster child discourse. In this chapter, I introduce the authoritative discourse of the poster child and its encapsulated views and values.

Early in the research process, I had made references in field notes to ‘poster children’, although in no way had I set out to discover anything about such images. To my surprise, almost every disabled participant – including disabled gatekeepers - had been a poster child for a disability or disease related agency. Many still had their images used in promotional materials such as the ‘Dreams are possible’ poster mentioned above. As these young people grew older, they continued to act as live models for charitable organizations. Eventually, they moved ‘off the page’ to become charity spokespeople – sharing their stories of support and success, implicitly and explicitly attributing their accomplishments and sometimes their very existence to their sponsors.

The vignette above captures a watershed moment for me. As I wrote up the incident in field notes, all the small and mundane mentions of the poster child suddenly seemed to take on a new salience. I wondered how the poster child had become an important element in the workshop activities, participants’ videos and most importantly in the work of securing support. I began to conduct a form of textual tracing (Smith, 2006), seeking out mentions of the poster child in the data. These led me to participants’ stories about current and past modeling as ‘poster children’, their casual references to charitable symbols in workshop dialogue and interviews (“shaking my tin cup”, “I’m a March of Dimes kid”, “that’s so Timmy”, “my Easter Seals smile”), and to their interactions with material objects (e.g. posters, video footage, medals, brochures and other promotional materials). I paid attention to the larger dialogic context of these utterances, tracing how they moved through different conversations, taking on new meaning and purpose when voiced by new speakers.

At the same time, I began to notice that participants’ descriptions of and talk related to support seemed to ‘taste’ (Bakhtin, 1981) of the poster child. In the 1940s, the phrase *poster child* emerged. It referred to a child with a visible impairment or physical difference whose picture was used on charity promotional materials to generate sympathy in order to raise money or enlist volunteers. Charity posters rely on several standardized images in order to communicate
their (implicit) requests for assistance. Rosemary Garland Thomson (2001) describes how, in charity posters, the disabled person is depicted in a lowly or diminished position, establishing a ‘parental’ relationship between viewer and the viewed. This relation is reinforced as children are often used as models. David Hevey (1992) has noted that the lives of disabled people are typically portrayed as limited or restricted, almost exclusively as a result of their impairment. Individuals in the images seem meekly resigned to their fate: a bleak, one-dimensional future as ‘broken’, dependent and childlike. In order to inspire philanthropic actions among the general public, charities rely heavily on these depictions of disabled people as submissive, deficient and socially, spatially and temporally constrained. Hevey contends that although the charitable depictions of disability have undergone considerable revision in recent decades, the original messages remain intact. Hevey specifically points to promotional materials which make use of a disability rights analysis such as those with images that draw the viewer’s attention to environmental, design and attitudinal barriers. Despite their apparently politicized message, Hevey argues these images reassert disabled people as incapacitated victims. Throughout my analysis, I noticed that some aspects of participants’ talk about support seemed saturated in these depictions. The poster child ‘appeared’ as a set of authoritative utterances and messages that participants turned to (or from) in order to do the work of securing and providing support.

In what follows, I primarily take up the poster child as what Mikhail Bakhtin suggests was an “authoritative” discourse: a set of utterances that are ideologically centralizing and deterministic. To briefly review from Chapter 3, an utterance does not simply communicate content, but expresses the speaker’s attitude towards others’ utterances. As Bakhtin and his followers note, the utterance is two-sided (Volosinov, 1986/1929). Every utterance is always a response to some degree, a response to what has already been said, even utterances from the distant past. When we use an utterance, we also anticipate how the utterance will be heard and understood by others. When we speak, we have “faith that somebody will understand us, somewhere at some time” (Bakhtin, 1986: 92). We have this faith because every language emerges from a sphere of use which develops its own relatively stable forms of utterances. For instance in disability circles, utterances like ‘confined to a wheelchair’, ‘suffering from this or that condition’ or ‘overcoming impairment’, can be understood by participants in conversation as emerging from distant historical moments in time, and the view, values, standpoints, experiences surrounding disabled people. What is communicated by these utterances in any specific moment
depends very much on the context of their creative usage – the other utterances with which they are juxtaposed, the intonation and stylization brought to the utterance by the speaker.

Authoritative utterances, however, are of a different order; they are privileged and absolute (Bakhtin, 1981: 421; Bakhtin, 1986: 162). Authoritative utterances have several key features. First, they are often *extra-contextual*, that is, they do not emerge from the speakers’ immediate social sphere, but originate in some distant point, from an anonymous author. (e.g. the Sacred Writ, the Golden Rule, absolute truth). These are privileged forms of language, gaining force from their resistance to evaluation and alternate points of view. Their encapsulated views, values, messages remain relatively enduring regardless of the speaker who voices them and the social context in which they are used. This is a second feature of the authoritative utterance, the understanding or definitions of an authoritative utterance cannot be easily relativized. Like the promise, the prayer, the nursery rhyme, the threat or the metaphor, boundaries between these authoritative utterances and the speaker’s specific intentions are rigid and impermeable (Bakhtin, 1986: 164). The views and values encapsulated within an authoritative utterance are difficult to parody, stylize or to interact with creatively. This leads to a final feature. The authoritative utterance is highly centralizing; it “retards and freezes thought” about a given social phenomenon or process (Bakhtin. 1986: 142). We cannot respond to, evaluate, agree or disagree with the authoritative utterance, we can only react by passive conciliation with its messages, or with their wholesale rejection (Yakubinsky & Eskin, 1992).

In what follows, I outline three dimensions of the poster child discourse: a set of authoritative utterances that encapsulate the value of deference and the view of disabled people as deficient and futureless. As with any authoritative speech, these views and values are associated with authoritative speakers. In this study, those who provided or held the key support resources (referrals, transitional support resources, knowledge of where to locate supports) were authoritative. My analysis presented below is based largely on the data from parents and professional gatekeepers, whose authority came both from their adult status and from their control over scarce support resources. While their relatively powerful social positionings lent force to their utterances, the poster child discourse did not originate with them. Instead, I view parents and gatekeepers as ‘conduits’, simply disseminating authoritative discourse. My goal in this chapter is to lay out these three dimensions in turn as a foundation for understanding the work disabled young people do to secure and maintain support.
Seeing disability as futureless

The first view of disability held in the poster child discourse was that of disabled young people as futureless. Parents and workers spoke of disabled young people as essentially stuck in time, without clear adult futures. There are at least two ways that parents and workers perpetuated this view of disabled young people. First, they persisted in describing participants in child-like or infantilizing ways. This could go beyond mere characterizations of disabled young people as a group, to continually defaulting to seeing an individual young person’s interests, talk and actions as consistent with immaturity. The second way in which parents and workers disseminated the view of participants as futureless is by failing to acknowledge or imagine their futures as adults. Instead, they put forward a truncated and restricted imagining of the lives disabled young people could expect.

Infantilizing disability

In both interviews and everyday conversation, family members and workers discussed disabled young people in infantilizing ways. First, they always referred to the participants as “kids” or “youth”, never young adults – even though most participants could have been characterized as such. They consistently described participants as naive, immature, delayed, childish, juvenile, innocent, and spoiled. As a social worker noted:

These guys are like kids, little kids really. I’m not sure you’re going to get much good info from them. They’re just too immature and naïve, you know what I mean? Like it’s mommy and daddy do everything and they’re just little…well they aren’t really like…they’re just moving through life as if they’re going to be children forever. (Gatekeeper 7)

This layering of infantilizing language was overwhelming at times, revealing and reinforcing an almost cynical stance on disabled young people’s ability to comment maturely or competently on any aspect of their lives, including the support they received or required. These comments, repeated extremely often throughout the entire project, laid the way for participants’ requests for support to be viewed as poorly informed and therefore illegitimate. I return to this argument in my discussion of deference.

Often, parents, gatekeepers and personal support workers expressed a desire to see young people as young adults, believing their assessment that young disabled participants were immature. They took pains to normalize the tastes and interests of young people (particularly those with intellectual impairments), redirecting their preferences around music, movies, stories and recreational activities to more mature alternatives. For instance, when Gerry wanted to use a popular 1980s children’s song by Raffi as background music for his video, both his workers and his parents tried to dissuade him, deriding his selection as “for babies”. His parents repeatedly ‘forgot’ to bring the album to the workshop despite our reminders. Similarly, Cynthia loved the cartoon figure Barney, and often asked others to draw its picture. Workers suggested and then drew other figures – such as ‘Hello Kitty’ images more typically enjoyed by teenage girls. In another example, Graham’s parents often expressed frustration with his interest in animation, and connected it with his apparent “refusal to grow up”. As his mother complained

We told him if he wants to continue in the project he can’t make another cartoon.
We told him that cartoons are kids’ stuff and he’s got to put it behind him now.

Graham resisted his parents’ wishes and did attempt to make another cartoon during the third workshop series. Making good on their threat, his parents refused to drive him into the city to complete his project. With no alternative transportation, Graham had to leave the project. For many parents and workers, such refusals to support “childish” activities were informed by ‘social role valourization’ (SRV). They cited key figures in the SRV movement to justify and often even fuel their decisions. This service philosophy typically directed those who worked with individuals with intellectual impairments to challenge ‘wounding’ stereotypes about disability and “preserved (young people’s) dignity” (e.g. Armstrong, 2007). Since many of these stereotypes are tied the portrayal of disabled individuals as children, parents and workers did as much as possible to resist any activity or interactions that might be read by others as childish.

Paradoxically, their actions had the opposite effect in at least two ways. First, while well intended, parents and workers derailed disabled young people’s autonomy and self-determination by over-riding their preferences and tastes. Unlike caregivers and professionals who work with non-disabled young people, their opinions could take precedence. They would simply refuse to provide assistance for any activities they deemed ‘too childish’ (or otherwise inappropriate). While all parents may do this with both their disabled and non-disabled children, there are unique consequences for disabled children. It became practically impossible for disabled young
people to pursue these “childish” interests, whereas non-disabled children could find alternative means. In these instances, parents and workers undermined young people’s autonomy and self-determination, the basis of adult citizenship.

Second, their responses marked disabled young people’s interests and actions as juvenile or childlike, despite the possibility that they might be viewed otherwise. For instance, Graham’s keen interest in animation was consistent with that of his peers, given the increased popularity of anime or manga among teenagers at the time of the research. His interests might have been interpreted as transgressive, or as serving a specific aesthetic purpose within his video. Rather than view participants’ interests as providing satirical pleasure, parents’ and workers’ responses were to mark them as a negative indicator of immaturity. Often ‘infantilizing’ utterances were more subtle. Josh’s father, as he assisted with his son’s shoot, thanked me for the opportunity Josh had been given to make a video.

This is a great thing. I want him to fool around with videos because he needs something to fill his time. He’s never going to have a wife and family of his own. So he might as well have his hobbies.

Here Josh’s father appears to both literally and emotionally support his son’s interests. He indeed followed Josh’s directions, allowing him to pursue his own vision for the film. However, he failed to acknowledge his son’s aspiration of turning his filmmaking into a career, instead diminishing it to a hobby. Perhaps more troubling, he suggests that this hobby can stand in the place of more adult pursuits, such as getting married or having children. Infantilizing perceptions and interpretive frames could gradually efface disabled young people’s efforts to be viewed as adults through acts of citizenship, such as social reproduction, participation in work or education. Disabled young people’s activities were not viewed as legitimate activities for an adult (citizen). As a consequence, parents and workers laid the groundwork for disabled young people to constantly question the validity of their claims to support – and ultimately citizenship.

Failing to see the future adult

In viewing disabled young people as childlike, parents and workers held a narrow and truncated vision for their future. In a sense, disabled young people were stuck in time, doomed to remain eternal children. This was most striking to me in the ways in which parents and some workers viewed disabled young people’s potential for partnership. Throughout the project,
parents and care-providers voiced their skepticism about young people’s potential partnerships with little reservation. The form of their comments – while not explicitly linked to any reference of a ‘poster child’ reproduced its monologic properties in two key respects. First, by maintaining the construction of participants as childlike and then, second, by viewing potential partnership as little more than an alternate form of charitable support.

Both these monologic properties were evident when Graham’s mother frankly shared a grim vision of his future with me, while he sat between us.

I’ve made arrangements for his sister to take care of him after we’re gone. That’s his future. I mean if I could count on him finding a wife maybe she could look after him… but… well what girl is going to settle down with him anyway? Look at him. (I weakly interject that he’s a good catch probably and then wildly wonder to myself how I can salvage this exchange with everyone’s dignity intact). A catch! Huh! Well I guess some woman might take pity on him one day. That’s the only way he’s gonna end up living on his own. But what kind of desperate woman will she be?

Other parents were more gentle about their children’s fate – although their images of the future were equally bleak. For instance Elena, a peripheral participant, explained how her mother had shaped her expectations of her future.

I used to cry to my mother. I would say, I’m never going to have a boyfriend, no one will ever love me because I’m stuck in a wheelchair. And my mother said to me ‘baby don’t worry. I love you. You may never have a boyfriend. But that doesn’t matter. You’ll always have me. We’re always going to be together”. Then she died with cancer 3 years ago. So who’s going to love me now? Who’s my family now?

Here Elena poignantly recalls how her mother promised her what might amount to an eternal childhood, safe within the bosom of her family. Parents, and to some extent workers, were reluctant to speak about disabled young people’s intimate and adult futures. Although parents often spoke with me at length about any topic regarding their children, they rarely raised issues around their children’s dating, sexuality or future parenting. Perhaps even more significant was their response to participants’ videos that openly included images of participants as intimate, even sexual, such as those by Rochelle, Isabella or Melanie. Parents approached me after the screening to speak about the films in general, but most mentioned being surprised and even offended by the inclusion of intimate images. As one father queried: “what relevance does lovey-dovey stuff really have for them anyway?” In a sense, parents’ reluctance to see their
children as capable of being desired and desiring, seems to come from their failure to see their children as ‘growing’ into adulthood.

Marriage and partnership are, across many cultures, a rite of passage into adulthood. In the West we commonly believe that not only must we demonstrate maturity prior to forming a long-term commitment to another person, we also accept that the struggles and joys accompanying partnerships contribute to our continued growth and maturation. However, parents’ comments suggest that these opportunities for maturation are beyond participants’ grasp. Intertwined with the childlike characterization is a narrow, utilitarian view of their children’s future families. As Graham’s mother remarks illustrate, disabled young people were not seen as ideal or even possible partners. Like her, most parents saw partnership as a way for young people to get their physical care needs met. As some openly hoped, their children would eventually “hook up with (someone) who’s desperate for companionship”, “a nice place to live”, or “Canadian citizenship” and was “willing to work for it”.

Parents and workers also expressed scepticism about disabled young people’s capacity to accomplish other practices of adult citizenship. Many expressed a desire that participants might be employed one day. However, they also expressed concern about young people’s particular career aspirations. In imagining their offspring’s futures, they did not envisage participants holding full-time or permanent employment. Both parents and workers likely knew how limited disabled people’s employment prospects were – no matter what their career goals; nevertheless their expressed expectations were very modest. Indeed, in the many conversations I had about the project itself, most family members and professionals, saw it as a vehicle for participants to “keep busy”, “try something new” or participate in something “more dignified than a day program”. The notion of careers as a form of public presence, enactment of one’s aspirations or an economic or social contribution as citizens seemed elusive.

Some researchers (e.g. Antle, 2004; Hughes et al., 2005), have identified low parental and other adult expectations among an array of influences on the self-worth of physically disabled young people. However, I do not want to leave readers with the sense that parents failed their children through diminished expectations. Parents and other adults have ample cause for lowered expectations with respect to future work, relationships or education attainment among disabled young people. Disabled young people tend to fare worse than their non-disabled peers. Regardless of age or gender, disabled adults are less likely to be employed, earn an employment
income and form a family than their non-disabled peers (Reach Canada, 2006). They seem future(less); with poorer life chances. Parents and other adults could easily be accused of setting up false or unrealistic expectations if they promoted their children’s ambitions and aspirations. Instead their ‘failure’ to imagine an alternative future for their young adult sons and daughters could be understood as pragmatic acceptance of the future barriers their children would confront. Because I proceeded from the standpoint of disabled young people, I was not able to more fully explore how the adults surrounding them understood their own constrained expectations.

**Summary**

Parents, workers and professionals asserted a view of participants as looking forward to diminished or restricted futures in several ways. First, they referred to participants with a host of child-like terms. Second, they persistently put forward an interpretation of participants’ activities and interests as markers of their immaturity, eschewing other possible interpretations. Third, they constrained participants’ self-determination and autonomy by taking away supports for pursuits for which they described as immature. And finally, parents and professionals did not describe participants’ pursuits as consistent with the activities of future adult citizenship. While we cannot know from the data in this study why adults articulated a view of disabled young people as futureless, the implications for young disabled people remained. This view eventually created a sort of double-bind for participants. At one moment they were to understand themselves as too young, inexperienced and immature to legitimately make claims for support. However, in the next moment, their imagined adult futures were truncated – so that the only relationships or roles possible for them were those that seemed to entail their passive acceptance of support.

**Seeing disability as deficit**

The second view held in the authoritative discourse of the poster child was of disabled people as deficient. Throughout the project, care providers used professional *ideolects* (Bakhtin, 1981), or ideologically laden and stylized forms of language, which not only suggested disabled young people were immature, but also proceeded from and promoted a deficit model. In this section I present two ideolects that prevailed throughout the project. The first is developmental language, which relied heavily on psychological models of child development. The second
closely related ideolect was that of transitions. Talk about transitions was rooted in life course or developmental models, loosely referring to the movement of individuals through life stages and situations. A precarious life change, the quality of transitions could either prevent or produce deficits in disabled individuals.

**Developmental language**

Gatekeepers described much of their work as directed at moving young people “from one stage to another”. As the director of a large agency serving disabled children and youth explained “You know, I’m just trying to get them to where they need to be developmentally.” Or as another worker in a community agency stated:

> We find that a lot of what we do here with kids and youth is just try to get them on target for their age. Yeah we try to move them along so they approach their developmental targets (Gatekeeper 1).

Workers’ frequent use of developmental language introduced normative standards of rational, cognitive and other psychosocial accomplishments in their talk about disabled young people. In doing so, they not only framed participants in terms associated with children, but also, brought young people’s inadequacy or deficiency into relief. Developmental models contend that children acquire cognitive competencies according to a universal sequence, which individuals “ideally” progress through linearly (Burman, 1999/2007; Jenks, 2000). By frequently discussing young people as having a number of developmental tasks yet to complete, workers reinforced both their ‘incompleteness’ and immaturity. Moreover, workers and parents often drew attention to where young people were delayed along or deviated from the typical developmental trajectory. Caterina’s mother noted:

> People look at her and see this beautiful young woman. On the surface she’s lovely and…she’s so poised and ladylike, I know. But what they don’t know is that she really isn’t the same on the inside. There’s a mismatch I guess, her experience, her thinking…it’s just not….her internal and external development is out of sync.

Other parents pointed to how their child’s impairment had “stood in the way of normal development”. Several parents and workers described how disabled children’s physical impairment had meant they could not explore their environments independently, first as toddlers and then again at each successive developmental stage. They would refer back to these ‘missed
steps’ as the reason their children were not independent now. As one gatekeeper, herself a
disabled woman, described

Sometimes they’re like a blank slate. And you would think that might be good,
but there’s just nothing there. They haven’t been able to do the most basic things
for themselves, like picking out their clothes, making a telephone call,…and it’s
not like they have the skills that other young people their age might have had, you
know like baby sitting, walking the neighbour’s dog. If they had those skills we
would have something to work with. But we’re trying to build habits without a
foundation. How can we think that everything isn’t just going to collapse when
these kids turn 18, 21? (Gatekeeper 2)

Developmental references reinforced disabled young people’s deficits over and beyond
that of their functional impairments. In fact, following the worker’s logic suggests the deficits
will only worsen over time, casting a pall over disabled young people’s futures.

To appreciate how developmental language made participants particularly vulnerable to
being understood in terms of their deficits, it is helpful to think about the consequence of such
models for non-disabled individuals. A general consequence of development models has been
the reconstruction of youth as a social category. Youth is a period during which young people
are neither viewed as children, and therefore deserving of care and compassion, nor as adults,
and therefore able to take on the responsibility for their own and others’ care. Youth, then, can
be viewed as a period in which individuals are ‘incomplete’, socially liminal and flawed. Non-
disabled young people have an escape from this ambivalent social positioning, since
developmental models recast youth into a period in which they master cognitive, rational and
moral tasks to bridge this transition between childhood and adulthood (Jones, 2009: 167).
However, youth-specific developmental tasks create unique problems for disabled young people.
Young people who do not or cannot complete their developmental tasks are seen to have “failed”
in their transition to adulthood. I further elaborate on this in the next sub-section, where I
examine how participants become targets for certain forms of health and social welfare
interventions that have little to do with their actual aspirations as adults.

Transition talk: The second ideolec that perpetuated the view of disabled young people
as deficient was the language of transition. Transitions language was historically rooted in
programs designed to help disabled young people move from the pediatric to the adult health and
social care services. In Ontario, once young people reach eighteen, they must move to a de-
centralized, less coordinated and far less family-oriented health and social care system. Formal
transition programs were initially set up in paediatric settings to help young people acquire the skills to communicate their needs to and develop relationships with an array of health and social care providers they would meet in the adult system.

Gatekeepers in this study described themselves as working in programs that “help these kids make their transition”. Similarly, every participant, either had been, was currently or planning to participate in a transitions program. This meant that ‘transition talk’ permeated much of the discussion throughout the research, albeit often in a peripheral or off-hand way. It was not uncommon to hear participants being described as being “in transition”, by professionals, workers, parents and by participants themselves.

It seemed that when workers and parents spoke about young people as being ‘in transition’ they narrowed the ways in which disabled young people and their lives could be understood. On one hand, describing disabled individuals as ‘in transition’ retained a sense of hope about their futures, in that they were ostensibly moving along a life trajectory. However, using the language of transition also precluded other ways of understanding disabled young people’s concerns. Gatekeepers in particular described some disabled young people and their support needs primarily through the transitions they had undergone or were yet to undergo. In one striking conversation, a physiotherapist responded to my question about support within the education system as follows:

There are limited resources for helping children with bathroom tasks in the schools. Our summer camp program tries to address this. If children can transition to independent bowel and bladder care, then they’re probably going to have a better educational experience. Those resources will be freed up to help them with learning rather than, well you know, be wasted in the washroom. (Gatekeeper 1)

The professional speaking above makes a fair point – the more skills a young person has, the more everyday tasks he or she could perform independently, and the further scarce school resources could be stretched. But in making the young person’s problem one of transition, the problem of scarce resources itself could be set aside. Instead the salient problem becomes one of skills acquisition. In turn, issues of support and integration within the school system become the individual’s responsibility – one many inevitably cannot likely meet solely through amassing personal life skills.
I also noted that in interviews, workers often subsumed individuals’ histories and social and personal situations to the suggestion that they were in “a rough transition”, “were unprepared for transitions” or had an “unsuccessful” or “failed” transition. Moreover, both families and workers connected transitions to a sense of crisis in the lives of young people. For instance, one worker described how young people came into her transitions program when “crisis hits”.

They come in when team care got critical on the home front, in terms of they need to move on but don’t know how. The future seems scary to them. Often they’re not introduced to the supports that are available so the future can be scary to them. So they come in very, some of them, quite unsure of what the future holds. (Gatekeeper 3)

Both workers and parents emphasized transition as a critical decisive moment. Young people needed to gain skills, information, life experiences and sometimes resources immediately or during key transitions in order for them to be negotiated successfully. As such, success could seem elusive. More often though, transitions were viewed as crises in themselves. Events in the past, such as a family’s delay in encouraging their children to learn social skills, or young people’s unwillingness to “break old patterns from the past” or “let go of their old way of doing things”, were held up by both gatekeepers and families respectively as contributing to young people’s “poor preparation” for transition. Repeatedly, disabled young people’s challenges in making a successful transition were attributed by gatekeepers and parents to “poor timing”. Moreover, timing problems were easily exacerbated. Missing a critical transition ostensibly spoiled young people’s chances to navigate from one life stage to another. Not only did this figuratively hold young people back at some early (developmental) stage, but it suggested they were dyschronous with their peers, or as Caterina’s mother stated above ‘out of sync’.

The notion of transition to adulthood took up more and more of participants’ lives. At the time of the interviews, transition programs were growing in popularity and purpose; with a proliferation of programs addressing increasingly differentiated aspects of young people’s lives. I heard about transitions programs intended to facilitate independent housing, new forms of clinical care, movement between educational institutions, into sexual relationships, and so forth, from all participants. It seemed that any change in any sphere of a young person’s life could be viewed as a potential transition.

“Transition” also seemed to possess expanding age boundaries. One gatekeeper managed a program for transition to independent living open to youth between 17 to 21 years. Another
provided life skills support to ‘youth in transition’ 18 to 29 years; yet another worked with 16 to 29 year olds and so on.\textsuperscript{52} The age groups targeted by these programs spanned widely varying periods. As a worker in a transitions to independent living program pointed out, increasingly, younger groups were being targeted:

Well now we’ve begun a junior program for young people between 11 to 14 years. Because that’s an important transition that gets over-looked. You know…um adolescence and puberty, you know there lots of issues that come up then…So we wanted a program for younger kids to help them through that stage (Gatekeeper 3)

As age criteria for inclusion in programs ‘stretched’ to accommodate increasingly older and younger participants, disabled young people could move from one program to another. Several workers described such a trajectory, noting how certain participants had ‘graduated’ from one program and were preparing to move onto the next. In fact, in workers’ accounts, disabled young people were always in need of ‘further’ intervention, development and training. Taken together, the expanding life areas and age criteria meant that young people could be viewed as constantly in transition. However, because transitions were so difficult for disabled people to pass through successfully, this meant that every area of their lives could slip into a potential site of failure and deficit.

Summary

In this section I have described two professional ideolects that contributed to the view that disabled young people are deficient. As I have noted, participants’ deficits emerged from, but did not remain with their impairments. While highlighting deficits rooted in impairment might secure the ‘poster child’ some measure of support, the deficits referenced in these ideolects sometimes have quite the opposite effect. These deficits were largely viewed as resting in participants’ lack of skills, particularly the skills that would enable disabled individuals to secure and maintain appropriate supports. This view informed the administrative construction of service delivery and support work with disabled young people. These programs, based on the view that young people’s concerns were temporary and periodic, rooted in the lack of specific skills, were designed to promote individual change, particularly skill acquisition. Key among these were the social skills needed to secure and maintain supports. This brings me to the next

\textsuperscript{52} Some of these differences in age categories are attributed to different funding body criteria.
section where I introduce the final dimension of the poster child discourse, the value of deference.

Valuing deference

In the previous two sections, I presented two authoritative views, disability as futureless and disability as deficit/deficient. I now turn to a discussion of deference, a key value held in the authoritative discourse of the poster child. Unlike utterances about young people’s limitations or their constrained futures, “deference” as such was not explicitly identified as a value by participants in this study. Instead, parents and gatekeepers delineated a set of intertwined postures and gestures young people should adopt as they sought and used support. These inferred respect, graciousness and setting aside one’s perceived needs in favour of those of others. I grouped these together under the rubric of deference.

Deference often ‘emerged’ in interviews in terms of its reported absence. Parents and gatekeepers lamented young people’s disrespectful and rude demeanour in their requests for support. Their concerns were often closely linked to their view of young people as childlike and deficient in social skills, as evident in the comment below by a gatekeeper.

These kids, you know, they haven’t got a clue. It’s just everything gets done for me and I should just expect it – just like a little prince or princess. They issue commandments to the people around them. No please, no thank-you. Just “gimme, gimme”. So…a lot of what we do here is teach them that they just can’t make demands. The world doesn’t work like that when you’re a grown up. You can ask, politely and respectfully. So that’s the whole thrust of our program here. (Gatekeeper 6)

In these comments the gatekeeper establishes disabled young people as childlike, “they haven’t got a clue”, they are “kids”, but then builds on these assumptions to create a more damning assessment of their ability to discuss or manage supports. Workers and parents alike cast disabled young people as demanding, and even greedy. The worker’s pejorative description “little prince or princess” and imitation, “gimme, gimme”, was consistent with an overall view among workers and parents that disabled young people had been “spoiled”. They were viewed as having inflated expectations surrounding support, namely they “expect(ed) to be coddled”, or to be “handed everything on a plate”. Or as another gatekeeper stated:

A lot of these youth are fairly isolated, they’ve been in integrated settings (classrooms) because that’s what the policies are now, but they haven’t really
integrated themselves. They seem to lack the social skills to be able to get integrated. You know it’s all about ‘I need, I need’. And of course other kids don’t like that…So my work here is about helping kids develop those social skills learning how to behave with others. How not to be so demanding. Maybe even how to think about how you can help others! (Gatekeeper 4)

Here again, the gatekeeper focuses on young people’s ‘skills-deficits’, in this instance an inability to accurately moderate one’s requests. The implication is both that disabled young people are rude (“demanding”) and perhaps selfish that they do not think of others. Like the preceding quotation, there is an implied message that disabled young people request too much, that they may lack an accurate assessment of their needs. In these two comments, gatekeepers set out preferred postures of respect and grace – “they can ask, politely and respectfully”. They also indicate that young people might make a gesture of putting others’ needs above their own, by thinking about how they might like to “help others”.

To correct these apparent shortcomings, parents and gatekeepers stressed that young people learn to moderate their requests for support. They believed that young people must learn to recognize their “real needs”. Gatekeepers in particular tried to help participants to recognize how their expectations were impractical and unreasonable:

> Oh there’s always that one kid who was in the manual chair, and whose parents pushed him everywhere. Or the kid whose parents insisted that the school set him up with a buddy to push his wheelchair. Yeah that’s a totally unreasonable expectation that’s been set up there. And it’s not sustainable after they get out of high school. So we’re working really hard to get kids to see that and find more responsible patterns (Gatekeeper 5).

Although the problem identified in this quotation is ‘parents’, it is disabled young people who are instructed to adjust their expectations and to submit to what can be reasonably secured and sustained around support. Many times gatekeepers attempted to help participants “rein in their expectations” – even when their expectations did not seem unreasonable.

Like one of the first things we try to do is try to figure out their knowledge base. Because information is what they really need. That’s hard for them to accept. We find that kids are all like – ‘how do I find someone?’ or ‘how do I find dates?’ And we’re like, that’s not even a real issue yet. They don’t even know their anatomy, like very, very basic stuff. (Gatekeeper 7)
Although this sexual health worker’s concern regarding young people’s lack of knowledge of their bodies seems well founded in the context of her reproductive health program, she dismisses young people’s articulated concerns as ‘not real’. Both ‘finding a partner’ and ‘anatomy’ are integral components of sexual health education, yet apparently only one is a valid pursuit while in the context of her program. Similarly, a social worker described how she helped disabled young people make the transition from high school to post-secondary education. As she described earlier in the interview, a central focus of her work was to encourage disabled young people to lower their expectations around educational support. She described a typical conversation with a young person as follows:

So when we’re figuring out what you really need… (our work) involves a lot of identification of who is doing what in order to accomplish what. So you’re getting 80% in math. Okay, so how do you do that? What did you do? ‘Well I do four hours of math homework every night and my father helps me.’ ‘How does your father help you?’ You know sort of trying to get them to think in those terms, to break it down. You know and look at why you are spending four hours. Why is your father sitting there for those four hours. Is that how most 18 year olds are getting 80% in math... Just drawing their attention to patterns in families sometimes, or patterns at home or that happened at school that have become routine and expected. I want to get the student to be thinking and reflecting and think – ‘you know... it’s true... I spend at least four hours, at least three nights a week on math. Is that normal? I don’t know if that’s normal.” (Gatekeeper 8)

At first it seems as if the social worker tries to determine real needs by deconstructing the student’s everyday experience of schoolwork from his own perspective – bringing the hidden work of support into view. However, she ultimately tries to get him to re-organize his perceptions of his experience so that they aligned with an institutionalized narrative of disability. As in this illustration, workers often described having young people question the ‘normalcy’ of their routines, the legitimacy of their support requests/usage, and even the burden they were placing on others. Rarely were they asked to reflect on other accommodations that might be helpful. Even workers who had a strong disability rights analysis, such as the manager of an Independent Living housing and advocacy program implied that remaining mindful of one’s requests was an important strategy in maintaining supports:

Gatekeeper 2: Recently we were contacted by a 19 year old from Ottawa who was hoping to be part of our IL program. In speaking with her we realized she had a strong circle of support at home – you know family, friends, subsidized housing, she knew the workers – all the ingredients for a good independent life. She was
looking into coming to school here in the city, in Toronto. We thought about it and then I called her and I said “look you have a lot of support where you are. You just can’t be certain you’re going to be able to organize that here.” In the end we didn’t give her a place here. We thought ‘no way’, this was too risky for her. So we encounter situations like that from time to time.

E: Where youth risk losing their supports if they move? Is that what you mean?
Gatekeeper 2: Yes and that sometimes, as disabled people we just need to appreciate what we’ve been given. If we start asking for a lot, I think we risk looking like we aren’t grateful for our current resources. It’s really critical for youth, well, all of us, to understand what we can ask for, how to ask for it, and when to stop asking and just say ‘thanks, that’s good’.

In these comments, the worker draws attention to the tacit ceilings on the supports available to disabled people. She ties the work of “looking grateful” to the practical considerations for making requests. Given that supports are limited, such expression of appreciation and gratitude took on an added salience. However, the worker also glosses over the young woman’s desire to pursue post-secondary education. As the conversation progressed, the worker could not explain how the applicant would pursue her educational goals. At no point did she consider whether the young woman’s supports were actually adequate. What is particularly significant in these comments is that ‘appearing appreciative’ seems to involve material compromises and consequences. In several of the preceding comments, disabled young people’s desires - for dating tips, a good math grade or in this instance, moving to a different city for university - were deemed too excessive and set aside. Repeatedly, I heard adults describe their efforts to teach young people how to recognize, submit, and accommodate themselves to the limitations of support resources. Indeed as the worker implies, what disabled people really “need” is to appreciate available support resources.

Gracious acceptance and gratitude were often cited by parents and workers as important responses to support. When Graham accepted assistance from one of the workshop support workers without saying anything, his mother reacted immediately. She cuffed his ear and instructed “show a little grace you, say thank-you”. A social worker directed a similar sentiment towards me.

We focus on how to accept support graciously. You know, you just brought up the example of people trying to help you across the street. If you were a youth in

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53 In this and the previous comment, the workers were disabled women who had grown up in the system in which they now worked. Their lived experience of impairment and disablement to these statements added a certain force to their message.
my group I would tell you that it's your responsibility to say 'thank-you' to that person. That's the type of social skill we try to provide. (Gatekeeper 4)

Interestingly, this worker was responding to a story I shared of being misled while trying to find her agency. A man had escorted me across a street opposite to where I (correctly) believed I should be going. While a well intended gesture, I was not grateful. I had raised the story in an effort to open a discussion on unwanted or unhelpful supports young people might receive. Instead, she saw it as an opportunity to stress the importance of gracious and grateful acceptance of support. As she asserts, gracious acceptance is a “responsibility”. One gatekeeper, who had grown up with a serious physical impairment shared her own experience:

I tell kids this story. When I was a kid we used to have the TV in the family room downstairs. It was kind of a walk out to the backyard, so it was the place where me and my brothers hung out. Now, when I wanted to go down there, I would go to the top of the stairs and yell down for one of my brothers to come and get me. Then one would come up and carry me down. But they’d always already had the TV on and they were always watching re-runs of Bonanza or Star Trek or something. And I’d be like, I don’t want to watch boys’ stuff, I want to watch...oh I don’t know, Get Smart or something. And I’d sit there and whine and whine until my mom would yell down and tell them to change the channel. One day there was a coup. We started the whole thing – me whining, my brothers telling me to shut up. Then my oldest brother just picked me and brought me back upstairs and just left me there... Just there on the floor. I’ll never forget, he just crouched down and said “Next time, shut up with your complaining and say thank you. No one has to carry you anywhere.” I sat there against the wall listening to them watching TV downstairs. And now I tell kids, remember to say thank you. It’s so easy for someone to shut you up. You just can’t let it get to that point. (Gatekeeper 5)

This woman captures and asserts the different facets of deference. Not only should she have thanked her brother (and not complained), her story suggests she should have also set aside her preferences around television-viewing. In order to receive support, disabled young people must be prepared to defer to those around them. Their self-perceived needs and preferences cannot always take precedence. Certainly they should not rudely press forward with them.

Gatekeepers and parents also emphasized the importance of teaching disabled young people how to make polite, respectful and realistic requests for supports and services. Most gatekeepers for instance, had developed and implemented life-skills programs that included instructions on how to “be nice: and secure assistance without causing "too much fuss".
So a big component of what we did in the group was teach youth…we talked to youth about how to, how to get along with people. Like HOW to ask for support. (Gatekeeper 4)

Workers linked how to ask and ‘getting along’ with those providing support. This linkage was, in part, pragmatic, since “getting along” might help young people access more supports with fewer impediments. In fact, when participants’ annoyance or frustrations surfaced while they were receiving or requesting assistance, others often cited the truism “you’ll catch more with honey than vinegar”. Even parents, who young people would later describe as advocating tirelessly for formal support and other social benefits, would describe encouraging their children to “go with the flow”. Zachary’s father for instance, commented on his son’s “sunny disposition”.

Yeah he’s a good guy isn’t he? What’s really great about him is that he can just go with the flow. When he was younger, he would kick up a real fuss if things didn’t go his way. Like if his favourite shirt wasn’t washed or I don’t know… his sister didn’t turn the TV clicker fast enough. But now he’s learned how to be laid back, takes things in stride.

Finally, I noticed that parents and workers often demanded that disabled young people exercise physical deference to cultural norms. Just as young people were expected to concede to social norms and systemic constraints, they were also expected to literally assume postures of deference. Workers shared many incidents as evidence that these young people were unaware of the impact their appearance, demeanour and behaviour had on those around them. For instance, a social worker described how a young man in a youth group she facilitated would repeatedly stick his fingers in his eye. When she confronted him about his actions, he explained that he had a prosthetic eye and was attempting to ‘unstick’ it. She recalled her comments at the time:

I took him aside and I told him “You have no idea of how disturbing it is to see you put your finger in (your eye). I suggest that you go into the bathroom and do this in a stall, where it’s not going to upset people”. (Gatekeeper 4)

She went on to state that she believed the sixteen year old had never received adequate feedback on his behaviour, promoting the view of disabled young people as socially deficient or poorly socialized. She also emphasized that other people’s comfort must prevail over his. Although she does suggest he take care of his own needs, she notes that these should be set aside until he is in private. Others expressed similar concerns regarding disabled young people’s “behaviours”,...
recounting how youth engaged in “off-putting”, “offensive”, “upsetting” and even “gross” habits. They, like the social worker who made the comments, above helped young people acquire the skills to present themselves in deference to the aesthetic sensibilities of others. In the following, an occupational therapist illustrated her descriptions of her work with a seventeen year old:

When she talks she tightens up. I mean she rises up in her chair and tightens up. (Demonstrates by stiffening her upper torso and raising her shoulders tightly around her neck.) And then she talks. And I guess it was an OT who was presenting the group and said that was a bit off-putting for her. Only she couldn’t talk without doing that. I guess it’s organizing the presentation of disability in the culture, so that people can accept it better so that they're working within the cultural understanding of acceptable. (Gatekeeper 3)

In these comments the occupational therapist makes an important link between physical presentation and people’s acceptance of disability. She, like others, implies that posture, gesture and demeanour all speak. In my field notes I had many references to incidents in which disabled young people’s actions or comportment—particularly those with developmental disabilities—were scrutinized and corrected by workers. Each time, workers would explicitly make a link between the offending behaviour and threats to future relationships. They openly suggested that without mastering a physical curriculum, young people would ‘turn off’ others and risk isolation. These ‘causal linkages’ and their authority as workers, meant that the work of containing their embodied presence in the world was a powerful determinant in participants’ attempts to secure and maintain support.

Summary

In this section I have outlined deference, a value held in the authoritative poster child discourse. Deference included gestures of setting aside one’s own desires in favour of others, and polite and gracious postures towards those providing support. Gatekeepers and parents voiced this value most clearly in their prescriptions for how disabled young people should request and receive support. Practically, this sometimes meant teaching young people to accommodate themselves to the material constraints of support programs and willingness of those who directly provided them with support. While their efforts encourage young people to change their desires, demeanour and even their bodies to be ‘undisruptive’, restrained and ‘grateful’, they did little to promote a broader analysis of disability and support. Young people were not only expected to put their desires, preferences and interests aside, they were also repeatedly denied the
opportunity to see these as legitimate. This would eventually lead young people to self-impose limits on the supports they requested and used, in turn shaping how and what sort of citizenship they could accomplish.

Towards the next chapter

In this chapter, I have introduced three dimensions of the authoritative poster child discourse. These included the views of disability as deficit and futureless and the value of deference. As I indicated in my introduction, parents and gatekeepers represented a conduit for these views and values. They not only articulated the poster child discourse privately with me in interviews, but, as I have noted, in the presence of disabled young people. For their part participants did not freely take in the views and values inherent in the utterances of parents and workers, rather they were compelled to acknowledge and act upon them, quite independently of whether or not they found them persuasive. As I detail in the following chapter, disabled young people could be compelled to uncritically take up the discourse, assuming its views and values as instrumental to securing and maintaining support. Although parents and gatekeepers rarely threatened to withhold supports, there were many occasions when that is precisely what occurred. Sometimes this happened openly, as when parents refused to support certain activities they deemed childlike. Other times, support was withheld far more subtly. For instance, failing to imagine disabled young people as pursuing further education, employment or relationships, made it difficult for young people to articulate – or even possess aspirations, let alone request support for their accomplishments.

In the end, the views and values disseminated through voices of parents and gatekeepers determine how disabled young people might understand themselves and their requirements for support. Their utterances transmit and reinforce the idea of disabled young people as having no clear claim to full adult citizenship. In the following chapter, I argue that the authoritative poster child discourse forms an interpretive scheme through which disabled young people understand and act upon their support needs. Participants reproduce these ideas about young disability in their talk and actions as they attempt to maintain and secure supports.
CHAPTER 6
Reproducing the poster child: deferring citizenship

Introduction

In the last chapter I introduced the poster child discourse, a set of values and viewpoints that lend coherence and unity around current understandings of disability, young age and support. I reviewed three key views and values within the poster child discourse: disabled people as futureless, deficient and deferential. I outlined how the poster child discourse was authoritative, in part, because it was often available to participants through the voices of their parents and workers, who provided them with support. As such, the discourse’s authority was ‘layered’, building force from its connection with valued and scarce support resources and intrinsic to its speakers. However, the poster child discourse is primarily authoritative because its utterances cannot be easily re-defined or re-interpreted. In this and subsequent chapters, I examine how participants assimilated, rejected and enlivened the ideological views and values of the poster child, and how the discourse shaped their consciousness of themselves and their requirements for support.

In this chapter, I present three sequences of activities linked to participants’ efforts to secure and maintain support: focusing on deficits, doing deference and doing deferral. My argument throughout the chapter is that participants assimilate the authoritative utterances of their parents and workers through engaging in these activities. The authoritative discourse of the poster child forms an interpretive scheme through which participants can understand and act upon their requirements for support. I suggest that disabled young people take in and repeat, almost by rote, the voices of their parents and workers. Consequently they reproduce the authoritative discourse of the poster child in their efforts to secure and maintain support. Finally, I suggest that reproducing the poster child discourse, enabled participants to accomplish a marginal form of citizenship that deferred and denied their full adulthood.

Focusing on Deficits

Consistent with the discourses of the poster child, one view disabled young participants had assimilated focused on their deficits. Throughout the research, I witnessed many occasions when participants echoed the voices of parents and workers as they commented upon their support requirements.
I’m always going to need help at a job I guess. My dad said that I need to accept my limitations better. I have some deficits, and I will need to accept that. (Ainsley)

People need to help me because my mum told me that my head does… my head doesn’t work too good. I forget stuff. (Bernard)

I need help because I don’t think. My mom and dad, they say I don’t think good. I don’t pay attention. I forget things. So they said I need help. I need help to think. (Joanne)

Well I guess like they (clinicians) would say, I have some physical deficits. I don’t have a lot of strength in my arms so I need Ted or the attendant to help me lift pans into the oven or lift heavy pots. It’s also why I have to use a scooter rather than crutches or what have you. (Melanie)

In these comments participants cite their parent or worker as they link their use of support with their impairment. In instances like these, participants seemed to merely echo what they had heard from authoritative others. Participants expressed little clear analysis or critique of this assessment or view of their support requirements. Instead, they repeated these statements. Indeed, each speaker elaborates on and reinforces their parents’ or workers’ comments by providing ‘body-based’ evidence.

‘Deficit’ is a key focus of the comments participants echoed. Participant above described their impairment as a functional deficit (“my head doesn’t work too good”, “I don’t have a lot of strength in my arms”, “I forget things”). Participants often focused on what they could not do, tending to emphasize their personal limitations. Furthermore, I noted throughout the research that participants spoke about support in terms of ‘needs’. ‘Needs’ position their use of support as filling a ‘lack’ of some kind – it differs from talking about support as something they ‘use’, ‘acquire’, ‘negotiate’ or ‘maintain’. In the following exchange, Graham places responsibility on his incapacities to explain why his parents gave away his dog.

Graham: My parents didn’t let me keep my dog because I couldn’t really walk it. I couldn’t you know, clean up after it when it …you know went on the sidewalk. Esther: So it was up to you? You had to give up the dog because you were looking after it by yourself? Could anyone else walk her? Graham: No I had to give up the dog, because I couldn’t clean up after the dog – cause I can’t really get out of my chair or anything.
Of course, many North American children and teens are not allowed the privilege of owning a pet, or pet care does not fit well with a particular family. However, it does remain a key way many young people learn how to provide care, and exercise daily responsibility. As a gatekeeper quoted in the previous chapter noted, pet ownership is a key opportunity, often denied to disabled children, to learn a range of skills. In this conversation, Graham cites his impairment, implicitly defined as functional deficit, as the reason he was unable to keep his pet. I expected him to more explicitly link his difficulties in caring for the dog with inadequate supports. Instead Graham seemed to evade my questions, reiterating the precise personal and physical nature of his challenges.

Graham’s comments construct deficit as personal rather than as a structural problem in support provision. He leaves no room for any discussion of the supports he does not appear to receive. Many disabled and non-disabled young people may have been denied pet ownership because they were unable to care for them; however, in Graham’s case, pet ownership, like schoolwork, changing a DVD, making toast for breakfast or other tasks would require assistance. Under ideal circumstances, Graham would have directed an attendant to leash, pick up after, feed, groom or otherwise manage the dog. But in no way does this emerge as a feasible use of support in our conversation; instead he returns to his ‘inherent’ shortcomings. Years later, I heard participants similarly refer to their personal limitations rather than articulate systemic critiques in cases where support provision was inadequate. For example, several former participants have complained about their struggles to control bedbug infestations. Rather than emphasize the many factors that make bedbug infestation difficult to resolve, including the lack of adequate or cooperative personal support, former participants cite their inability to independently complete preventative measures independently.54

In the above examples, participants framed support as simply remedying their personal deficits. Support allowed participants to meet the everyday tasks of domestic, academic and work life (“help lifting pans”, “help me think”, “help with a job”). However, while participants clearly needed to highlight deficits in order to identify and request appropriate assistance, sometimes this focus on deficit obscured the absence of support provision itself.

This tendency to view deficits as personal, rather than located within the system of support was apparent in participants’ conversations about dating and partnerships. Across the

54 Two participants recently gave me verbal permission to include this detail.
three workshops, Isabella, Caterina and Melanie were the only three disabled participants who were in sustained intimate partnerships, although Rochelle, Rosalyn, Therese and Zachary dated periodically. The remaining participants did not seem to form romantic relationships, despite their expressed interest. Indeed all participants spoke of wanting to be parents and partners, but were quick to point out how their personal deficits thwarted this dream. For instance, in the following comments Isabella complained about the difficulties in finding physical supports to sustain her relationship with her boyfriend.

Sometimes I don’t think Kyle and I are going to make it (as boyfriend and girlfriend). It’s stupid, we’ve just fooled around...so you think I would be fine doing anything with him. But I hate having him help me in the shower, or clean me off after sex. And he’ll just say, Isabella, am I supposed to just leave you here until your next booking? (But I think) what if we slip? How’s he gonna get my fat ass off the floor? Besides I feel like a tool. He wants me to just let him help, but I don’t know, I feel so...like it...how can I keep it sexy like that? I’m just not too hot.

Like others in relationships with disabled partners, Isabella worried about accepting support from Kyle, who was also a wheelchair user. The supports she needed were physically demanding, and the risk of falls and injury were always present. However, she and her peers were confronted with practical limitations in support services. Personal support worker training does little to prepare future workers for the assistance around sexuality (O’Brien, 1990), limiting the pool of workers willing to take on even minimally intimate support roles (i.e. transferring two partners to a shared bed, buying condoms, hygiene tasks post-intercourse). Even on the rare occasion when couples could access this support service, institutional work schedules limited when they could take advantage of the services. The structure of supports for intimate relations was such that young people reluctantly relied on their partners to provide basic personal supports around intimacy – or would forego intimacy altogether.

In her comments above, Isabella notes that the threat to her future partnership with Kyle lay (in her view) not in the lack of adequate support or in systemic shortfalls, but the ultimate deficits these produce in her own desirability. As she notes, relying upon her partner for support means she will no longer be “sexy”. Although for all people, the mechanics of physical intimacy (e.g. safe sex, reproductive control) can entail the messy transitions between the private and more public and obligatory aspects of sexuality (see Plummer, 2003), Isabella’s comments belie a romantic imaginary in which body limitations, excesses and waste are invisible. In practice
however, such invisibility was impossible for Isabella and other participants. Instead they needed to direct others to carry out tasks outside of conventional formal or informal support provision, exposing the fussy, messy, unromantic aspect of sexuality. Moreover, as I noted in Chapter 4, relying on family and friends to perform intimate tasks transgressed the boundaries of personal relationships, and in this case could transform them from private pleasure to public work. Isabella, like others, was reluctant to share this symbolic burden with a partner, worried that it spelled the end of their relationship. However, rather than look to how supports might offer her and Kyle an alternative, she locates the source of the symbolic burden in her impairments.

Being spoiled as deficit

Another way that disabled participants reproduced the authoritative discourse of the poster child was in their understanding of themselves as spoiled. As in the preceding section, the focus of the discourse they assimilated was deficit. However, in understanding themselves as spoiled, deficits were more tied to their character and maturity, rather than to their physical or cognitive functioning as above. Almost as if quoting parents and workers, participants described themselves as “spoiled”, “greedy”, “over-indulgent”, “immature” with respect to their use of supports.

Once I got to university I realized how spoiled I really was. In high school there was always someone around from the resource room to scribe for me. But at university people aren’t so willing…I can ask other students from my lectures, but they aren’t like a scribe. They just write down what they want to, not what the prof says. Yeah, it really made me realize how spoiled I was. I didn’t know at that time though. (Ainsley)

I guess I am pretty spoiled. My parents drive me places when I can’t book Wheeltrans. Yes, they help me out, but I know that’s lucky, that’s getting spoiled. (Caterina)

My mom said I got to learn to do it alone. But I can’t do it alone. I’m spoiled! (Joanne)

I’m SO spoiled. The workers in this building are SO nice. Like they’re really pleasant in the morning. (Zachary)

In this set of comments, participants do not cite parents or workers as in the preceding section, but their comments resonate with the infantilizing language described in Chapter 5.
Also, although the focus is on deficit, the childlike references suggest a developmental limitation or shortcoming with respect to maturity. In each of these comments, participants make sense of their unique situation with respect to supports by viewing themselves as being ‘spoiled’. Each speaker makes reference to supports in excess of those typically expected or formally provided within the health and social care system - such as timely transportation or friendly workers. However, they characterize such supports as damaging. Participants sometimes spoke of exemplary or even adequate support as having led to false expectations, “setting (oneself) up for a let-down”, and having left them unprepared for the reality of support provision. Participants, at least initially, attributed their ‘spoiled’ state to the generous support they had received in the past or in other situations. In fact, in Joanne’s comment above, simply using support was enough to view oneself as spoiled.

When participants refer to themselves as ‘spoiled’, they are compelled to view their support requirements as not legitimate. For instance, in Caterina’s comments above, difficulty booking Wheeltrans is usually the result of booking at the last minute\textsuperscript{55}, or being unable to secure a ride at the needed time. While she is indeed fortunate that her parents were able to bridge these public transportation gaps, her transportation needs were likely not excessive. However she, like other participants, suggested that these needs surpass a tacit support provision ‘threshold’. Being spoiled was less an identity as it was a means to explain away the perceived inadequacy of their current supports.

Sometimes participants made this link quite explicitly. During a break in a workshop session, Isabella described her experiences of moving into independence and how these shaped her understanding of herself.

Isabella: It’s hard. Really hard. I didn’t realize how spoiled I was before.
Therese: So like you don’t get as much (support) as you did at the (transitional housing)?
Isabella: Yeah I don’t. That’s one thing about the (transitional housing) is they give you a lot. Like especially if they like you, I didn't realize at the time, but they spoil you so much. But I didn't realize how much.
Anna: Like how do they spoil you?
Isabella: Like it's really hard to take the same amount of time. Yeah time wise we’re totally spoiled.
Anna: What do you mean?
Isabella: It’s very hard to get the same amount of time for your bookings. (Anna: Oh yeah?). Like my bookings almost got cut in half. (Anna: Oh man). And the

\textsuperscript{55} Participants must call at least 24 hours in advance. It is difficult to use accessible public transit spontaneously.
attendants aren't as friendly. And all the bookings are back to back. It's very hard to switch, because everyone has so little time. So when you want to switch, you have to negotiate with the other person.

Anna: Do you make an appointment. Like do they talk?
Isabella: Not really.
Anna: None of them?
Isabella: Some of them. But on the whole they're just very picky.
Therese: Picky?
Isabella: Picky. They're not friendly at all. (Anna: Oh).
Therese: That's bad. (long pause)
Anna: How are they picky then? Do they get mad at you?
Isabella: Not to your face. But they go and say things to the manager. That's why you've got to be very nice to the manager.
Therese: God you're serious? (Isabella murmurs confirmation).

In their conversation, the three young women begin to learn about the complex functioning of the systems which provide support. They become aware of its pitfalls, for example, that workers ‘talk behind your back’, that the manager has the power to allocate support resources, that support resources are limited and must be rationed among residents, and so forth. Yet, despite these systemic shortcomings, participants come to see the challenges of accessing support through their own flaws – namely their unrealistic expectations. Part of doing deference was to blame oneself and not the lack of supports. As Isabella points out, they have all been spoiled with respect to practical aspects of support: the amount received, its timing, or the friendliness of the workers. If Isabella receives longer bookings and more flexibility with her support services, it is only because she is ‘spoiled’. She links ‘wanting more’ with a younger self – the teenager who entered the transition program, not the adult who seeks to live independently.

Summary

In this section I have introduced how participants situated their support needs in their personal deficits, interpreting support inadequacies through “their own”. Whether their deficits were based in their functional impairments or in their spoiled and flawed expectations, participants had clearly assimilated and reproduced the authoritative discourse of the poster child which constructs disabled young people as deficient, flawed and immature. This discourse both positions disabled young people as needing support and must be reiterated and enacted if disabled people want to access and maintain that support. In assimilating and reproducing the
poster child discourse, participants could not attend to the deficits within the broader system of public support provisions, instead absorbing and taking ownership of them, locating the problems with support within themselves.

I turn now to a discussion of the deference work that is also apparent in the final dialogue presented in this section. In the next section I examine how, in seeing themselves as needing support due to their disability deficit, participants are compelled to assume a deferential demeanour.

**Doing deference**

The dialogue between Isabella, Therese and Anna above, not only reveals a focus on deficit, but also introduces the work of ‘doing deference’. It is noteworthy that Isabella does not wholly attribute workers’ inability to meet her needs and desires to the structure of support services, but their personality traits. In her words, workers are unfriendly and picky, not overworked or regulated. As such, this shapes the work that young people must eventually take on to secure support. Relationships, based on affection, captured in Anna’s questions “Are they nice?” and “Do they talk?”, are no longer the secure basis of maintaining support, as they may have been with family and friends. Isabella’s comments draw attention to the time management and diplomatic work to be mastered and performed. Young disabled people must learn how to curtail their support demands to fit short bookings. They must also learn how to avoid angering support staff. They must ‘always be nice’ to the manager, if only to strengthen their position in conflicts with the worker. In short, they learn the importance of putting forth a deferential demeanour. As such their efforts are directed towards “keeping the manager happy” or otherwise ensuring that workers remain inclined to provide assistance.56

Throughout the project I witnessed participants assume a posture of deference when needing assistance across a whole variety of scenarios: from getting strangers to open doors, attempting to curry favour with personal support workers, arranging rides when Wheeltrans fell through, re-organizing a dinner booking for the third time in an evening and many others. In Chapter 8, I describe instances in which assuming this posture was expressly purposeful and strategic. Below, however, I describe those in which these activities seemed a more

56 Although participants did not always attribute their thinking to parents and workers they often ‘spoke in their voices’.
unquestioning assimilation of the authoritative voices of workers in particular. These ‘authoritative voices’ came through in participants’ descriptions of the work that they did to secure and maintain support. I present two examples of the ways in which participants ‘do deference’: doing everyday deference, involving a series of small compromises about largely mundane, everyday activities, and doing innocence, involving a submission to cultural expectations about how young disabled people may maintain and secure support.

Doing everyday deference

Participants practiced deference in what appeared to be a ‘taken-for-granted’ manner in their everyday/everynight activities. In the preceding section, Isabella explicitly described the importance of ‘being nice’, other participants made references to assuming a deferential, accommodating demeanour in a less explicit manner. In the following vignette, Douglas described the struggles he faced in learning how to direct a worker:

I think one of the hardest things about living on my own was learning how to work with the attendant. It was frustrating at first because I couldn’t get things to be the way I wanted them to. The attendant would be nice enough, but things never really worked out. (I asked Douglas to give me a concrete example). Like making my mom’s chicken. I didn’t realize all the steps it took to make chicken. First I tell the attendant I want chicken for dinner – but I haven’t bought the chicken. Okay so then I have to remember, buy the chicken. The attendant buys the chicken. I want white meat, the attendant bought dark. So I have to suck it up. Don’t complain, because I forgot to tell the attendant what I wanted. (E: couldn’t the attendant have asked you?) I guess, but he didn’t. Next step, get the attendant to bake it. But I forgot to ask the attendant in the morning, to take it out of the freezer. It’s still frozen, so I can’t have chicken for dinner. I had mentioned it to the attendant the night before, but I was supposed to remember to get the other attendant to take it out first thing. Mornings are sort of busy, so I forgot. In this building, you’ve got to wait for the next attendant to come before it can come out of the freezer again. Eventually I got that all figured out, but I still had to learn to book my attendant visits to time the cooking – cause the chicken’s gotta get marinated and then it goes in the oven for forty minutes…like it was a lot of trial and error. I had to learn how to book it so I could get it done in time. I have a schedule worked out now – but I can’t have chicken too often ‘cause it’s kind complicated and I pretty much have to call in a few favours too.

Here Douglas outlines what amounts to a ‘project plan’ for making his dinner. His account might easily reflect the steps any of us take when preparing a new recipe for the first time: we break down the task to its constituent parts, ensure we have our ingredients on hand,
work out a schedule of tasks and come to see the invisible work of cooking that never appears in a recipe. However, for Douglas, these tasks are further complicated by an additional layer of negotiating, scheduling and planning work.

The process Douglas outlines followed those that were taught to many participants in transitions programs. His comments illuminate how his training went beyond the acquisition of ‘life skills’, to the mastery of social skills in deference. Part of his mealtime planning includes knowing to ‘suck it up’ when the attendant makes a mistake with his grocery shopping. Participants were loathe to challenge workers, fearful that their needs would be neglected. As one participant noted, “workers cut corners all the time, you’ve got to do what you can to make sure it’s not with you”. Although not explicitly stated, Douglas suggests that to call attention to the mistake might interfere with future support services. Throughout the project, this additional and frequently unacknowledged work involved becoming intimately familiar with competing and crowded schedules of different workers. Douglas and other young people developed a deep understanding of the labour and living conditions of their support workers. They quickly learned to tailor their support requests to both complement and mitigate workers’ actual everyday working lives. In Chapter 8, I trace how such familiarity could be employed strategically by participants. However, here I am more interested in how disabled young people were compelled to both gain this insight, and accept the constraints it imposed, largely in an effort to “get along”. Participants like Douglas, Bernard, Anna or Ainsley would sympathize with workers: “they’re busy, just so busy”, or “it’s hard for them to get all their work done. They just have so many people to get ready”. Disabled young people recognized that asking workers to step outside the established routine of attendant care, let alone repeat tasks, increased their workload. Douglas’ reference to help around cooking specific meals as a favour, may reflect this awareness. “Favour”, a word that tastes of the poster child, suggests that the requested assistance is above and beyond typical work expectations, is contingent on the good will of the granter, tied to gratitude from the grantee and certainly is not a citizenship entitlement. Doing deference then meant that participants were reproducing the conditions that made support such an ambivalent resource, enabling some activities, while simultaneously shutting down many others.

In doing deference, participants not only went along with the individual providing support, but were also deferential to larger systemic demands. For instance, Douglas had few ways to correct his own mistakes in meal preparation. Forgetting to defrost ingredients could
happen to anyone, and probably has. But the worker’s timetabling constraints deepen the repercussions of the error. Where many people could go home at lunch or choose to spend a half hour defrosting the chicken in a microwave, Douglas had to acquiesce to the institutional demands. Similarly, when we were working on Rosalyn’s video, a number of small mishaps arose and her shoot was delayed, into the late afternoon. We ran so late that Rosalyn ended up moving her ‘dinner booking’ three times. Each time she called the attendant office, she politely made her request and then negotiated a less complicated meal. By the time she arranged her final dinner booking, she had compromised herself into boiled hot dogs.

On the surface, these may not seem like serious compromises. However, the effect of these small acts of deference, to keep workers content, to not be viewed as “a problem client” and to accommodate oneself to the broader organization of support services, compounded. Together they progressively undermined participants’ self-determination, even at the level of what they ate or drank. Over time they had more serious implications for the sort of citizenship participants could accomplish. For instance, a common problem for participants was obtaining adequate and early morning bookings. Most described running out of time to comfortably meet all their personal tasks. Although some participants complained about this, many absorbed the systemic shortcomings and the consequences these had for other areas of their life. Ainsley confided that she failed a co-op class in university because her morning booking was scheduled for 7:45 to 8:15, leaving her too little time to wheel to her placement that began at 8:30. Similarly, after many attempts to negotiate an exception with the LSAT boards, Isabella gave up her dream of going to law school because she could not book a personal support worker early enough to begin the exam on time. Sometimes, as in these two examples, I was surprised that participants did not take it upon themselves to protest these shortcomings in support provisions (or alternatively, challenge the refusal of the other institutions to offer them some flexibility). But when I tried to explore this further, participants would counter by telling me that would require them to “make a fuss”.

Participants were often concerned with “making a fuss”, “putting people out” or otherwise disrupting others. This is not surprising given the dominant construction of disability as a “burden” in the popular press (e.g. Manning, 1997; Siebers, 2008). Participants’ awareness that family members had or were making sacrifices to fill in the gaps in formal support services likely also contributed to their desire to not unduly disrupt or trouble others. However, I would
also suggest that “making a fuss” was incompatible with doing deference. To cause a fuss or insist on a particular form of support would be tantamount to rejecting the authority of the poster child discourse. This, as I demonstrate in the next chapter, carries negative consequences with respect to the support disabled young participants could request.

Disabled young participants appeared to passively go along with the compromises and deferrals dictated by individual workers and the structure of support services in general. They remained polite and respectful, putting the needs of others before their own. They did this everyday around all types of mundane interactions – preparing a meal, wearing a particular item of clothing, brushing their teeth and so forth. In putting the interests of others first, participants assimilated, reproduced and deeply entrenched the value of deference, so closely tied to the poster child. But as I have indicated deference was not only practiced in relation to individual workers – but to the system of support provision and the broader public discourse of disability. I present one example of this in the following section.

Doing innocence

Another way participants ‘do deference’ more broadly is to ‘do innocence’, embodying the stereotypes literally represented by the image of the poster child. In this section I argue that disabled young people tried to remain above reproach, stripping their public actions of any misdemeanour. They did so by abiding by rules, such as formal laws or social benefit program regulations, in deference to a cultural image of innocence.

In Western culture innocence and disability are closely linked. Fictional disabled characters, including the iconic depictions of Charles Dickens’ Tiny Tim, Johanna Spyri’s Clara and Robert Zemeckis’ Forrest Gump, have come to signify innocence. Each of these characters is represented as guileless; in a sense their moral strength and wholeness offsets their marked and spoilt bodies. Their non-fictional, but equally legendary, counterparts Helen Keller, Terry Fox and countless poster children have also come to represent young, pure and uncorrupted individuals who are the innocent victims of fate – a fact that only enhances their achievements and the legitimacy of their claims for support.

Disabled people are viewed as innocent because of their imputed lack of life experience or failure to fully appreciate the (suspect) motives of others. For instance, people with intellectual impairments are uniquely positioned as innocent – cognitively unable to recognize
the hidden or underlying intentions of those around them and innocent of any ulterior motives of their own. Innocence, although signifying a moral status, is widely considered to be the embodiment of purity. But such purity is fragile, its integrity always a little under threat, and as such in need of protection. This protection has come to disabled people as well-intended unwanted ‘support’ in the form of supervision and institutionalization.

While all these linkages have some relevance to the findings presented below, the ways in which disabled people have carved out a public identity of innocence in relation to the state is particularly significant. In the western world, disabled people have been positioned as the innocent and deserving poor. From the very inception of the Poor Laws, disabled people have been privy to a different standard of social welfare - or at least a different means of accessing such support (see Stone, 1984). While other social rights movements (e.g. LGBT rights movement, women’s movement, anti-psychiatry movements) have been focused on de-criminalizing and/or de-medicalizing their identities, disabled activism has been focused on being written into legislation in a more thorough manner (Berube, 2003; Putman, 2005). Whether through medical legitimation or through critical environmental/policy analysis, disabled people have sought to maintain some sort of social welfare by claiming the veracity and legitimacy of their needs. Working against the system, such as abusing beneficence, potentially collapses the fragile security disabled people have been afforded. Maintaining innocence becomes a primary way in which disabled people secure and maintain their support.

I first became aware that participants ‘did innocence’ in my interactions during the workshop sessions. At first, Nas and I tried to occasionally ‘bend the rules’ in the workshop setting, but participants were not willing to follow our lead. For instance, Nas and I had planned to teach participants about the parts of the camera through a game of ‘sabotage’. Nas reviewed the camera parts and operation with the group. Participants were paired off, and each pair was asked to take a turn leaving the room. When the pair left, the remaining participants would sabotage the camera in some way (e.g. leave the lens cap on, remove the battery, change the camera settings). The pair would be invited back in and asked to figure out how the equipment had been sabotaged. I was paired off with Bernard. We left the room and I tried to listen at the door for how the camera was being altered. Much to my amusement and chagrin, Bernard became very upset with me for “being bad” and informed me that it was “rude to cheat”. When we re-entered the room, Bernard kindly, but firmly, told me I “couldn’t play” because I had
broken the rules. While this incident may seem to be an attempt to abide by rules, it also speaks to a purity of intention that I saw from each participant at some point in the project.

I often observed participants worrying about the consequences of transgressing legal and moral codes. Throughout the project, participants expressed uneasiness with overt and public flouting of “the rules”. I witnessed participants struggle to act in ways that would be above reproach, to be literally innocent. Perhaps because they would be disseminated to the broader public, the videos became a focal point for participants’ anxieties. For example, Isabella struggled to obtain permission to use clips of several documentaries in her own video. In requesting copyright permission, she identified herself as a student who would not generate income with the video. However, the production companies refused to grant their permission. Isabella seemed immobilized by the refusal, unsure of how to proceed. At one point she despaired that her video was “ruined” and she would need to abandon the project. She was certain that the production companies would charge her with copyright infringement. Repeatedly, Nas and I, and others from TSV, assured her that her video was likely too insignificant to warrant any legal action on the part of the production houses. Yet Isabella remained reluctant, worried that the possibility of a charge might preclude her admission to law school one day.

In order to allay her fears, Nas suggested that she digitally alter the video clips so they would not appear as they did in their original context. For instance, her video included a clip from the educational documentary *Sexuality Reborn*, featuring a heterosexual couple, engaged in intercourse. In its original format the scene was clinical and utilitarian in its depiction. Isabella edited the clip, intermittently interrupting the scene with other shots, softened the focus and slowed down the footage. In this way she did not violate copyright regulations.

Unfortunately, Isabella found herself in violation of more abstract, broadly held ideas of innocence. While she stayed within the copyright rules, the intimate content of her film depicted disabled people as sexually experienced and as violating the strict stereotype of disabled people as chaste, pure, and naïve. This became apparent through two incidents. First, a representative from UNICEF, had eagerly inquired about using all the videos in the organization’s work promoting the rights of children with disabilities. However, she felt Isabella’s video was too explicit, radically transgressing the perceptions of disabled young people held by UNICEF members. The representative cited Isabella’s inclusion of a scene of two disabled men kissing
and another scene with a sex shop worker holding and discussing various sex toys as “simply too much”. In this instance, any depiction of sexual content no matter the age or disability status of the participants could be deemed ‘inappropriate’. However, Isabella encountered similar concerns closer to home. She discovered upon completing her B.Ed, that her best prospects for employment as a disabled teacher were with the Catholic School Board. The less than innocent nature of her video presented a serious dilemma to her potential employment. In 2007, she and I spent considerable time strategizing about how to address the apparently illicit content of the film in potential job interviews. Had Isabella been non-disabled, the content of her video would not have carried such troubling consequences. For instance, almost all the artists and film technicians who provided support to the Poster Child project identified as “queer”, produced socially and sexually transgressive artwork, and disseminated their video work in both the mainstream and alternative film festival circuit (e.g. Inside/Out; Mayworks; Images; ReelAsians). All also worked as teachers within the local school boards – some having been sought out for their technical, activist and advocacy expertise. Similarly, participants in similar youth art projects – such as Inside/Out or Rendezvous with Madness, have found they can include their artwork in portfolios for graduate school or scholarships. Isabella’s high support and accommodation requirements meant she had a very small pool of potential employers. Most of her options were in conservative Christian schools. Her video, a possible asset in more progressive settings, risked limiting her teaching possibilities even further. These unfolding dilemmas related to Isabella’s video demonstrate how disabled young people needed to practice innocence in various ways. They needed to avoid transgressions such as breaking copyright laws. They also had to avoid culturally unsanctioned activities. The sexual content of Isabella’s video, while quite tame, transgressed cultural expectations that disabled young people were sexually inexperienced. Failing to ‘do innocence’ thoroughly risked shutting down new experiences and opportunities.

Disabled young participants ‘did innocence’ to protect their current support resources. Therese became distraught, in the midst of editing, about the possible legal repercussions of using images of a specific hospital in her video. Despite reassurance from Nas and me that the shots of the institution were neither inflammatory nor especially critical, she could not be calmed. On one occasion, she began weeping and shaking with fear while we were in the editing suite – attracting concern from staff at TSV and neighbouring offices. We consoled her just
enough to quickly wrap up the editing session, but she remained upset as I waited with her for her Wheeltrans pick-up. The next day, we agreed to omit any shots in which buildings could be identified. In discussing this incident in later weeks, Therese appeared to conflate avoiding transgression (“I will get in trouble if I show a public institution”) with maintaining her integrity. She worried that if she criticized the hospital, it (the doctors, nurses, social workers) would regard her use of its services with suspicion. As she stated, “I will look two-faced”, and therefore lacking in integrity.

Both these incidents gesture towards a sense of accountability to institutions. In creating a public visual image of disability, the risks of triggering repercussions weighed heavily on young people. Both Therese and Isabella assumed guilt for misdemeanours which they had not (yet) actually committed. I do not wish to question the psyche of these two young women, but to think about how important it was to them to produce a textual innocence in their videos. The innocence they sought was in part the innocence of ‘lack’. They sought to ensure their actions and public voice were free of or lacked the cynicism, insight or worldliness of their peers. As much as they could they tried to produce a public voice that was innocent of institutional criticism and misdemeanour. In ‘doing innocence’ they submit to the law, to broader pressures to remain pure, to cultural stereotypes.

This desire to do innocence sometimes extended to other parts of participants’ lives. Participants were often concerned about the loss of ODSP. This was acutely apparent as the participants, involved in the second workshop, planned their community screening. As part of the planning, they began a tentative discussion about future distribution of their videos. Participants were surprised to learn that they would receive a screening fee each time their video was part of a film festival.

**Therese:** We get money for this?

**Nas:** Yes if it goes out to festival. V-tape only sends your tape out to places that will pay for your tape. And what happens is they charge a screening fee. And what happens is 30 percent goes to Vtape and the rest of it goes to the artist. And in this case it would be … it would go back to the project and then it would be up to the project to distribute the money.

**Anna:** On the other hand, not to discourage you, but I know that we are all on ODSP.

**Therese:** That's right.

**Anna:** And you know what ODSP is like right? And if you make a lot of money, they start to penalize you.
Kari: I'm wondering then if the money goes to the project in a way that doesn't interfere with… In a way that better fits with concerns around ODSP. So the project fund could distribute money in a way so that it doesn't have to go out all in one chunk. So it can be divided up over a number of months.

Anna’s insertion of an ‘institutional voice’ by citing ODSP practices imposes various constraints on her fellow participants. First it shifts a discussion of finding audiences for their artwork to financial and welfare obligations. In doing so, participants’ citizenship practices shift from public participation, voice and presence to basic concerns about maintaining minimal income supports. Moreover, concerns about ODSP, as I discuss in the next chapter, seriously truncated young people’s efforts to envisage themselves as making economic contributions through (artistic) labour. Even Kari’s comment, although offering an alternative, bolsters the authority of ODSP, by suggesting that participants have something to hide in receiving honoraria. This conversation shifts from concerns about work, recognition and voice (the point of the project) to concerns about integrity. Although in this instance, Anna flags the consequences for skirting around the ODSP rules, she goes on in the conversation to contend that the central issue is one of honesty with respect to social welfare.

Nas: (interrupting) There's not going to be a lot of money.
Isabella: That's what I was thinking. There's not going to be a kejillion dollars.
Therese: Not at all. That's for sure.
Nas: Artists don't make a lot of money.
Isabella: I'm not expecting to make a fortune (Caterina laughs in agreement) Or even to get off of ODSP, but I don't think ODSP is that nit-picky, like. You could just say that… I don't know, I never heard of anyone being audited by ODSP, even though they do have your bank records - but they don't keep on top of all the money that you ever got. I probably got more money from my mother in there, (but) they've never asked.
Anna: Well it still isn’t honest.

Innocence, then, is not a matter of appearances; when participants ‘do innocence they do not try simply to make others think that they are innocent. Rather, they reproduce innocence in their everyday activities as Anna does above. I will return to ‘doing innocence’ in Chapter 8, but here, I wish to draw attention to the ways in which some participants assimilated the imperative to be rule-abiding, to demonstrate integrity and to honour dominant notions of legitimate claims to support. In each of the instances, participants were reluctant to enter into dialogue about these
values. To be a respectful (and deserving) recipient of support, participants were compelled to follow the rules and to maintain honesty and integrity.

Summary

I have presented the deference work that disabled young people do to secure and maintain support. By assuming a deferential posture in everyday interactions with those providing support, by accommodating their requests and expectations to the structural limitations of support provision and by submitting to cultural notions of ‘the innocent and deserving disabled’, young people maintained a fragile skeleton of support. Doing deference reproduced poster child discourse almost exactly as it was articulated by workers in transitions programs – it was if disabled people had bought its ideological message, hook, line and sinker (Diamond, 2006).

An inevitable component of deference was ‘deferral’. In order to do deference, participants must put aside their own activities, interests and preferences in favour of those who are providing them with support. Thus, participants actively altered and restricted their futures, always in the short-terms and sometime irrevocably. The final sequence of activities I will discuss are related to deferral: postponing, waiting and ignoring.

Doing Deferral

A third way participants reproduced the poster child discourse was through doing deferral. As described above, I observed disabled young people continually putting aside their own interests, feelings and plans in favour of those of workers, families and others. Participants engaged in a process of continuous prioritizing and paring down their everyday activities. Inevitably they deferred or postponed their hopes, desires and needs, touching every aspect of life from career aspirations to the most intimate body-based activities. In the following sections, I argue that deferral is closely tied to the view of disabled young people as ‘futureless’, suggesting that inadequate support provision puts young people in the position in which they must put their futures ‘on hold’. I focus my discussion on two sets of findings. First, I begin by reviewing the instances in which participants delayed, revised and truncated their life aspirations – particularly their educational and employment goals. I then examine how participants were even compelled to defer their bodily functions in the context of scarce support resources.
Doing deferral may seem like a different order of activities from focusing on deficits and doing deference, since participants were often more vociferously aware of the link between postponing, waiting and giving up activities with inadequate supports. Deferral seemed much less a response born out of the desire to maintain supports than it was an outcome of the patchy or inappropriate supports participants received. However, in other ways deferral was an indication of the authority of the poster child discourse. Doing deferral was often a compulsory response to poor supports where participants could either put aside their needs and desires or, as I demonstrate in Chapter 7, risk losing supports altogether.

Deferring dreams

Throughout the project I observed young people continually attenuating their dreams and goals, particularly around future careers. I heard participants attribute these delays and deferrals to the difficulty in obtaining adequate supports when in post-secondary and job-training opportunities. They recounted how, as they moved deeper into post-secondary life, educational supports were not as promised. At the time of her exit interview, Therese had made a decision to attend her early childhood education college program on a part-time basis.

Therese: I decided, you know what, I work hard all the time. I’m in this program full-time – and for what? Who is so impressed with that? It’s not like anyone takes it into consideration. I have trouble remembering stuff and working through the homework and assignments. No extensions – no I hand it in all on time and what do they think? What do they do for me? Nothing.
Esther: Who is ‘they’?
Therese: The teachers, the placements.

Therese went on to say that no one was willing to accommodate her needs in the classroom. I assumed she had meant physical accommodation.

Therese: No, no that’s okay – I just sit on the ground and I take my time to get up. No problem. It’s all the things you have to think about and remember. They’re all excited when you join the program – oh yeah, (imitating) we’re so great, we are all about diversity. We’re a rainbow. (herself now) Yeah you’re all so great. You bring me into this school. You tell me you want me here, but I’m only here to be part of this idea, you can point to me and say look at how great we are. We have this disabled student – we’re wonderful. We’re so progressive. Oh yeah. But when it comes to actually teaching this disabled student (pointing to herself) then they don’t know what to do. I go to them with a problem. Yeah like, I have trouble remembering all the instructions that the placement teacher gave me. How can I talk to her about that? Nobody knows. And they say that: “We don’t know”. And I think, okay, you have me here now. Did you think it was going to
be like teaching other students? They’re teachers! You know what I am? I’m their guinea pig.\textsuperscript{57}

Unlike some the comments I presented earlier in this chapter, Therese is not passively reproducing the poster child discourse in a monologic way; she does not immediately attribute her slow pace through the program to some inherent deficit. She seems to have honed a critical analysis of her ‘iconic’ role as a token disabled student in an ECE program. Other participants also spoke of their initial warm welcome to post-secondary education, followed by a “disinterested” approach to accommodation and educational support. Although institutions were eager to include disabled youth, their inability to anticipate, let alone provide, the full range of required supports led participants to describe themselves as part of and inclusion “experiment” – as Therese says “guinea pigs”. Once in the program, they were evaluated alongside their peers with little intervention.

Therese’s comments highlight the challenges this ‘experiment’ produced in her teaching placement with respect to her invisible learning impairment. As she notes, physical supports were available (a test-writing centre, chairs, physical work modifications). However, the college failed to anticipate and work with her (invisible) differences in memory and organization, of which they were informed. Her frustrations are heightened by the fact that she had not taken advantage of other supports to which she may have been entitled\textsuperscript{58} – such as assignment deadline extensions.

In order to maintain her academic standing in the absence of support Therese moved to part-time study. Unlike ‘focusing on deficits’, Therese does not construct limitations as personal, but locates them firmly within the system of educational support provision. Nevertheless, her individualized and individualizing response complies with the implicit message that her challenges at school are personal. Ultimately, her decision to move to part-time study obscured the systemic deficits in the same way as if she claimed responsibility for her educational challenges. First, it kept the college’s lack of action and other institutional shortcomings invisible. Her actual support requirements both for herself and for other disabled students were subsumed under the tacit (and arguably unintentional) admission of her inability to keep up with

\textsuperscript{57} Therese seemed to face unique barriers because her impairment was invisible.
\textsuperscript{58} In Chapter 7 I more fully explore the disadvantages faced by disabled young participants in refusing supports. Therese fails to draw in the poster child discourse to help organize her activities during her placement. As such, it seems more difficult for her to secure the supports she does want to use.
her academic work. Consequently, if and when Therese continues to perform poorly, both she and the educational institution can continue to lay responsibility on her shoulders. Perhaps most significantly, Therese’s response to her support situation, to move to part-time study, lengthens her time during which she will remain a student, thereby less available for work and dependent on her parents. Her actions reproduce the poster child’s ‘futureless’ dimension.

Like Therese, other participants expressed frustration by the lack of support they received in post secondary school. Echoing Therese, their responses were remarkably uniform. Participants either moved to part-time study or dropped out of a program of study altogether – deeming full-time schooling “impossible”. Participants deferred their educational and career aspirations in other ways as well. Several hoped for careers working with children, yet each confronted numerous barriers in their efforts. Rosalyn wanted to enter a midwifery program, but found no one could answer her questions about personal and physical supports to assist her. Eventually she followed the advice of transitions workers, and trained to work in disability services, Rosalyn allowed her goals to slip away in favour of pragmatism. Douglas also seemed to allow his dream of becoming a minister to evaporate. Although he had wanted to become a pastor, he was no longer studying and had moved on to ‘helping out’ with web design that he could perform from home. When I asked if he was still planning to become a minister, he responded by saying that it’s slow. Graham spoke frequently about becoming an animator, but was told he would need to wait until he finished several extra years of high school and a bridging program at community college. Isabella revised her career goals three times within the course of the project. Josh and Zachary were waiting for the wider availability technological innovations that might allow them to attend film school. Anna completed journalism school, but found home and school personal supports so difficult to manage that she elected to “wait a few more years” before she would actively pursue her dream again.

Deferring educational and employment opportunities constrained participants in various ways. For example, the decision to move to part-time study, stay in high-school for a couple of extra years to prepare for independent living, or dropping out of one academic program in favour of those deemed more suitable prolonged disabled young people’s time as students. This had implications for other parts of their lives. Staying in school longer generally is more expensive both in terms of tuition and the other related costs (housing, technologies, specialized supports, transportation). At a pragmatic level, young people delay their entry into full-time, permanent
work of adulthood. Their delayed labour force entry will diminish their earning potential; they will contribute less to retirement and disability savings plans; their CPP will be negatively affected. In addition to these economic implications, young people may potentially face social consequences, since delayed labour force entry may lead them to put off owning a home, entering a serious long-term relationship or starting a family. Non-disabled young people also frequently fail at a first job and often do poorly when they embark upon post-secondary education, but when disabled young people are forced to defer these ‘firsts’ they are left with little margin for error. Presumably older than their peers, they will have less time and opportunity to explore their options; and any initial faltering could easily be interpreted as proof of their unsuitability for employment or poor academic potential – rather than as ‘experimentation’ or ‘finding oneself’ as with their non-disabled peers. All of this conspires to delay, and possibly derail, disabled young people’s adult, full citizenship. Perhaps most significantly, however, the deferrals in this study were often connected to a lack of adequate support. While other young people may wind their way around complicated and imbricated transitions, the participants in this study were not always well positioned to change their circumstances.

Deferring the body

The work of negotiating support also involved body-based compromises for participants. Most physical support requirements were complex and took time. Deference to workers, parents, institutional protocols and practices around support provision and limited support resources meant that participants had to learn which body-based needs they could risk postponing and which would carry too great a physical or social cost.

Zachary explained that he often missed or deferred opportunities to socialize with friends because of support scheduling problems.

Zachary: I don’t let just anyone help me with getting ready or getting dressed. Sometimes one of my friends from church wants to help me get ready faster…you know they don’t have the patience to wait for the PA. They start trying to put on

59 Of course, disabled young people will continue to work outside the paid labour force – build skills through domestic and unpaid labour. For non-disabled young people, this is integral to gaining the skills to be a good waged worker. However, when disabled young people gain the chance to do the same tasks these risk going unnoticed. They are seen as a way to ‘keep busy’ rather than as a training ground. More sinister perhaps, these skills are viewed as obligatory – yet invisible.
my shoes. I always stop them, I don’t want them to do that. (E: Why do you stop them?) They don’t know what they’re doing. I worry they might hurt me, then I’ll be stuck in hospital. Like and if they hurt me by accident, they’re going to feel like crap.

Although participants would accept informal support from family members, like Zachary they were reluctant to rely on friends. Zachary’s rationale here points to two separate concerns. First, he worries about possible injury, very much in keeping with broader concerns about maintaining one’s health and well being. A second concern is with the feelings of others. Zachary worries that should his friends injure him, they will pay an emotional price. This regard for the emotional burden of others is consistent with the work of doing deference as discussed earlier, but is somewhat more complicated. As Caterina explained in a separate discussion, when she did not allow friends to “hurry me along”, she found that they would not include her in future social outings. In fact, it is also possible to consider that accepting assistance from friends uncomfortably shifts the dynamics of their relationships. Disabled young people may feel that by accepting help they are casting themselves into the subordinate, more vulnerable position. Similarly, participants may have worried that friends who provide help may also find themselves in a more vulnerable position with the responsibilities and stigma of ‘workers’, without work’s benefits. Whatever their reasons, participants found themselves in a paradoxical position, where in order to avoid making demands on others, they had to defer opportunities to go out into and participate within their community.

Sometimes informal support alternatives are not available. In these instances young people could only elect to prioritize some body-based requirements over others in accordance with limited formal supports. Getting dressed, showering and setting up one’s work for the day were often prioritized over eating, drinking or toileting. A running joke in the workshops for participants made reference to their efforts to restrict their fluid intake so not to “overwork” Kai, Caroline, or other support workers who joined us in the workshops. However, participants seemed to engage in these restrictions in other arenas of their lives as well, often with resignation rather than humour:

My mom said no drinking because I have to hold it until I get home. I don’t have anybody to help in the bathroom. (Joanne)

No I can’t have a drink. Me and Ainsley are going to the Carlton (movie theatre) after. We don’t have Wheel trans pick up until 8. (Zachary)
My mum has a mammogram later this afternoon. I better not drink anymore, cuz I don’t know how long she’ll be. (Rochelle)

Participants described how they were simultaneously aware of their *body clocks* and the larger schedule of support services. They used this knowledge to anticipate when they might be able to request assistance with personal care. In each of the three examples above (there were countless others), disabled young people knew to put off drinking knowing they would have no one to help them in the washroom. As another example, participants were often eager to snack late in the workshops. In this way they could eat a “light meal” with support and skip a dinner booking in favour of another task that might require support. Unfortunately, these snacks could not adequately replace a meal.

In a similar vein, when at home participants would forego more complex healthier meals opting for what workers could quickly prepare with as little direction as possible. As I described above in Douglas’ and Rosalyn’s experiences of directing workers in their kitchens, complicated meals involved a greater investment of personal support work. When support hours were limited on busy days, young people would prioritize supports that might enable them to leave their apartments, deferring those that would allow physical comfort and well being.

Part of what made it possible for young people to defer body-based supports, was the haphazard way in which they were supported. When participants did not prioritize their own support requirements, over-worked workers would make decisions for them – albeit perhaps not consciously. Graham, Adam, Cynthia and Isabella all shared harrowing accounts of how they had been left on the toilet for long periods as workers ‘forgot’ them and moved on to other clients. Douglas, fearful of being fed too quickly to breathe if a worker was rushed, chose to ask for smaller portions with certain workers or in certain situations. Anna had given up eating foods such as pasta or salads, because “if the attendant feeds me in a rush, I end up with food all over me – like even in my hair”. Zachary described how he was not supported into bed on many Saturday evenings as support workers, exhausted from the week fell asleep in the staff lounge. In Zachary’s case, he had negotiated later bedtimes in order to watch his films. Unwilling to lose this unsanctioned extra support, Zachary elected to sleep on the floor with a sofa cushion rather than complain about the sleeping workers. In all these examples, participants remained compliant
and uncomplaining, but put off and aside food, hygiene, physical comfort and sleep: basic physical requirements.

One area of difficult body-based deferrals for young women was menstruation support. Almost every young women in the group required support – albeit, not always formal. For instance, Caterina and Melanie were for the most part able to perform personal care activities on their own. Yet, if their period began while out in public, and they found themselves without sanitary products, they quickly ran into trouble. Ironically, sanitary product dispensers in public washrooms are rarely low enough for women using wheelchairs to reach them unassisted. Even Melanie, who could stand with support, had to engage in physical contortions to place coins in the dispenser, twist the handle and remove the item while supporting herself by leaning against her locked scooter. Participants pointed out that even buying tampons or pads was difficult, since such items, particularly those of better quality, are often placed on the upper shelves, out of the reach of women in wheelchairs/scooters.

Other participants required significant intimate assistance. For women with fine motor impairments or spasticity, positioning a pad independently was impossible. Participants who experienced this, described the work they performed to negotiate a number of social barriers in order to secure support. Young women privately recounted how they tolerated complaints from family caregivers and workers about menstruation support. Each young woman had been encouraged to go on the birth control pill with the partial intent to stop their monthly bleeding. Although young women were reluctant to explore this topic in detail in conversations with me, none followed the suggestion from support providers. I consider this in more detail in the next chapter.

These deferrals of physical needs may seem small and subtle, perhaps even hardly noteworthy. However, Nora Groce (2004) in her review of the global health of disabled adolescents has suggested that it is precisely these sorts of small and subtle deferrals that have dire health consequences for disabled young people. Parin Dossa (2009) briefly touches on a similar theme in her narrative research of Mehrun, a Ugandan refugee with post-polio impairments. Dossa includes Mehrun’s account of her efforts not to drink during the day, so that she would not have to use the washroom before her mother came home from work, allowing her unemployed father to provide personal support. John Callahan (1989) expresses anxiety about eating too much in his autobiography, since he had difficulty hiring personal support workers.
who will consistently support his bowel care. The efforts of these writers, like those of the participants, speak to their active participation in deferring not only basic physiological requirements, but in deferring their dignity. Deferring the body eroded participants’ self-determination, putting them at risk of becoming literally futureless by curtailing their health and well-being. Moreover, the accretion of small deferrals over time undermined their dignity.

Summary

Deferral of needs and desires involved more curtailed social opportunities – diverting youth by default to more socially restrictive paths of education, family and career. Even participating in the workshops was a challenge for some youth – since they couldn’t work out consistent attendance with transportation, with mealtime bookings, with any other activities through the day. Educational qualifications, independent housing and secure employment are critical to western definitions of the ‘good citizen’. By deferring their needs and desires, disabled youth are often compelled to actively participate in missing this standard.

Towards the next chapter

In order to make their support requirements visible and thus able to be acted upon, participants must work with utterances that can be commonly known in objectified ways and that extends beyond their own actual everyday experiences of support (Smith 1990b; 2005). They must draw upon words, utterances and discourses that are familiar to those around them, bringing them into their own speech. But they do so with little regard for the unique character of their individual subjectivities, their practical needs or their life conditions. I suggest participants readily assimilate the poster child discourse, the authoritative accounts of their lives - as young, as deficient, as futureless, as needing to be deferential and put these views and values into practice.

The poster child shaped young people’s consciousness; it constrained how they thought of themselves and how they were able to secure support as they attempted to carry out the work of accomplishing adult citizenship. In order to secure and maintain support, participants assumed a demeanour, actions and utterances typically associated with the poster child. In so doing, they reproduced its ideological underpinnings – actively becoming passive. Support promised to the poster child is not an entitlement, but an ad hoc act of benevolence, contingently bestowed upon
the young, the infirm and the deserving. In this chapter I have presented three sequences of activities that disabled young people pursue in order to secure support. These activities involved assimilating the poster child utterance at once reproducing its views and values. In doing so young people did not fully live out the promise of adult citizenship, instead practicing a sort of marginal citizenship that might be associated with individuals of a much younger age. In the next chapter I present a second reaction to the poster child discourse, resisting the poster child, in which participants turn away from its views and values.
CHAPTER 7

Resisting the poster child, deferring disability

In this chapter I argue that the poster child discourse operated on a second authoritative level where participants rejected it entirely. I suggest that there were many instances in which participants were reluctant to assimilate and parrot the views and values represented in the poster child. Rather than ‘answer back’ or otherwise creatively respond to these views and values, participants resisted them. It is this second possible reaction to the poster child discourse that I present below, focusing on three forms of loosely organized resistance activities. The first sequence of activities are those where participants tried to minimize or even mask their deficits. I focus primarily on the ways this emerged through their video-making processes. Second, I look at how participants resisted the imputed constraints on their futures by positioning themselves as workers. By striving to become adult contributing citizens, participants engaged in opportunities to give back to their communities, help out others, secure employment and form ‘normal’ relationships. Finally, I argue that resisting deference entailed a refusal to react in a conciliatory manner towards the wishes or judgments of others.

Throughout my discussion of these three sequences of activities I point to how participants risked the loss of supports as they resisted the poster child discourse. By refusing to mobilize the discourse, participants failed to make their support requirements visible, understandable and actionable by others. In resisting the poster child discourse, participants deferred disability such that their impairment-related support requirements were not immediately apparent to others and therefore were inadvertently ignored. In other instances, resisting the poster child discourse worked against the conditions that may have inspired others to offer and deliver support.

Minimizing deficit

Throughout the project I noted how participants sometimes seemed to resist becoming the embodiment of the poster child, mostly through minimizing or masking signs of their imputed deficits. There were at least two forms of deficit that participants masked. The first revolved around observable differences in appearance, movement. The second entailed a masking of their
‘mistakes’ or limitations that might be attributed to their functional deficits. I am not suggesting here that young people were attempting to pursue normalcy – since all were quick to assert how elusive such an endeavour was. Instead, I believe that participants actively chose not to engage with the poster child discourse from time to time – but always with consequences for the support they could secure.

**Masking visible difference**

Most participants had visible impairments. Even participants with intellectual impairments expressed an awareness that most people could tell “just by looking” that they were disabled. Despite this, all participants went to great lengths to mask or minimize their impairments in their visual images. In part this practice seemed instilled from childhood. Participants had few photos in which their impairments were evident. This was a practical concern because participants relied on these images to reference their ‘disabled childhoods’ in their video. The exchange below in response to Caterina’s childhood photographs was typical.

Isabella: You were so cute! Look at that snowsuit!
Graham: Is that your sister? (Caterina nods). You guys look alike. It must be hard to remember which one of you is which. In those pictures I mean.
Nas: Are these all you have? (Nas surveys the photos and seems concerned).
There are none here in which you’re actually in a wheelchair.

In fact there were many photographs of Caterina at the beach, leaning against a beach-ball. Caterina at Christmas, holding a doll that her sister seemed to be eyeing enviously. Caterina sitting in the snow beside a beheaded snowman. Caterina on a horse in riding gear. In all these images, she was as Graham noted, indistinguishable from her non-disabled sister. In my view, Graham’s comments referred to the fact that it was impossible to tell that Caterina had a physical impairment.

Caterina: I don’t have any pictures in the chair. My parents only took out the camera when I wasn’t in the chair.

Throughout the project, all participants had difficulty locating images in which their impairments were clearly evident. In preparation for her shoot, Rosalyn had searched family photographs for images in which she was using crutches or her wheelchair. She commented casually as we later set up her shoot that she was unable to find a photograph in which it was apparent she had a disability. She noted that she could not remember ever seeing such an image,
but had never thought of it until she sought one out. Others still only had ‘head shots’ from when they were younger, or were held by relatives in family group shots –propped up between pillows and large stuffed animals. When I later directly asked why they were not photographed in their chairs or with crutches, Ainsley summed up their responses “It’s hard not to look like an Easter Seal stamp if you’re a kid in a wheelchair”. The general agreement with her comment led me to speculate that families had deliberately avoided signs of impairment from their children’s photographs.

Visible impairments could become a source of consternation for participants when producing images for their videos- a challenge to be overcome for the sake of visual aesthetics. For instance, Graham raised some aesthetic concerns as we shot his footage.

Graham: Can you see the handles?
Nas: What? What handles?
Graham: The handles - you know the things you use to push around my chair.
Nas: Oh. Um…sort of, I guess. Do you want to see? (Nas turned the view screen to face him so he could watch the shot as she focused the camera.
Graham: Yeah, you can see them. You can see one. Can we do something to get rid of it?
Nas: I don't know that I can. It's just there by your head. (Nas tries several times to re-angle the camera). Okay Graham - this is the best I can do.
Graham: (resigned) It's going to have to be okay. I hope my parents won't get mad.

After the sequence was shot, Graham called Nas and me over to him.

Graham: So how did that look?
Esther: Good, really good. You were clear and you didn't look down too often.
Graham: No, how did I look?
Nas: Good, like yourself. You can watch this tape when we've finished shooting the rest of your artwork.
Graham: No. Did my head move around?

Graham had a neurological impairment in which his eyes would involuntarily track from one side to another. In order to compensate, Graham would move his head back and forth in the opposite direction. In this way, Graham would be able to focus on an object despite the fact that he appeared constantly in motion. While his eye movements were involuntary, his compensatory head movement had become habitual, but in his control. He went on to explain that in home movies he tried to keep his head still.
Graham’s concerns were echoed by other participants when their image was being captured. Cynthia did not want to smile and reveal her crooked, discoloured teeth. Melanie, Anna and Rosalyn removed themselves from their wheelchairs and seated themselves in ‘regular’ chairs. Isabella, who had spinal curvature, threw her upper body forward so that her face would be in line with the camera lens. Douglas and Rochelle asked that their hands be taken off the joysticks that operated their wheelchairs, thus resisting what they claimed was a “typically disabled” pose. Other times they asked to be shot from “the shoulder up”. Others, less able to conform to photographic ideals, such as Zach, submitted to having their picture taken only very reluctantly or in such a way that only parts of their bodies could be seen. Each resisted being held in visual images as different, each tried to minimize the visibility of their impairment.

Graham had been moving his head quite a bit in his shots. He put a trick his parents taught him into practice. He carefully edited his film in such way that his writhing movements were digitally ‘interrupted’ – each time he was about to move on film, we helped ‘insert’ a cutaway shot to another image. In this way he (more or less) appeared still.

In part, participants’ efforts could be understood as concessions and submissions or deference to the normative aesthetic standards and bodily comportment and expressions of cheerful striving (Longmore, 2005). Efforts to minimize physical differences could be interpreted as reproducing the poster child discourse. However, I came to understand participants’ as actively resisting any visible trace of their impairments in pictures as part of a larger effort to resist depictions of their deficits or differences. Participants minimized their own differences in order to not “spoil” images.

Participants refrained from imposing their deficits upon others by ‘playing down’ disability, often in instances in which they were to be photographed for special occasions. ‘Playing down’ disability involved efforts to minimize one's impairment or at least hide its signs (equipment, scars, spasticity, certain movements). One situation in which participants played down disability was wedding photographs. Several young women in the project shared tips about how to manage photographs for weddings they had or were about to attend. Complaining that their physical impairments often meant they were excluded from weddings, even when part of the wedding party itself, they had crafted ‘visual tricks’. These might include strategies like convincing the photographer to suggest that several in the wedding party were seated, posed in
flattering angles or informally sprawled on the ground when the photograph was taken. Melanie went so far as to convince a friend to stage her wedding photos around a set of swings, so the bridesmaids could be photographed on the equipment, ‘propped up’ by ushers. These efforts suggest that young women implicitly accepted that visible signs of impairment would “spoil” the photos and an otherwise beautiful occasion. However, as they explained, their strategies prevented photographs from “being ruined” by the inclusion of a disabled wedding party member. The young women could participate and maintain a presence in the valued tradition of wedding photos.

Minimizing mistakes

Another way participants minimized deficits was by trying to discard evidence of mistakes that they believed resulted from their impairment. The visual and aural images they produced in the media workshops were often a source of consternation and embarrassment for participants. Conventions inherent to image and video-making shaped much of what they were first willing to accept in terms of their own video production.

When participants first reviewed their images, many wanted to discard their bad shots or their mistakes. Nas and I encouraged them to reconsider these decisions, since such images provide unique insight into disabled peoples’ lives. We stressed that in ‘making art' or 'doing creative work', unintended outcomes are often the avenue to innovation (see for instance, Gablick, 1998). However, participants persisted in discarding these shots. They wished to portray themselves in the best possible light; they wanted not only to convey particular images of their lives, but also their technical abilities. Certainly normative aesthetic standards are at work in the production of their “good shot”. It was striking that many of the shots which youth wished to discard were those that were out of focus, off-centre, or taken at an unusual angle. In nearly every instance participants disagreed with Nas and myself, insisting that the shot in question “makes me look like I don’t know what I’m doing”. Or “it’s like that because I can’t hold the camera steady”. In my view, their resilience in the face of our encouragement to re-consider speaks to how deeply they resisted deficits. They not only want to discard the shots, but guard against repeating such ‘mistakes’ – going so far as to ask others to operate their cameras.

Most made reference to a specific photograph of the wedding between Prince Charles and Princess Diana in which the wedding party was ‘on the ground’ and leaning against one another.
In an act of ‘counter-resistance’, Nas and I continued to encourage participants to re-cast their notions of mistakes, and turn towards the view of deficit with renewed interpretation. For us, their mistakes spoke to an embodied perspective of those who live with fine-motor, visual or cognitive impairments, use a wheelchair or crutches or experience involuntary body movements. These shots potentially allowed participants to see themselves as the embodied subject behind the lens who had something to say. Indeed the presence of ‘disability’ in the image could be celebrated as artistically generative. At one point in the project it appeared that participants’ desire to only show “good shots” and “normal angles” would shape the 'stories’ and 'images' of disability that would become public, and by default, those that remain hidden (Ignagni & Church, 2008). Given that the project was participatory, this struggle was potentially consciousness-raising. As such we devoted considerable time re-considering and expanding conventional and constrained notions of video-production, image-making and disability itself.

We were unsuccessful, however, when it came to expanding participants’ ideas of an acceptable voice-over. Most participants passionately claimed the right to speak in their video. Even in instances in which it might have been more powerful to allow images to communicate, young people spoke. However, like visual images, they found it difficult to achieve voice-overs that presented a normative aural depiction. As with visual images, participants resisted representations of deficit in the narration of their videos.

For instance, Isabella struggled to bridge her desire to represent disability, with the pressure to ensure her video “sounded competent”. She had written her voice-over well in advance. Her vision was to have various friends read lines of the script so that the video would capture the diversity of voices within the disability community. She wanted voices that carried the sound of disability, ‘cp’ voices – pitched a little higher, perhaps articulating words a little more slowly with audible effort.

On the day of her shoot she gathered a group of eight friends including fellow project participants to narrate the voice-over. Interested in the project and thrilled to be part of the video, they were a group with considerable social and material resources: student leaders, athletes, community activists – all in post-secondary education and in Isabella’s estimation, capable of and willing to read the voice-over. She had opted for these young people over most fellow workshop participants because she wanted to ensure they could read her script with little effort. Melanie was the first to read. She started well and then she stumbled.
With a constant smile, Barbie is an always standing figure, for her legs can never bend to have her sit in a comfortable-looking position. And her feet are permanently destiny (sic) for long slick (sic) stilettos…. A common held belief is that people with disabilities are not sexual beings. Everyone, from birth to death is a sexual being, and disability does not stop an individual being (sic) a sexual eternity (sic).

Nas asked if Melanie wanted to re-read the paragraph, explaining that the words were to be read as written. After an awkward shuffling Melanie read the offending passage again, only to make the same mistakes.

Kyle, Isabella’s boyfriend was next. He had the cp voice that Isabella wanted. But faced with the printed word the script seemed to drag on tortuously. Worse yet he fumbled in all the places where Melanie had had difficulty, making it difficult to consider editing their voice-overs into a single track. Nas did not ask him to re-read the passage.

Each participant struggled, prompting Isabella to ask Nas to read as well. Nas read the piece effortlessly. Later in the editing suites at TSV, Isabella noted the irony that the non-disabled voice was the only one that could “actually read” the voice-over. In order to achieve a flawless narration, she eventually asked TSV staff to read it. She retained the diversity of voices – integrating some words from every narrator – but included no audio with reading errors.

Mistakes and disability have an uneasy relationship. Disability is increasingly viewed as resulting from a wide array of mistakes: genetic errors (Wilson, 2006), poor mothering – from conception onwards, (Reist, 2006), wrongful births (Saxton, 2006), medical iatrogenesis (Illich, 1979), errors in judgment leading to accidents, failures in public health prevention (Bickenbach, 2005) and so forth. For the participants, mistakes drew attention to their impairments and their supposed deficits in being able to keep a camera steady, read text as written, enunciate clearly or other functions related to video-making. I heard similar anxieties around schoolwork, job placements, team sports, public activism, volunteer work and so forth. Participants often expressed reluctance to take on new or public activities in case they “messed it up”. As Joshua pointed out as he justified his refusal to read his own voice-over “if I make a mistake, I’ll just end proving what losers gimps are”.

Statements like Joshua’s and the worries about “messing up” arguably reveal an assimilation of the poster child as deficient. I suggest that this aspect of the poster child discourse
was part of young people’s inner speech or self-consciousness. Their efforts could be understood as efforts to “fit into what’s culturally acceptable”, as a gatekeeper noted in Chapter 5. However, rather than passively echo these messages, participants tried to avoid reacting to them altogether. By minimizing their limitations, differences and mistakes, participants neither had to overtly acknowledge the authoritative poster child discourse, nor did they have to reproduce it within their talk and actions. They merely turn away from the poster child – neither activating nor refuting the view of disability as deficit.

Summary

In this section I have presented two ways in which participants resisted the image of themselves as deficient. This included efforts to minimizing visible difference, in which young people masked or diverted attention from their visible physical impairments. The second sequence of activities involved minimizing mistakes, where participants worked at removing signs of mistakes that seemed related to their impairments. In a sense, these activities seemed to be directed at diminishing the degree to which ‘disability’ appeared in their public images.

Consequences of minimizing deficits

Resisting deficits carried paradoxical consequences for participants. First, in refusing to take up the poster child discourse in any substantial way in their own talk, participants leave its force and authoritative meanings intact and unchecked. Unproblematized, the discourse’s authoritative and ideological messages remain a viable way to understand and speak about disabled young people’s actions.

A second consequence is that in minimizing their impairments, participants weakened their claims for support. Some participants, like Melanie, Rochelle, Josh, Isabella and Rosalyn were very successful in minimizing their differences. Ironically, whenever they resisted the image of themselves as weak or deficient, others could not anticipate or offer appropriate supports, since they seemed so “capable” or “normal”. For instance, when participants attempted to highlight their competence, they inadvertently obscured their requirements for additional assistance. Melanie often sighed that because she had a job and performed well academically, professors did not understand that she actually required additional time for assignments or to travel between classes. Rosalyn and Joshua both complained that people with spina bifida did
not have the ‘disability voice’ and therefore were expected to also have good fine motor control and physical strength, “like Jeff Adams or something”. In Chapter 6 I noted that Therese could innovatively negotiate the physical space of a daycare placement while using a cane. Her agility in what must have been an environment filled with obstacles, may have meant that teachers were less likely to recognize her needs around memory and organization. Even those of us in the research team found ourselves failing to recognize the effects of impairment on participants. For instance, Bernard was so competent with the video equipment we asked him to lead a group of his peers on a video scavenger hunt. We were chastened when we realized he could not count, tell time or read the scavenger list – abilities necessary for completing the task. Moreover for all participants, minimizing deficits in public images meant that the public presence of disability in general was obscured, limiting the opportunities they and others had to hear and acknowledge a disability perspective – particularly on support. One instance in which this was apparent was at the community screenings, where several audience members refused to believe that participants had actually created the videos. By minimizing deficits, participants hampered the ability of others to recognize their requirements for support without explicit requests. They also inadvertently diminished their legitimacy in their claims for support.

Unfortunately, when participants direct their efforts to minimizing deficits, they cannot simultaneously articulate their needs for help. I initially empathized with participants’ desire to minimize their signs of impairment. Many years ago, I experimented with hairstyles and cosmetic contact lenses to hide my own ocular scarring. I learned to hold my head in a way that made it impossible to see both my eyes in photographs. I thought at first that participants were similarly managing stigma. Indeed I thought the stakes were even higher for them. I wondered if, in minimizing deficits, in photographs for instance, they were resisting the literal (re)embodiment of the poster child. Since poster children for disability charities are always visibly impaired, I imagined at first that disabled young participants were attempting to remove these visible signs from their persons. While this may have been in part the case, minimizing deficits had consequences for participants’ consciousness of their own difference and their worlds that do not account for those differences. Photographs in which impairment did not

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61 As a committee member pointed out, this seemed be the reverse of the psychological notion of “spread” rather than impairment and absence of certain skills and abilities being extended to non-impaired areas of the individual, here the skills and abilities are inappropriately extended to areas of impairment (Eakin, personal communication).
appear, erased participants’ deficits across a temporal continuum. Looking at the photograph in which impairment was not visible, reached backward into the past to erase childhood impairments. Young people lost a full visual history of themselves (Orbach, 2009) and were left with the images others wanted. Looking at the same photograph also reached forward into the future, producing a visual monologue in which disabled young people presented themselves as free of deficit and difference. Without a sense of one’s difference, it could be difficult for participants to identify the ways in which their impairments were not accounted for within their everyday life. In order to seek even liberal forms of accommodation, disabled people must express their needs, they must draw attention to the things they cannot do within a specific (inaccessible) context. As I noted in my discussion of consumer-directed support, personal assistance can be understood as remedying a ‘functional limitation’, and helping to make the person ‘whole’. However, in order to identify, secure and use personal support effectively, disabled people must understand themselves as having an impairment in the first place.

Turning away from deficit – turning away from the poster child – also makes it impossible to identify disabling social and environmental ‘deficits’. Just as when they assimilate the poster child discourse, resisting the discourse by minimizing deficits means that disabled people cannot point to the ways in which they are systematically excluded from normative social arrangements. If we return to the image of the poster child itself – at the very least – it provides tangible evidence that young people can point to their past ‘public contributions’. It is on the basis of their impairments, their always visible physical difference, that young people were recruited into poster child work. It was these differences, put to the service of philanthropy, that contributed to the generation of charitable donations. Perversely, it was their work as ‘deficit-bearing’ poster children that fuelled the health of charitable systems that enable the retrenchment of social citizenship rights such as funds for personal supports. While I am not suggesting that disabled young people (or even charities) are responsible for the shortcomings of the current system of support provision, I contend that by minimizing their deficits, participants cannot easily participate in any critique.

Disabled young participants’ past contributions as poster children raise a key aspect of citizenship. In the preceding paragraph, I suggested that posing as a poster child could be viewed as a form of work that contributes to charitable economy – a contribution to which young people
eventually laid claim. In the next section, I look more closely at participants’ work of positioning themselves as workers.

**Positioning oneself as a worker**

A second sequence of activities disabled young participants carried out to resist the poster child discourse involved positioning themselves as workers. Discussions of work dominated most aspects of the project. For instance, work was an organizing idea in most of the videos, sometimes forming the overarching theme, as in Gerry’s “Working” or Bernard’s enactment of his dream of being a ‘Live Eye’ cameraman in “Number One”\(^\text{62}\). Allusions to future careers were key components to Rosalyn and Anna’s video, as well as those by Ainsley, Joanne and Melanie. For the remaining participants, videos were part of a planned career trajectory: a stepping-stone to activist, creative or other career goals.

Most striking were young people’s descriptions of their work— that is their everyday/every night coordinated practices or activities (Smith, 2005). From our first meeting, young people offered up detailed accounts of their accomplishments and activities. Most of these focused on the informal and ‘semi-paid’ labour they did for others or voluntary activities taken on in anticipation of future careers. In this section I review some ways in which participants positioned themselves as active contributing workers: helping out, giving back, doing the work of finding a job, and planning partnerships and parenthood. By focusing on their work or labour, participants established themselves as contributors ready to take on adult responsibilities. By attempting to focus on their work or labour, participants established themselves as persons who could support others, rather than always being the passive recipient of care. Most significantly, positioning oneself as a worker resisted the view of disabled young people as futureless, since to aspire to work was to see oneself as a potential adult full citizen. In the section that immediately follows, I present participants ‘helping out’ or providing help or support to others. I open the section with a brief vignette of the moment in which I first became aware that a claim to status as a ‘worker’ might constitute an act of resistance.

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\(^{62}\) “Number One” and “Working” were youth video titles.
Helping Out

One of the first sites where Rita and I recruited participants for the media arts workshops was Dream Town. We were invited to spend an afternoon at a drop-in program for young people with intellectual disabilities. When we arrived, the coordinator introduced us to the gathering of thirteen youth waiting to begin their activities. He briefly explained that we would join the group for the afternoon and later would speak about the video-making workshop. But his introduction was ignored. The young participants were mesmerized by my indicator cane. Finally one teenaged girl directed a question to me. “What happened to your eyes?” I quickly offered my usual two-sentence reply, not wanting to be the centre of attention. “Does the stick help you see?” This question came from another participant. I held off on my impulse to change the topic and tried again to respond efficiently. I tried to make my standard joke that the cane warns people to pull their small children and dogs out of my way. This was a mistake – the group heard the comment more seriously than I intended and I found myself explaining away the comments. Eventually I made note of the passing time, hoping they would choose to begin their activities. This moved the crowd into a clamour. “Here, I’ll take you to our room”. “No, I’ll help you”. “No, me. My gramma’s blind. I can do it.” The teenagers shoved each other out of the way, jostling one another to grab my elbow. Rita, who no one had acknowledged yet, intervened, asking several youth to help her, while I accepted support from several others. Her entourage accepted their ‘consolation guest’ grudgingly. (field notes, June 2002).

This rush to service seemed more than an effect of my visual impairment. In the process of planning the research, many gatekeepers reiterated how much support disabled participants might need to complete the project. I did not expect that my first encounter with support ‘in the field’ would be a struggle among disabled young people to provide help. As the afternoon continued, the program participants remained attentive to my needs, ‘helping’ me at every turn, reiterating their unique capacity to provide help (my grandmother is blind). Over time, I saw these and many other disabled young people move in to provide assistance to others, offering to “help out”. Very much like the incident above, assistance was eagerly offered to, and perhaps even thrust upon others. ‘Helping’ in this fashion often turned the tables on deference, in which young people put others in a position of needing to appreciate the proffered support.

For instance, Gerry, Joanne and Bernard were particularly keen to assist with the media workshops, stepping in to serve food to their peers, clean up messes, distribute workshop materials and so forth. One activity that was especially well-loved by the threesome was holding the tape-recorders. In order to capture workshop dialogue, I always had two tape-recorders running in different parts of the workshop room. Gerry, Joanne and Bernard noticed and were keen to help me ensure that the tape recorders were operating and positioned correctly in our
space. Dubbing themselves the ‘sound-men’, they wielded the tape-recorders during group discussions – getting up to move it close to whoever was speaking. Often this entailed a fair bit of activity: shushing the group, making participants remain quiet until they moved the recorder, moving about the room and so forth. Nas and I tried vainly to distract them from this task, mostly because their ‘assistance’ was disruptive and curtailed their own participation in the group. They were undeterred and quick to reproach our lack of appreciation for their efforts.

‘Helping out’ also seemed to re-interpret one’s own requirements for support. When I first directly asked young people to describe their use of social care services – or personal assistance specifically - they attempted to re-shape my questions. The most common response was to retort I help people!! In the pilot workshop, Bernard forcefully resisted my question by pointing to all the work he did to support me.

I help you! I help you walk. I help you take pictures. I help you get coffee. I help shoot camera. I help you find chairs. I help you with papers… (Bernard seemed almost indignant that I had apparently forgotten how he supported me. But then he softened.) You give me cameras. You help me too.

Despite this concession, Bernard consistently pointed out to me how he helped others. It was primarily through observations that I was able to learn more about the supports he used.

Others seemed less outraged by my queries into the support they received, but were equally reluctant to position themselves as consumers of social and health care services. Rather than directly respond to my questions, they spoke at length about their work supporting others. Like Bernard’s statement “you help me too”, they acknowledged that some exchange or reciprocity seemed to underpin the support they provided to others.

‘Helping’ was synonymous with working for many participants.

Esther: What do you do here (day program)?
Cynthia: I work.
Esther: Work? What work do you do?
Cynthia: I work with kids. I help the kids.
Esther: Is working with kids your job?
Cynthia: I help kids, I work with the kids!!
Esther: So it is your job?
Cynthia: I work. I help the kids!!

In fact, Cynthia did not have a paid job, but was involved in a jobs skills training initiative (a form of support in itself). Her pairing and interchange of the words ‘work’ and
‘help’ suggest that the two have similar meanings for her: to help children is to work. Douglas made a similar linkage in his discussion of work.

Douglas: I wanted to enter the ministry. I wanted to be a pastor, but I need to improve my grades.
Esther: Are you still planning on becoming a minister?
Douglas: Yes. It’s slow. I won’t be able to make a living from it for a while. In the meantime, I try to help out where I can.
Esther: Help out? Do you help out with a church or…
Douglas: No, no. I design websites. I designed a website for a friend’s business.
Esther: Is this a business you’re starting up? Like are you starting a website design company or something?
Douglas: No I don’t get paid really. I just like to work. I want to help out.

Pressed further, Douglas described how he ‘helped’ a number of friends and acquaintances with computer-related tasks. While he sometimes accepted money in exchange, he claimed he was satisfied to “simply do the work”.

Participants’ use of the word help in discussion of work may suggest their view of themselves as (potential) workers. In all three of the above quotations, young people were drawing my attention to the efforts they made in the world – efforts that supported others. These statements actively challenge the view of disabled people as passive. Their statements force us to see them as more than recipients of care, as active contributing members of their immediate communities. As I demonstrate in the next section, helping out was implicitly aimed at fulfilling obligations surrounding past support.

Giving back

Joshua: I don’t agree with the whole point of this project you know.
Esther: You don’t?
Joshua: Yeah, you think people with disabilities should be getting more from society than we do right now. I personally think that you’ve got it backwards. I think we’ve already got a lot. I think we should be asking ourselves ‘what can I give back to society’?

Another way young people positioned themselves as workers was to talk about “giving back”. Like ‘helping out’, ‘giving back’ resisted messages that young people were passive, child-like, spoiled consumers of support.

Melanie: You’re going to church tomorrow instead of the dance?! Are you turning into some kind of Jesus freak?
Zachary: (Goes on at some length about his relationship with religion). But I’m actually going to church because I’m volunteering to help prepare the leaflet. It’s my job. I go there because it’s something I do every week. I feel like I’m giving back, that I’m doing my part…in the community.

Here Zachary places his regularly scheduled voluntary obligation before a popular social event that, in my years working with disabled young people, trumped other events. His choice suggested that volunteer work goes beyond filling his time or even spiritual engagement. Here, I believe Zachary is pursuing at least two different ends. First, this is precisely the dependable, predictable activity that concerts with the organized activities of others. Regularly scheduled activities facilitated Wheeltrans and personal support bookings. Second, in pursuing regular activities, Zachary makes his work visible by carrying it out “every week”, invoking almost a Fordist notion of routinized, compartmentalized tasks. Other participants expressed a similar desire to ‘give back’. For instance, Anna, Rosalyn and Therese all continued to regularly participate in charitable events despite their developing critique of the sponsoring agencies. Therese summed up their sentiments on the issue.

I know charities, they keep us down, like they keep us disabled I guess. They don’t show us in the best possible light. But (name of agency) helped my mom a lot when they found the first tumours. So I look at this as my way to give back.

Giving back was not only directed at charities. Others were keenly aware of the sacrifices made by family members, particularly parents, to fill the gaps in formal support provision. But rather than bemoan how “spoiled” they were as I described in the previous chapter, participants could position themselves within a tacit exchange relationship. “Giving back” was often evoked as a way do “something in return” for support (broadly defined) received in the past. Getting a job, volunteering, community work, participating in church activities and serving as a spokesperson were all cited by participants as means of ‘giving back’. I would argue that in Therese’s comments above, ‘giving back’ shifts philanthropy (of which she is critical) to reciprocity. This sort of reciprocity is characteristic of adult citizenship ‘benefits and obligations’ or ‘social rights and responsibilities’ (e.g. Marshall, 1950).

63 Rigid schedules, regular appointments detracted from more spontaneous, flexible flow of activities that characterize the non-disabled ‘youth scene’ (Hesmondhalgh, 2005). Participants’ efforts to fit themselves into predictable schedules could be understood as almost anachronistic in light of the contemporary pointilistic, fragmented organization of time (Bauman, 2007) in which individuals seize, consume and discard opportunities (for recreation, work, education, etc.) before quickly moving on to the next.
Although my argument here is that by ‘giving back’ young people resisted the poster child discourse, I noticed several instances in which both ‘helping out’ and ‘giving back’ were authoritative utterances in their own right. There were many occasions in which workers or parents make comments similar to the one a day program worker made to Cynthia.

You gotta get out there and work. Can’t just sit around making movies and having fun all day long. It’s time for you to be a responsible citizen’. Can’t just be taking stuff all the time.

Other young people experienced less chastising, yet similar messages. Throughout the project, Ainsley’s mother joked with me about how her daughter’s video needed to be completed quickly so “Ainsley can get a summer job at a camp or something and take care of kids rather than staying home making me hire someone to take care of her”. Gerry’s parents and support workers constantly complained to him that he needed to “buckle down and work”. Every time he was taken to television or film shoots, a worker would brightly proclaim: “time to go give something back to the world”. Perhaps most poignantly, when Anna introduced me to her mother at the community screening of her video, her mother reacted slightly to the name of the project. “Well of course Anna is such a beautiful girl, being a poster child was her way of giving back something for all those wonderful things (charity) has done for her. (Nodding towards her daughter) I don’t think it’s appropriate for these kids to expect something for nothing”.

Even when parents expected that their children would never work, such as Josh, Graham or Zachary, they always voiced regret that their children were not able to repay all that they had received. It was rare to hear the corollary: that young people had entitlements that went along with their citizenship.

‘Helping out’ and ‘giving back’ then could be understood as participants trying to position themselves as active worker-citizens, who do not want to “get more from society”. Tarasuk and Eakin (2004) found similar practices among food bank users. In their study food bank users talked about ‘giving back’ and ‘helping out’ in a reversal of their dependency situation. The authors interpreted their talk as being, at least in part, about re-positioning themselves as being among those who give as opposed to those who receive. Similarly in the present study, disabled young people articulated the many activities they pursued to make active contributions to others, and positioned these efforts as ‘work’. Without ever directly repudiating the poster child discourse, participants actively resisted echoing any utterances that suggested
disabled people had diminished futures. Working to help others and reciprocating past support can be understood as adult activities, not those of dependent, grasping, ‘eternal children’.

Doing the work of finding a job

A third way in which participants positioned themselves as workers, thereby resisting the poster child discourse, was by actively trying to find a job. Throughout the course of the project, every participant either actively pursued or attempted employment, although very few were successful in their efforts and fewer still could sustain success. Their efforts were largely shaped by their receipt of income assistance. All the project participants received income transfers through the Ontario Disability Support Plan (ODSP) once they were eighteen. While planning for their major life transitions: post-secondary education, independent living or finding a life partner, young people had also been planning their application for income assistance.

Income assistance put disabled young people in a precarious position vis a vis paid work. ODSP rates are significantly higher than income transfers through the provincial general welfare plan, Ontario Works, yet they still fall far below the low-income cut-offs (LICO) for single people living in a large Metropolitan Centre (Chouinard & Crooks, 2005; Schizophrenia Society of Ontario, 2007). Several participants – Gerry, Douglas and eventually Joanne – attempted to mitigate this through supported employment schemes – although the amount of money received through this route was minimal.

Throughout the course of the research, participants relentlessly tried to secure paid employment. Unfortunately, they were largely unsuccessful. Potential work opportunities not only had to accommodate young people's impairments, but also provide income and benefits at least commensurate with their current social assistance benefits. Like most Canadian youth however, participants’ employment opportunities were precarious and underpaid at best (Dubois-Reymond & Blasco, 2003; Reach Canada, 2006), a situation likely more severe because they were disabled. Unwilling and unable to risk losing benefits, participants could not readily take on employment.

As an alternative to sustained paid employment, most participants patched together a number of volunteer, recreational and spiritual activities. Each participant was involved in at least two other ongoing activities in addition to the workshop. Among themselves, the second workshop participants held active positions in seventeen different organizations, ranging from
sports teams to student councils. They were so busy that I found myself mapping out participants’ voluntary obligations, part-time work and exam schedules to ensure that video-making workshops could be attended by everyone\textsuperscript{64}. Participants proudly shared their schedules with me. Rosalyn went so far as to show me her colour-coded daytimer. Each moment of each day seemed accounted for. Below is an example of an entry she had made.

8:45: Morning booking.
9:45: Wheeltrans pickup (confirm)
10:35: Class
12:15: Lunch in access centre
1:15: Therapy Garden volunteer.
4:00: Mentorship meeting.
5:30: Wheeltrans.
6:15: Disabled and dating meeting.
7:30: SSLU Youth Council Meeting.

Other participants were eager to share their time-tabling methods with me. They captured their schedules in wall-mounted calendars, computerized reminders on desktops, programmed talking clocks, color-coded binders systems and so forth. In each instance, the schedule was packed – there was hardly a free block of time. Rosalyn’s schedule of appointments above may seem unremarkable for a contemporary person inspired by a North American work ethic, but the barriers faced by Rosalyn in its accomplishment made it impossible to carry out fully. In practice, participants’ schedules masked the absence of activities. The presence of such elaborated schedules betrayed the reality that disabled young people had the time to construct them in the first place. More concretely, the organization of transportation and personal support schedules represented one of the greatest obstacles to actually fulfilling these obligations. In fact, on any given day, participants could only feasibly meet one or two of their planned appointments. However, I suggest Rosalyn’s timetabling and colour-coding attempted to make her work visible to herself and others. I suggest that by filling up their time with activities, disabled young people established, to themselves and others, their public presence in myriad communities as contributors.

\textsuperscript{64} Although young people spoke of social activities and some had a strong network of friends, their lack of clearly defined social time was glaring. In some instances, social life was built around voluntary work activities out of necessity – there were either no concrete opportunities to socialize in other ways (e.g. go clubbing) or the voluntary work demands were so high that no time was left over. In other instances, some participants had not yet developed a strong social network, and used these voluntary work opportunities to begin to form friendships.
It is noteworthy that participants also hoped these activities would somehow shift from symbolic to material returns. Voluntary activities often could open the door to ad hoc temporary paid employment. Not unlike working class young people’s pursuit of ‘fiddly jobs’ (MacDonald, 1984; Willis, 1979), participants’ engagement in voluntary work had entrepreneurial motivation, rather than a purely altruistic one. Participants hoped to parlay these voluntary stints into “job experience”. They were willing to take on countless voluntary and token employment activities in order to build up their resumes in the hopes that they were on the early steps to a future career. As Caterina noted, “this is the work you need to do to find a job”. These activities may be true for all Canadian young people in light of high unemployment rates among people under 30 years (ILO, 2008). However, for disabled young people, these efforts were designed to work against a notion of them as childlike or futureless. Unfortunately these contributions from young people may go unrecognized, commonly dismissed as “keeping busy” (Groce, 2002; Kittay, 2002; Butcher & Wilton, 2008). Without the support, these activities were both difficult to carry out and to parlay them into more regular employment. In some instances, pursuing these activities could even undermine support.

Participants counted on little pockets of undeclared income that helped them stretch their limited budgets. As such, young people rejected a deference to or cooperation with the larger system of income assistance, by eking out small chances to be a ‘paid worker’. However, such resistance had to be considered in light of the risks they impose on fiscal security. Like any of the activities that resisted the poster child, positioning oneself as a worker carried consequences for disabled young people. Accepting undeclared income had consequences that threatened both disabled people’s already precarious economic conditions and shut down their efforts to ‘turn away’ and resist the poster child discourse.

It is noteworthy that looking for a job carried negative consequences for participants. Within the course of the three workshops, four participants were audited and then more fully investigated by ODSP. Isabella, who had attempted to piece together additional income through honoraria for public speaking engagements, was required to re-pay several thousand dollars of overpayments. She had never exceeded a monthly income of $1500. Her ensuing income penalty articulates a contradictory experience that goes well beyond the participants in this project. In a recent study of disabled women’s experience of accessing disability income support programs in Canada and the UK, Malacrida (2009) noted that income support policies were
written in a way that constructed disabled people as “dishonest adversaries who require surveillance and supervision” (p. 684). As Chouinard & Crooks (2005) noted in their qualitative study of women receiving ODSP benefits, recipients were enjoined to work, but were faced with deepening economic precarity as their income exceeded allowable maximums. Consequently, income support recipients face the equally untenable choices of ‘passive welfare dependency’, relegation to the ranks of the working poor (often not a real choice for individuals who require social-assistance-dependent medical benefits) or participation in the ‘hidden economy’. Isabella’s choice to turn away from the deserving but childlike and dependent welfare recipient by pursuing paid work, resisted the poster child discourse, but diminished her financial support.

Participants in high school were in a somewhat different position. Not yet eligible for welfare assistance, they could engage in paid work without risk. High-school aged youth were also eligible for summer camp, various transitions and other extra-curricular programs geared at disabled teenagers. These opportunities fell off as participants began to receive income assistance, almost as if one’s futurelessness was established at that point. As these young people move into adulthood, they are faced with difficult decisions: do they continue to build up their profiles and experience as workers, assuming a threat to their income security, or do they forego paid employment in order to maintain their income supports.

One consequence was that positioning oneself as a worker did not guarantee ‘a job’. Like helping out, giving back or using words such as career, business or skills training skirts around the idea of ‘a job’. ‘Jobs’ “a small piece of labour one performs in exchange for money” (Sennett, 1998: 9) were almost always absent from young people’s discussions of their lives. Only two core participants: Gerry and Melanie found ‘paid jobs’ within the course of the project. Even then, both were part-time jobs, and Gerry’s was part of a supported employment arrangement in which he earned below the minimum wage. Others had placements, internships, practicums, volunteer positions, training opportunities, supported employment opportunities … but none had consistent waged work.

**Planning partnership and parenthood**

A final way disabled young participants positioned themselves as workers, or more aptly, as contributing citizens, was through their future partnerships and parenting relationships. Domestic labour, tied to relationships, was on the horizon for some. Although the disability
studies literature positions parenting as a reproductive health right (Booth & Booth, 2006; Saxton, 2006; Shakespeare, 2006), participants also envisioned bearing and raising children as a potential citizenship contribution. This is consistent with traditional views of citizenship, in which the formation of a family of destination - choosing a life-partner and parenting children - is among citizenship obligations (DuBois –Reymond & Blasco, 2003; Pilcher, 2007; Willis 1979). For participants in the present study, partnership and parenthood often seemed beyond reach. As I noted in Chapter 6, participants rarely could access the personal supports, social opportunities or privacy that made these citizenship practices possible. Despite the many barriers to pursuing relationships, let alone parenthood, many participants, both male and female, expressed a desire to ‘get married and have kids’. In order to position themselves as making these citizenship contributions, disabled young people had to resist the deficit and futurelessness encapsulated in the poster child discourse.

Participants could indirectly resist the view of disability as deficit in their projected future partnerships. Most participants expressed scepticism about entering a relationship with another disabled person. Although participants wondered if potential non-disabled partners could leave them for another non-disabled person, relationships between disabled people were often viewed as involving insurmountable challenges. As one young woman who appeared in a video stated:

Elena: I would prefer to have a normal husband. Who will do everything if we both have a disability? I want children someday – who will take them to the park? Who will bring them to school?
Esther: Couldn’t you do those things? You might like to share the playground or the first day of school with your children.
Elena: No I think children need one normal parent. That way they’ll be normal too.
Melanie: Ted (her boyfriend) doesn’t have a physical disability and he hates all that shit – going to parks and walking. I think he’s going to be one of those fathers that watches the Three Stooges with the kids. (teasing and coaxing voice) I think it’s me that’s going to have to show them how to be normal.
Elena: Maybe so. But I can guarantee if you tried to have a marriage with a man (who used) a wheelchair too, it could never last.65

Like Isabella in the previous chapter, Elena raised practical issues about the possibility of relationships between disabled people, although with a slightly different focus. She appears at first to be assimilating the view of disability as deficit, particularly as she deems partnering with

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65 Conversations like these evolved over time. Isabella in particular challenged this fatalistic picture of relationships between disabled people. In 2007, Elena married a man who uses a wheelchair. They now have a child.
another disabled person as deepening her deficits as a parent. But then Elena turns away from
deficit as her comments bring partnerships squarely into the realm of citizenship. Her comments
believe how the goal of relationships within the state is not pleasure nor desire, but the
reproduction of normality. Normality, a word Elena repeats seven times in this short exchange, is
embodied in healthy children who ‘play in the playground’ and ‘walk to school’. Elena’s
comments imply that her disability disqualified her from this form of social reproduction labour
– and so must be completed by a future non-disabled husband. Elena also suggests somewhat
gender-neutral parenting activities, thus ensuring that her imagined husband will be ‘normal’ in
every sense. In this way, partnership can truly achieve its ultimate purpose – to produce healthy
future citizens for the nation (Pilcher, 2007).

There are several consequences in Elena’s planning work for future partnerships. First it
buys into normative notions of citizenship that suggest that in order to exercise rights and
obligations one must be ‘healthy and whole’, or at least able to deny and compensate for one’s
deficits. Second, such planning work subsumes a fuller discussion of partnership and parenting
rights. Intimate, marriage, sexual and reproductive, rights historically were denied to disabled
people (Rogers, 2009; Saxton 2006; Shildrick 2004). It could be argued that the lack of adequate
support to foster intimate relationships and the formation of families among disabled people are a
contemporary extension of this history. In resisting deficit in their plans about partnerships and
parenthood, disabled young people deny their difference, the very ground from which they could
claim supports to foster their aspirations.

Planning parenting also seemed to involve a number of activities oriented to participants’
futures as parents and partners. Many of the young women in the group read parenting books
voraciously, claiming, at the ages of 19, 20 and 22 years, that it was “important to learn as much
about being a parent as possible”. Several sought out and attended every reproductive health and
parenting workshop they could. Others spent time researching accessible baby furniture online
and at local disability trade shows, trying always to find an opportunity “to practice” with this
“equipment”. Female participants who were enrolled in post-secondary training in the education
field philosophically stated that if they were not able to secure employment in their chosen
discipline “at least I will be a well-trained parent”. These activities may be typical of all young
people. Alternately these activities may be a way of fighting back against the well-documented
expectation that disabled women in particular will never be (good) parents (e.g. Lloyd, 2001;
Newman, 2009; Reist, 2006). Certainly, in light of emerging evidence of the very poor preparation and social support expectant disabled parents receive, participants’ efforts seem prudent (CILT, 2011). However, my argument here is that these activities cast disabled young people as future ‘domestic workers’ who will make contributions within their relationships, in the lives of their future children and their broader communities. Like other work-oriented activities described earlier in this section, participants neither articulate nor acknowledge utterances that position themselves as immature, childlike or futureless.66

Summary

In this section I have presented four sets of activities through which disabled young people positioned themselves as workers. These activities included ‘helping out’, ‘giving back’, ‘doing the work of finding a job’ and ‘planning for parenthood’. As I argue above, these activities were not an outright negation of the poster child discourse, but they did resist the passive assimilation and recitation of statements asserting the futurelessness of disabled young people. These activities proceeded on the assumption that young people were or might eventually be adult workers or contributors. Through carrying out these activities, participants filled their time with meaningful tasks that they seemed to enjoy. They also seemed to use these activities to build up a public presence for young people as involved and active, working against the dominant perception of disabled people as passive and isolated. In fact they counted on these activities to build the network and experience for future secure employment.

However, it is noteworthy that positioning oneself as a worker entailed a number of troubling consequences. The work they did was often voluntary or poorly remunerated. In many instances, these experiences did not actually lead to stable employment (although this may change in the future). More significantly for the overall purpose of this research, positioning oneself as a worker seemed to entail a denial of one’s needs for support. Participants often redirected queries about their support use to a discussion of their support provision. In other

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66 Although both male and female participants discussed future relationships and families, I never observed or heard young men explicitly discuss the challenges of dating or anticipate how they would practically engage in parenting and partnering. Traditionally young men may view their relationship to parenting and partnership through a breadwinner role. Young men may have hoped to support families through employment income as their major means to accomplishing this practice of citizenship. Also, as is apparent in several vignettes involving Zach and Graham, young men’s activities may have been directed towards partnership; however I have more narrowly interpreted these as forms of sexual expression and dominance. This perhaps is an instance of participant objectivation in which my own gender and political positioning has shaped the findings (Bourdieu and Wacquant, 1992).
instances, any overt recognition of their support requirements seemed masked by jam-packed schedules or altogether absent as in their imagined parenting. At the most extreme, participants actually threatened their economic supports, such as ODSP, by pursuing small insecure work opportunities.

Denying support requirements was an unintended consequence of minimizing deficit in the previous section. In contrast, participants seemed to willingly deny support in positioning themselves as a worker. In the discussion that follows, participants demanded support; but without taking up the poster child discourse, these supports were not always forthcoming.

**Resisting deference**

A final sequence of activities through which participants could resist the poster child discourse was by refusing to adopt a posture of deference. In the next chapter I discuss how participants assumed this posture enabled them to surreptitiously pursue their own interests. However, here I describe how, on some occasions, participants rejected deference altogether.

In what follows, I focus on Rochelle’s reluctance to ‘do deference’. Of all the disabled participants, her actions offered the clearest and most sustained illustrations of resisting deference. However, my intention is not to single her out as someone who refused to exercise grace or respect for others, for on many occasions she did. My intention is to highlight activities that eschewed the poster child discourse, and draw attention to the implications this had for support.

Rochelle’s requirements for support were significant; she needed assistance with eating, drinking, hygiene and scribing. She directed her support around these tasks in what I described in my field notes as a utilitarian and authoritative manner. She ‘snapped out’ a direction, not even framing a request. These directions were unadorned with any social niceties – no please, thank you and so forth. If she wanted a drink, she simply directed the worker (or whoever happened to be available) to support her in pouring and holding the drink. For the most part others followed her direction, including other disabled young people. It was rare, however, for workers to demonstrably anticipate her requirements as they might for other participants.

Where Rochelle had more specialized support requirements, she experienced more difficulty. Rochelle’s unique preferences for transfers and washroom support proved difficult for many support workers to master. She continued to demand practices developed and still carried
out almost exclusively by her mother. The process involved a worker reclining Rochelle’s chair, so that she would be lying flat on her back, staring at the ceiling. Rochelle’s chair was so large that accessible private stalls were too small to accommodate her and an attendant when it was reclined. Thus her personal care process always took place in the main ‘public’ area of washrooms. When at Ryerson or TSV, an attendant brought another chair to the washroom, posted a hand-written ‘temporarily occupied’ sign on the door and then blocked the washroom door, by jamming the chair under the door handle. Unfortunately, this was not always effective and the support interaction would frequently be interrupted by strangers trying to enter the washroom. While this was difficult, workers also found Rochelle’s preferred hygiene process more “unusual”, “involved”, cumbersome, “undignified for everyone” and “invasive”, than any other person they had supported. Rochelle requested support for this process three to four times during a five hour workshop, an additional complication for workers who found the half hour process “exhausting”.

Although Rochelle could direct her care with aplomb, only her mother and very experienced, flexible support workers could accomplish her preferred washroom and transfer style without complaint. Three different workers refused to provide her with support after one session with her and others refused over the telephone when they learned they would be supporting Rochelle. One attendant told me after a fairly successful afternoon that she felt the transfer method transgressed some sort of boundary. She described the work as vaguely sexual, far too intimate and wondered if I would be willing to ask Rochelle to consider other methods of washroom support. Others took slightly different tactics. After assisting Rochelle for the third time in one workshop session, a support worker refused to pass her a drink so she would not have to go to the washroom again.

Several workers attempted to introduce simpler toileting and transfer techniques, but Rochelle remained worried these would leave her vulnerable to falls – and ultimately to insults to her dignity. Rochelle’s care preferences meant safe, consistent and respectful support was precarious. Although Rochelle expressed no ambivalence about her preferred method of washroom support, her workers were unanimous in their assessment that this sort of care breached social boundaries in a way that was not always definable nor acceptable to them. Workers and other disabled young participants wondered privately if Rochelle was deliberately making herself vulnerable, both in the support interaction and more broadly in support
arrangements – thus manipulating the relations of disability inherent within personal support provisions such that she could remain ‘in control’.

Whatever her reasons, Rochelle made no apparent concessions. She wanted supports carried out without compromise – a demand well in keeping with the aims of the disability rights movement (see for instance, Priestley, 1999: 79). By not participating in the deference work however, she could not consistently secure support. A recipient of individualized funding, she continues to post advertisements seeking personal support workers. At last check, Rochelle was not able to secure a worker for longer than several weeks.

Rochelle may have actively resisted deference through many of her interactions with others, however, all participants needed to resist deference occasionally. In the following vignette, Anna does deference throughout much of a typical morning routine with her personal support worker. By the end of the morning booking, Anna finds herself in a position in which she had little choice but to resist deference altogether.

At the close of the project, Anna had been living independently in a supported living apartment for about six months. In one of our last conversations under the auspices of this research Anna described how she worked with her new personal support workers. Three years earlier she had expressed uncertainty about what I meant by home or personal support. Later she was excited and nervous about having a place of her own, managing her supports on her own terms. Now she was disappointed with how her dreams had not been realized, describing herself as “depressed” by the work involved in maintaining support workers. The schedule below is derived from the stories she shared in this final conversation. In the writing I try to capture the pacing and rhythm of the everyday/everynight work of doing poster child work.

7:30 Alarm goes off. A little later than she would like given that she was really more of a morning person. But two of her neighbours attended a community college program that ran 9 to 5, no exceptions made for the fact that they, like Anna, needed support with their morning routines. Thus their schedules organized the worker’s schedules, who in turn had to prioritize the residents who had the first Wheeltrans drives.

7:32 Rose is the worker this morning. Not Anna’s first choice of people she wants to see while she’s lying in bed. But Rose is scheduled and there simply aren’t enough workers on at any shift to ask for someone with whom you have the best rapport. Anna brightly calls out a greeting trying to set the emotional tone for the next half hour.

67 I elaborate on this work in Chapter 8.
7:33 The countdown begins. Rose needs to be done by eight no later – there’s a Wheeltrans pick-up to prepare for. Anna optimistically speculates that they might be done early. It’s a risky move setting up expectations like this. But immediate slight easing of Rose’s stiffness is nice.

7:35 Rose asks a question with an implied answer. Are you washing your hair? There’s really not a lot of time. Anna considers what she had to do today. She was hoping to meet with a teacher. This will make it the second day in a row that she hasn’t washed her hair, but the teacher has seen her limp tresses before. Skip the shampoo – a body shower is enough for today. Besides Anna’s period has started.

7:45 Get dressed. Wear the Tuesday outfit. Sanitary pad doesn’t seem to be positioned quite right. Anna mentions this, Rose moves towards preparing to brush Anna’s teeth. Anna follows.

7:50 Breakfast now - toast and a yogurt drink. Anna hates eating after brushing her teeth, but she’s lost this battle long ago. Rose likes to finish the bathroom tasks before she moves onto the kitchen tasks. It’s more efficient this way and she’ll get to her next client on time. Anna is not getting used to the positioning of her pad. She mentions this again. Rose responds by asking Anna if she needs any help with dinner.

7:54 Anna would have liked chicken tonight. Rose doesn’t have time to prepare the marinade. Anna wonders if the chicken should go in the freezer until a weekend. She’ll have a pizza pocket tonight. She asks Rose if they could return to the washroom to fix the pad. Rose points to the clock.

8:00– Rose is washing up the dishes. Anna surveys her computer. There’s no time for a mistake. The next few requests have to be made delicately. Please turn on the computer.” Than ks so much”. “Open that book”. “Thank you very much”. Anna looks at her khaki pants and realizes dismally that they’ll be stained if she leaks…

8:03: Anna positions herself in front of the apartment’s door. As firmly as she can muster she tells Rose that she needs her pad changed. “Now”. Impatiently, Rose eyes the clock and informs Anna that they’ve run out of time. Anna grows angry. “Change the pad now”. Rose resists. Anna rallies and wins. In silent anger the pad is changed, positioned correctly this time.

In the silence Anna reflects on the TV dinners she’ll be eating for the next week and despairs inwardly as she realizes that she’s asked Rose to open the wrong book.

8:10 Rose shuts the door a bit too loudly. Anna’s top lip is slick with perspiration 68.

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68 In this study, menstruation support was one area where women consistently demanded support on their own terms. Although there were many pressures on young women to suppress menstruation, as far as I know, none conceded. Although female participants could (or did) not articulate the reasons for their resistance, I would argue that menstruation serves as a significant marker of femininity, adulthood and reproductive potential. To hormonally manipulate monthly bleeding would be tantamount to deferring female adulthood. Nevertheless, each shared some story in which she pushed with formal workers or family members for support only to be met with anger and as one young woman stated “a bit of the silent treatment”.

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This overall sequence of activities re-played itself over and over again for each young person in the project. Each repetition of the sequence involves amiable concessions conforming to the demands of institutional timetables and priorities. As described in the previous chapter, participants worked at weighing what activities can take place now, what can be supported later on and which will be deferred indefinitely. However, each participant eventually encountered a breaking point where they could not yield any longer. When this happened, some dissolved into anger and frustration. Participants with intellectual impairments, like Joanne or Gerry, simply refused to move or to cooperate and became verbally belligerent. Others, like Anna, communicated their own interests quite clearly and relatively calmly. However, as Anna does in the passage above, to prioritize one’s own desires or interest over another’s was to refuse to act in deference to workers, parents or their disabled neighbours.

Anna’s final thoughts in the above interaction belie the risks of resisting deference. She knows her insistence means she will sacrifice more complicated meals or help with organizing her homework. Participants described incidents during which they insisted on pursuing certain activities or making specific claims – often because not doing so would have entailed difficult consequences. However, participants also lamented how refusing deference might secure an immediate gain, but would entail many future compromises and deferrals. As Ainsley noted: “be demanding now, and do without later”.

Summary

Resisting deference meant participants put their needs and interests before those of others, even when they knew the repercussions would threaten sustained future supports. The benefit to participants is that refusing deference in certain instances, maintained a small measure of personal autonomy and self-determination, often around fairly intimate aspects of their person.

Conclusion

I opened this chapter by suggesting that the poster child discourse worked on two authoritative levels, in that they are either assimilated, as I described in the previous chapter or resisted. In this chapter I focused on the latter. When participants resist authoritative utterances they do little to re-define its meanings. As such, the discourse remains intact, unchallenged and unevaluated with other competing voices, views and values. Instead, throughout the three sets of
activities I presented, the poster child discourse almost seeped through participants’ talk and actions. For instance, in order to minimize deficits, participants must, at some level, acknowledge that there are deficits to obscure. In positioning oneself as a worker, participants must continually confront the fact that they are not ‘in jobs’ and that their futures are not as promising as their non-disabled peers. In resisting deference, participants set a tone that makes it difficult for others to provide them with support. Disabled young people find themselves conceding the supports (or lack of) that others are willing to offer.

In the next chapter, I suggest that participants may dialogize the poster child discourse. Rather than attempt to resist or ignore its views and values, participants put them to use for their own purpose.
In Chapter 6, I discussed how participants assimilated the poster child discourse, echoing and accommodating themselves to its ideological values and views. They made do with constrained supports, often postponing or letting go altogether their own interests and desires in favour of those around them. This secured support, but not on their own terms and often meant that their opportunities for choice and control, participation and public presence, and even contribution as citizens were seriously curtailed. In Chapter 7, I suggested that participants sometimes eschewed the poster child discourse – and as such placed their supports in jeopardy. While in a restricted sense they retained some self-determination by resisting these views and values, their opportunities for community participation, voice, public presence, and the corresponding opportunities for work and post secondary education were either shallow or precarious. Those who resisted the poster child discourse could not guarantee secure and consistent support that enabled the practices of citizenship as those who more readily reproduced the discourse.

In this chapter I move to participants’ more playful work with the poster child discourse. I examine how participants bring the poster child into dialogue or dialogize it. Dialogizing refers to the process in which utterances, originating from different places and times, are mixed to reveal and innovatively unify differing views, values and standpoints. In what follows, I suggest that participants signal competing definitions or understandings of the poster child discourse (Bakhtin, 1981: 427) and they bring its utterances into their own speech. Rather than assimilate or reject the authoritative utterances, participants respond to and re-work their ideological messages of disabled young people as futureless, deficient and deferential. I open the

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69 It could be argued that the use of the word ‘playful’ in this context belies the seriousness of the work young people must do to accomplish citizenship. However, Bakhtin uses the terms (carnival, comedy, play, parody) to describe situations in which there is a “new mode of interrelationship between individuals counter posed to the all-powerful socio-hierarchical relationships” that generally prevail (1984, p. 123). By ‘playing’, I refer to the activities participants pursue to bring different discourses, views, values, or thought together in new ways. For Bakhtin, this mixing, like that of the carnival, brings together “the sacred with the profane, the lofty with the low, the great with the insignificant the wise with the stupid”. Through play, otherwise self-enclosed worldviews, values and thoughts” are mixed and form new unities allowing hierarchical relations to be (briefly) “exposed and debased” (124).
chapter with illustrations of disabled young people taking authoritative utterances and mixing them with the utterances of others. As they blend together multiple voices with their own, I argue that they are better able to infuse the poster child discourse with their own intentions. I then provide specific examples of how participants take up deference - in conjunction with deferral and deficit as needed – and dialogize it to enhance and expand their supports. While dialogizing the poster child discourse defuses its authority, it continues to centralize or unify conversation. The discourses’ past uses and meanings carry forward into the present conversation. Participants counted on this as they anticipated how others would respond. However, by placing these authoritative utterances in juxtaposition with others, by incorporating other views and values into their talk, and through play with intonation, humour, dissent and parody, they defuse its force and diversify its possible meanings.

**Bringing authority into dialogue**

In this section, I present two vignettes that illustrate how speakers dialogize authoritative utterances, or stated differently, how they bring the speech and ideas of others into their own talk and consciousness. The first story has a tangential relationship with support, but it illustrates how all disabled participants took up an authoritative voice (mine) and set it within a new intentional context. Thus, rather than passively assimilate or wholly reject authoritative voices and utterances, participants brought them into dialogue. Sometimes these were literal conversations, in which two or more individuals took turns speaking. More often, participants drew in stories, ideas, bits of expertise – different voices, authoritative, alien and personal utterances, and juxtaposed them alongside one another in their own talk. In doing so, participants shifted the meanings and force of each unique utterance, allowing their own ideas, views and values to inform the meaning and anticipated responses to their talk.

**Vignette: ‘Dress’ rehearsals**

Throughout the media workshops, I noticed that as participants conceptualized their videos, most seemed to delight in ‘rehearsing’ their stories, deliberately seeking out new audiences for their reactions. A little like changing clothes in a change room, participants ‘tried on’ different stories testing out audience responses. For instance, they watched for whether their
stories seemed to make others uncomfortable, encouraged peers to share their own stories or elicited praise and appreciation from others.

Accompanying this rehearsal was a type of researcher reversal – in which the participant turned the tables on the research team. For instance, in constructing her video about swimming, Joanne asked other participants and members of the research team if they swam. Bernard asked the research team to describe where they lived. Anna sought out stories and expertise around first jobs. Soon, I noticed that elements of our experiences began to appear in their stories.

The first time I noticed one of my stories turning up as a participant’s was when Rosalyn was brainstorming for her storyboard about friendship as a support during transition to independent living. She planned to integrate her recent experience of shopping for clothing at a popular clothing store for urban young people without her mother for the first time. Rosalyn who had just turned nineteen, was about to enter college and felt that this was a key step in transitioning to independent living. Turning the tables, Rosalyn asked me “how old were you when you bought clothes on your own?” I replied that I was probably in grade nine (14 years old), but then, sensing her embarrassment, I hastened to add that my mother continued to buy most of my clothing in spite of this early step in autonomy. I explained how, when I was twenty-two, I had my cataracts removed and could see what I was wearing and what I looked like for the first time in about ten years. When I came home from the hospital and opened my closet, I was horrified! It looked as if someone had filled it with candy floss- the majority of my wardrobe was pink! My mother loved this colour but it was incongruent with my emerging radical feminist sensibilities at the time.

Variations of this story resurfaced several times within other participants’ narratives, but was most striking with Rosalyn. When developing her shot list, Rosalyn indicated she wanted a shot of her closet with child-like clothing in it, followed by a shot of her entering a clothing store, then a shot of her closet filled with purple dresses – her favourite colour and clothing item. I was struck by how closely her story paralleled my own, as were others on the research team.

Rosalyn’s story illustrates how an authoritative voice might be dialogized – it gestures to the authority of the voice, it suits the speaker’s intentions and it becomes the speaker’s own voice. As the researcher, my voice was authoritative within the group. My words carried force, perhaps because of my age and status, despite my attempts to democratize the workshop process: participants listened to and followed my instructions, paraphrased me, sought out my opinion.
and otherwise afforded me authority. In a sense, Rosalyn acknowledged my authority by
drawing my story into her own. But by almost parodying (not in a mocking way), she softens the
force of my story, and uses it to help tell her own. Specifically she transformed the story into a
series of visual utterances\textsuperscript{70} that ‘document’ common and previously invisible experiences of
disability. Other scholars have reported that many who grew up disabled have privately shared
similar stories of having little autonomy over their hair and clothing as well as many other
aspects of their bodies (Rice 2002; Taleporos and McCabe, 2002), but there remain few public
depictions of these constraints on self-determination. My story, a simple response to a question,
and probably aimed at maintaining Rosalyn’s participation within the group, took on a new
purpose and meaning with Rosalyn. Infused with her own intentions, it becomes an indication of
her growing accomplishment of citizenship, as she established a public presence of her own
choosing.

Bringing an authoritative voice into dialogue was not always about finding new ways to
express oneself. Sometimes, participants more actively challenged an utterance, but
acknowledged it in ways that defused its authority. The following vignette, in which a worker
quite obviously attempts to ensure that a disabled young woman defers to a particular articulation
of support provision, demonstrates how bringing authoritative utterances into dialogue can be
transgressive. Joanne, the young woman in this passage manages to assuage the worker, while
maintaining her own view of supported employment, by mixing the worker’s utterances with
those of others and her own.

\textbf{Vignette: Learning the language of support}

At the time of the pilot workshops, both Joanne and her service organization were
undergoing a significant transition. Her day program was redefining its mandate to become
primarily a work preparation service for developmentally delayed disabled persons. The board
and executive staff were replacing many of the service’s enrichment activities with job training
and supported employment placements, very much an attempt to remain viable within revised
government funding priorities. Youth, like Joanne, were encouraged to direct their energies

\textsuperscript{70} I viewed participants’ videos as a series of visual utterances. Videos were deeply dialogical, layering images,
voices, utterances, music and so forth in ways that revealed and challenged the ideological grounding of each. In the
process of selecting, editing, juxtaposing these images, participants engaged in a process of ‘ideological becoming’
in which they evaluated authoritative and other views and values as they continually crafted their own.
toward finding work. Joanne had tried to obtain employment in a neighbourhood grocery store—but had not met with much success. In recounting her experience she explained that the manager refused to take her on, in spite of additional support from her day program. She said that she was told she would pose too great a strain on managerial resources. In her words—“It’s hard to find work. I’m having trouble because I need a lot of supervision in my job.” Confused by her choice of words I asked if she meant support. Joanne remained steadfast—“No, supervision”. A developmental support worker, who accompanied several youth to the workshop, interjected correcting “No Joanne, support. We’ve talked about this. We’re looking for a coach to help you with your work. Like your swim coach. Remember?” Joanne conceded—slightly “Yes, I need a coach to supervise me”.

The worker’s comments to Joanne illuminate the subtle discursive practices involved in articulating one's support requirements as a disabled person. Participants had to articulate their needs in a manner that would ensure their fulfillment. As the worker stresses through her correction, the first step in 'getting a job' and support for it, is performing a particular form of lexical work. In the dialogue, Joanne learns that in order to secure work she must yield to the worker’s ideas and voice only what is institutionally available and sustainable. The workers insistence that she do so demands that Joanne not only defer to her (as the authority on the subject), but to the broader social organization of supported employment. The worker expects and ‘demands’ deference from Joanne, in keeping with the authoritative discourse of the poster child. And Joanne partially complies—a dialogical act since she must respond to what the worker is saying.

The worker’s pairing of the words “coach” and “support” is also significant since the coupling suggests that Joanne's needs lie with a 'skills-deficit' and thus are both 'temporary' and easily remedied through education and training, something the agency can, and indeed must, supply in order to maintain government funding support. Thus the problem here is the agency’s potential financial deficit if it cannot make its work visible in light of government funding criteria. The use of words like ‘coaching’ redefines, re-locates and resolves the problem as an individual employment-skill deficit. Skills approaches elide both issues of systemic ableism and exclusionary work practices that bar young people from employment and community integration.
Instead, skills approaches place responsibility squarely on the shoulders of young people\textsuperscript{71}. Their eventual failure to secure work can then be linked back easily to their deficits – once again promoting the authority of the poster child discourse.

A disjuncture between alternate understandings of Joanne’s needs is evident in this exchange. Joanne's insistence that she 'needs supervision' may refer to what the word has come to mean to her. It is possible that she preferred the word ‘supervise’ because it seems in keeping with mainstream labour settings in which employees are supervised by their “boss” or “supervisor”. However, in the context of this study, I only ever heard participants refer to ‘supervisors’ as their boss or ‘teacher’. Throughout the course of the workshop, I noticed how support workers strived to “keep her on task”, correct her mistakes, ensure she arrived at the workshop on time, take appropriate breaks, help her express (or bury) her frustrations appropriately and otherwise monitor and guide her actions. When I first met Joanne, her mother’s instructions to me were to ensure I “supervise” her daughter if the workers were too busy. Throughout the project, supervision and support were often conflated\textsuperscript{72}. Supervision, often carried out by personal support workers, was a form of surveillance designed to keep participants, especially those with intellectual impairments safe and orderly. In fact, in the workshop settings (as in other settings with people with intellectual impairment) activities that might otherwise be understood as support (washroom assistance, mealtime assistance, prompting to ensure physical safety) were referred to as supervision. Moreover, supervision was often infantilizing, explicitly connected to parental and agency concerns that participants could not be safely left on their own. To adopt the worker’s analogy ‘supervision’ was not so much like a swim coach, as it was like a lifeguard. Far from enhancing employability, it was difficult to see how supervision might encourage participants’ vision of themselves as autonomous workers.

Given this experience of support, it is not surprising then that Joanne perceived a job coach or employment support as ‘supervision’. In contrast, the intent of a ‘job coach’ within the field of disability services is to serve as a form of ‘employment support’. The job coach works with an individual to locate part-time employment in the community, provides intensive training on the

\textsuperscript{71} Alternative approaches include community economic development, consumer-run business (e.g. A-Way Express, Raging Spoon), consumer-centered business (e.g. Lemon and Spice), parallel consumer education program (e.g. the Transitional Year /Bridging Programs at universities), peer-training networks or peer-mentoring models (Springtide Deaf Women’s Project).

\textsuperscript{72} The words supervision and support have distinct etymologies. Supervision means to ‘gaze from above’, while support means to ‘hold up from below’.
job and then fades out of the job setting (Wehman, Targett & Cifu, 2006). However, as Joanne suggests, the role may seem like one of ‘supervision’ – serving as a watchful eye for potential errors or other problems (harm, disruption). Joanne dialogizes these two essentially authoritative utterances, juxtaposing ‘supervision’ and ‘support’ in her conversation, both acquiescing to the worker’s direction while retaining and articulating some of her own understanding of support. This utterance is dialogical in that she exposes the support, in the context of supported employment, often entails supervision and surveillance.

Joanne integrates the worker’s utterance into her own talk (and perhaps into her inner speech and consciousness), but this is not passive assimilation. Instead, I suggest she was learning how to articulate her needs, but in a manner that is in part of her own choosing. Joanne inserts humour into her speech by blending resignation and resistance: “I need a coach to supervise me”. Through humour or irony Joanne minimizes the worker’s authority in a small way, making it an object of fun and even ridicule. Significantly, Joanne does this without threatening her support (the worker herself laughed in response to Joanne’s final “acquiescence”). In bringing together her own voice with that of the worker’s, she not only challenges the worker’s authority, Joanne also maintains some of her own voice and public presence. Her views come through in the juxtaposition of the differing articulations of support. She is able to maintain the supports necessary to accomplish citizenship – she keeps her support person happy, she valorizes work and contribution - while exercising some self-determination around her talk. Finally, she does all of this skilfully, undermining the view of disabled young people as innocent and deficient.

I have presented two examples of how young women took authoritative utterances and re-contextualized them with other voices such that they are ‘dialogically packaged’. Once various utterances are “dialogized” (Bakhtin, 1981), participants make use of their commonly held and historically-situated views, values and standpoints to communicate distinct and unique meanings.

Doing dialogical work

My argument here is that disabled participants are consciously and strategically doing dialogical work. Although they assimilate and utter the poster child discourse in myriad ways and presumably with various intentions, in what follows I only focus on utterances associated
with their work of securing and keeping support. Every utterance carries forward past meanings from its author, its past speakers, and the addressee(s). As participants, individual speakers may infuse an utterance with their own intentions, trying to make it mean something in anticipation of a desired response from others. However, speakers can never shed the past meanings or the interpretations others bring to bear on the utterance – it is as if all past, present and even future speakers are speaking at once (Bakhtin, 1981; 1986). Nevertheless I focus here on what it is that participants do with utterances with respect to support. I leave aside their other intentions or the unintended responses they may receive.

In the remainder of this chapter, I build on this argument. I examine how participants brought the poster child discourse into dialogue, in order to enhance their supports. In the next section, I present illustrations in which participants dialogized the poster child discourse; specifically I look at how participants ‘played with deference’ strategically. As I have described in previous chapters, participants did deference: they were (or felt) compelled to put the feelings, interests and needs of others before their own in an effort to secure support. They remained respectful, gracious and grateful, echoing the voices of parents and workers. As laid out in Chapters 6 and 7, this was a fairly monologic practice; participants did not respond to these discourses but either repeated or rejected them wholesale. Here though, I present participants’ work of responding or answering back to the poster child discourses in ways that simultaneously defused its authority, but took advantage of its intersubjective messages, enabling disabled young people to secure additional and exceptional supports. In other words, they wielded deference to their own advantage, mobilizing authoritative utterances to suit their own intentions. Their efforts secured fairly consistent support for activities that were often closely tied to their unique interests, desires and even dreams. Ultimately I suggest that by dialogizing the poster child discourse – using it but de-centering its force – participants were able to accomplish a thicker or more fulsome citizenship.

**Playing with deference**

As I introduced in Chapter 6, participants’ work of securing support was infused with their own deeper reflections of the location of support workers. Young people recognized that workers frequently laboured under time constraints and had little autonomy over their work. While supporting disabled people in independent living situations rather than traditional
institutional or supervisory care arrangements is apparently preferred by workers (Lilly, 2008), neither disabled people nor workers possessed much leeway in shaping the conditions of how support interactions took place. Personal support work is poorly paid, often non-unionized, offers few benefits, involves shift-work, heavy lifting and the risk of bodily injury and is often held in poor regard by others (see for example Ungerson, 1999; Rivas, 2002; Church et al., 2005). Disabled young people were also disadvantaged in the support interaction. One of their greatest complaints was the limited hours of support available for everyday activities. As noted earlier, even in a Support Service Living Unit (SSLU), no young person in this project had more than two hours of support per day (frequently less). Those who attended school could book attendant care for short – usually half hour – periods. This generally only met basic needs around personal hygiene, meal preparation and light housekeeping tasks. As with similar studies, other activities related to social networking or community participation were not viewed as priorities by service agencies (Antle et al., 1999; Lloyd, 2001; Morris, 2004; Priestley, 1998). Consequently such home and personal support for these activities was rarely available.

Throughout the project, young people categorized support for these sorts of activities as “exceptional”. Therefore both disabled people and their workers were externally compelled to work through the exchanges I present in this section in order to make their jobs doable. In the following vignette, I argue that participants took up the ideological value of deference, associated with the poster child discourse and put them into action in order to curry favour with workers and subsequently secure these institutionally unsanctioned, and sometimes unpaid, only exceptionally available supports.

**Vignette: Playing with graciousness**

Several participants described how they worked to win over workers in order to enhance their available supports. Throughout their accounts, participants made reference to deference, but rather than echo voices of parents and workers, they appeared to have taken some ownership over the value. Towards the end of the project, Isabella detailed her strategy of playing with deference to appease workers.

Isabella: I keep pictures of me and Kyle around. That works with the Jamaican ladies. They always think he’s so handsome and I think they try to be a bit nicer to me because I’m dating a black man. It’s even better when he’s around because
he flirts with them and they just eat it up. Like, I think they like to be
complimented…you know feel good about themselves. Somehow, seeing him
here –like it’s a cultural bond or something.
I use the cultural thing whenever I can. I ask them for recipes for rice or akee –
then they feel good because I think that’s kind of like acknowledging that they’re
more than just workers. I can’t really eat that food and neither can Kyle – but
that’s not the point. It’s important to make them feel like people….

Another thing is I always have Italian food on hand. I always get my mother to
bring me mortadella. The workers LOVE it! I can’t stand the stuff, but if I think
I need them to do something. Like let’s say I have an exam or an essay, so I have
to get my bedtime booking later, then I make sure I have the mortadella out. I
make sure that my mom brings a nice platter over and then I get (the workers) to
sit down and just take a rest. I swear it works – I can get them to do all kinds of
things for me, if I just treat them nice and act interested in them and their lives.

Esther: So your mother is helping you with this?
Isabella: Oh my mom doesn’t really know about this. Actually she thinks I love
mortadella – she always serves it to me now when I visit her. I always want to
gag, but I need her to keep bringing it to me. So I just don’t say anything.

Throughout her account, Isabella assumes deference, silencing her own feelings about
certain foods out of respect for her mother, and assuming the posture of a gracious ‘hostess’ or
kind benefactor. However, Isabella’s approach with support workers is obviously more
calculated; her deference is infused with her own intentions. Her actions were designed to elicit
“extra” support, seemingly a deeper commitment from workers than might be institutionally
sanctioned. Other young people carried out similar activities with similar rationales. For
instance, Ainsley and her mother moved the television and the computer to the kitchen and made
dinner bookings that coincided with the television program The Young and the Restless. Ainsley
found this arrangement ‘stretched’ her booking time as the worker would often “stay until the
next commercial” or the previews for the next day. These extra minutes allowed Ainsley to ask
for small supports around her computer use for school assignments. Rosalyn, much like Isabella,
asked her mother to prepare care packages of baking which she would then use to encourage
workers to have a short break in her apartment. As a worker was sitting for ‘tea and cookies’,
Rosalyn would use the opportunity to make other “unofficial” requests.

As in dialogue generally, there was an inherent ambivalence to these activities. These
activities were in part self-serving – an attempt by participants to “act” gracious towards and
interested in workers for their own ends. However, I was left with the sense that deference
‘worked’ on different levels in these interactions. Participants sometimes genuinely juxtaposed their own interests with those of the workers’.

Other comments suggested that participants were sensitive to the many challenges faced by workers and that their deference was a response to workers’ labour conditions. Participants enumerated them readily: their wages were low, they had little disposable income because they sent extra money “back home”, they worked multiple jobs with hectic schedules, they had to travel long distances to get to different bookings and so forth. For instance, Bernard and Cynthia spoke at length about how hard their day program staff worked. “She works hard…very hard” usually accompanied any mention of their names. Others noted the pace of workers’ schedules in the SSLUs. As Zachary observed:

> I think it’s go, go, go for them in the mornings around here. I let them know I’m okay sleeping in. I figure, they’re running around from one booking after the other getting people ready for the day. They’re exhausted by the time they get to me, so I’d rather sleep in, and then they can have a little break before the time they get to me. I’m a night owl anyway.

Zachary’s comments capture the spirit of many participants who could find advantage for themselves while recognizing that attendants worked under poor conditions. His easy accommodation of the workers’ schedule reflects a gracious deference to the situation they share. His acknowledgement that workers were “exhausted” (rather than lazy or slow), and then following up quickly with the suggestion of a break, implies he realizes the labour conditions (it’s just go go go here), require redress. He juxtaposes his easy posture with self-interest “I’d rather sleep in”. His deference, like dialogue, is two-sided.

In a similar way, Isabella’s gracious efforts in the vignette above also reflect a deep recognition of the actual everyday lives and labour conditions of her workers. She acknowledges the physical demands involved in personal support work. Her offer to workers to have a seat, take a rest and have something to eat all implicitly acknowledge that workers are often on their feet and may lose meal or break times to a prolonged booking. Rather than passively submit to the institutional organization – that both did not always provide desired supports and that exhausted workers - participants found ways for themselves and workers to transgress or find places of refuge within the system. For instance, Zachary described a purposeful effort to garner favour with personal support workers.
My dad bought me a PRD (personal recording device) last Christmas. I was really happy because I can’t always guarantee that I can be around when a film I want to see is on (television). The attendants don’t always want to set it up to record. Now I knew some of the guys really liked those adult channels. You know what I mean, right? Yeah. Anyway I made this one guy a deal. I said, come up on your breaks to help me set up my recorder and you can record your programs on the adult channel. I didn’t really want to subscribe to those channels – they cost more you know. But it’s worth it – he’s happy and I’m happy.

Initially I suspected Zach was not entirely selfless in his offer to let the worker record the adult programs – for surely he must have enjoyed these also. In recounting this story he noted that workers could not always get home between shifts. His apartment became the place where attendants could come to relax. While his efforts are strategic, they also graciously improve attendants’ working conditions – in the end everyone is “happy”. This sociable exchange, young men watching pornography together, may profane both benevolent and disability rights notions of support. Again, like dialogue, Zachary’s activities familiarize differently situated parties, interests and views around support. The differences between the worker and the disabled person, while not erased, are temporarily suspended as they bring together their different worlds in an innovative manner.

Sometimes familiarity between workers and disabled people could slip into exploitation. Participants also commented about the lack of respect towards workers from disabled people, employers and the general public. Although they could be quite critical of individual workers, participants generally agreed that their peers sometimes did not treat workers with respect. Young women in the group for instance, were particularly attuned to how young disabled men could be inappropriate with young female workers. There were many stories about their male peers “copping a feel”, making sexually inappropriate comments to workers directly or “behind their backs”. One striking moment in the project was when Graham shared his initial concept for his video. In other participants’ views, the story was a twist on the Disney account of Pocahontas. A white disabled adolescent boy was stranded, alone, on a tropical island, where he was discovered by “a 16 year old beautiful native girl”. The story continued with the “native girl” caring for the adolescent, until he was rescued and reunited with his family, leaving his carer behind. Young women in the group, mostly white, were quick to condemn his video as sexist and colonialist. They cited several problems, including the sexualized depiction of a
young racialized woman in a caring role. Participants openly worried that the images could be offensive to workers, many of whom were themselves racialized immigrant women. Their anxiety heightened when they saw the provocative animations in Graham’s video. As Therese noted in one of her final conversations with me in the project:

That video always bothered me. I know he’s only a kid (sic), but his video was disrespectful to the max. Disrespectful to women everywhere, but really disrespectful to attendants. I bet he has an attendant who’s from the Philippines or somewhere like that. There she is, there’s no way everybody isn’t gonna know that’s who he’s thinking about. That’s who he’s putting in his film. You know? Like you know, you know he sees her as a sex object. It’s not very nice at all.

Therese’s overall concern related to Graham’s video was about the impact on the audience’s perceptions of disabled people. Nevertheless, her comments illuminate a concern for the treatment of support workers. Respect, one of the postures of deference promoted through the poster child discourse, takes on a different valence in Therese’s comments here. Respect is not about submitting to another’s desires, but a demand for equitable treatment. In her comments she articulates deference through a feminist voice (“sees her as a sex object”), shifting the acquiescence typically demanded of deference to an almost activist sensibility. As well, it is noteworthy that Graham, in producing images of an (overly) familiar or intimate relationship with a carer, exposed the social power disabled young people might have in relation to a worker. Despite the fact that they were often compelled by shared external demands, disabled young people were privileged with respect to race, migration and in the case of males, gender relations in their exchanges with workers.

It is this dialogized form of respect that may be operating when participants seem gracious to attendants during bookings. For instance, just as Isabella ensured that certain foods were on hand, Caterina, who was of Central American descent, always had Latin American products for her Guyanese and Venezuelan workers, acknowledging that travel time constrained their purchase of these items. Creating opportunities for workers to feel attractive, as Kyle does with his flirting, and important outside the confines of their ‘job’ may allow them to feel validated or even special. While offering food and rest cared for the worker’s body, acknowledging a worker’s cultural or social position nurtured their personhood – as Isabella notes “feel like a person”. Parin Dossa (2009) identified similar activities in her research with South Asian Muslim disabled women, citing such cultural exchanges as enhancing the worker’s
capacity to see women as persons. I did not hear quite this sentiment among participants in this study; however, Isabella, Therese and Caterina, and several peripheral participants “used” their own immigrant and racialized identities to produce a “cultural bond” with workers, most of whom were also immigrants. These strategies were to their mutual advantage. As Isabella notes in her earlier comments, it made the workers “feel good” and ensured greater attention in future support interactions. Looking more closely at Isabella’s comments above, her efforts to utilize the Jamaican cultural connection between her boyfriend and workers seems more ambivalent. It could be argued that she, a southern European immigrant, was appropriating her racial power to her advantage. However, in observations, of and conversations with Kyle throughout the project, it was evident that he not only was a willing participant and may have suggested some ways to strengthen cultural connections himself. Moreover, Isabella similarly exploited her own ethnic links when necessary.

Recognizing workers’ personal lives seemed to be another way that young people kept workers invested. Participants drew on direct knowledge that their support requirements were best anticipated and met by those with whom they were familiar. They put that knowledge to use, actively listening to stories their workers shared, not only so they would feel heard, but also for useful details for the future. Young people had a skill for hearing and remembering little intimate details. They could recite workers’ family and friendship networks, cultural heritage, hobbies, sport and other leisure interests. These details helped them find any point of commonality with others, allowing them to develop it into a strategy both for securing support and for mitigating workers’ labour conditions.

One of the strongest examples of how participants’ deployed deference to mitigate workers’ labour conditions was in the way they were willing to share their intimate space with workers. Like support workers in other studies (e.g. Lister, 2008), many in this study lacked a home of their own. For instance, Kai, who worked as a support worker for the second and third workshops series, lived with his brother’s family. He described this as a temporary situation, but it persisted over the duration of the project. His brother’s home was in an outlying suburb, while Kai tended to work for residents from mid- and downtown Toronto. Kai worked 35 hours as an attendant for a major disability services agency, another 24 hours on weekends at two different SSLUs and many additional hours for the Poster Child project and other special events. He was described by participants (and I would concur) as gregarious, non-judgmental, discreet and easy-
going, and therefore popular among young disabled people. Given the small pool of male attendants, Kai was constantly in demand. Male participants carefully analyzed their social schedules, making sure to request him for outings he might enjoy and accept. However, Kai, eager to take any work opportunity, had trouble balancing his schedule. Working more than eighty hours some weeks, he often did not have time to go home. Young people, seizing the opportunity, moved in to offer assistance. They suggested he shower in their apartments between ‘jobs’ – particularly if one of those jobs involved them. Douglas went so far as to let Kai nap in his apartment, sometimes spend the night, sleeping on his sofa, store a change of clothing and personal hygiene items, so that he might secure extra bookings from him. Maureen, a popular female attendant, was similarly housed when her relationship suddenly ended during the project. When other participants remarked at Ainsley’s generous offer to share her home in this way, she brushed off their comments: “Are you kidding? I get my own live-in attendant. I could never afford that any other way!”

As participants shared their space with workers they (inadvertently) brought workers’ rights into dialogue with their own. In a sense their homes became a place where both parties could exercise situated citizenship rights. Disabled young people received the social right of support which they could exercise in the practice of self-determination and autonomy as a worker followed their directions. At the same time and place, workers relied on participants’ homes for relief and some autonomy in their working conditions. In the examples above, disabled young people’s gracious hospitality, however, self-interested, enabled workers to make a living wage, obtain the rest needed that may have allowed them to work effectively and safely, given the many hours they worked, and maintain some dignity. This speaks to the extent to which citizenship is not bestowed from above, but accomplished through externally co-ordinated sequences of activities – in the instance of attentiveness, respect, hospitality, generosity and self-interest.

In each of the illustrations provided above, participants were not only mobilizing the poster child discourse, but leveraging their material resources. Participants who lacked material resources (e.g. extra food, an apartment, technical equipment) leveraged emotional resources instead. For instance, most of the participants with developmental disabilities, who had few

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73 Even I found myself bringing him halal meals on the days he worked for the project. Participants’ desire and need to keep a good worker was overwhelming for me by then.
tangible assets, encouraged support workers throughout the workshop, to sit down, enjoy their coffees and share their stories alongside the participants. As I noted above, they were quick to acknowledge and thank attendants for their efforts, informing anyone who would listen that ‘so-in-so is a “great worker” or had done a “good job!” I could not ascertain whether these actions were as consciously strategic as the young people involved with subsequent workshops, but it could be argued that they were accomplishing some of the taken-for-granted work involved in disabled young people’s use of supports. Indeed, personal support workers eventually viewed Bernard and Cynthia “as easy to work with” because they were amiable and thoughtful. These may have been personality traits – but honed into concrete actions within the workshop setting, these quickly translated into greater attention for their support requirements and wants.

In playing with deference, participants exercised thoughtfulness towards others. Participants acted in deference to workers’ identities, their material conditions, their dignity, their interests. Young people kept items around the home that are not necessarily of their choosing. They gave up time and space; they temporarily put off and put aside their own lives, tastes, interests in favour of the workers, but always in anticipation of future supports for preferred activities. It is noteworthy that participants fit their strategies within the broader social organization of support provision. In a sense, participants assumed deference to the subordinated status of workers, by allowing them to have surreptitious breaks, a place to find dignity, or otherwise alleviating their material labour conditions. However, unlike ‘doing deference’, as discussed in Chapter 6, they attended to someone else’s wishes without letting go of their own.

Throughout playing with deference, participants also familiarized themselves with workers, creating moments of sociability where social divisions blurred and shared experiences of culture, disempowerment or institutional constraint brought them into a brief unity despite their different interest in the support exchange. Playing with deference then, illuminated power differences between workers and disabled people, but tried to respond by challenging and mitigating these differences.

In what follows, participants’ play with deference is more self-interested, less concerned with the situation of others. I examine how young people relied on the shared understandings of ‘innocence’ as they pursued their own ends. Like the activities described above participants were attuned to workers’ situation; however, this knowledge was used solely to their own
advantage. Ultimately, participants pried open a space for workers to provide them with enhanced supports by recasting their own ‘illicit’ intentions as innocent.

**Parodying Innocence: A wolf in sheep’s clothing**

In *Chapter 6* I discussed innocence as a form of deference, a value affiliated with the poster child discourse. Innocence is both proactive and imposed (McCoy, 1995: 413), escalating as young people absorbed the view that they must avoid transgression, be rule-abiding and maintain their integrity in their use of supports. With little apparent intention, participants enacted cultural expectations of disabled people as innocent: as pure, as lacking experience, as guiltless and guileless. In the section below, I argue that activating the image of innocence was not always about meeting its imputed standards. Sometimes doing innocence involved capitalizing on others’ assumptions that because one was disabled – and therefore innocent - one’s requests for support were legitimate and held no self-interested or other ulterior motive. Mobilizing ‘innocence’ enabled young people to access resources including myriad supports otherwise unavailable.

As I have already described, at some point many participants, if not all, tried to keep their behaviour above reproach. Others, however, mobilized innocence to suit their own interests; several noted this strategy drew on the belief that youth were innocent victims of their fate.

Joshua: I know we have it better than the paras or quads. We didn’t do anything to be this way. This just happened to us.
Zachary: Yeah like I never tell people that it’s ok to be this way. It works for me to have them think oh poor Zach.
Joshua: (wryly) Yeah we’re just innocent little lambs.

The young men’s tone here is pointedly mocking of the pity that both positions and compels disabled young people to be innocent. The phrase ‘innocent little lambs’ speaks to the literal image of the poster child that Josh references with sarcasm. It was this parody that allowed participants to manipulate the image of the innocent poster child to their advantage. In part this relied upon turning ‘innocence’ on its head by acting in ways that could be seen as illicit, cheating or transgressive, while all the time maintaining the appearance of innocence. Parodying innocence could undermine the poster child discourse, by reversing the balance of power between disabled people and those who insisted on their innocence. Like “dethroning the king”
Bakhtin, 1984:124), parodying innocence removed the controlling and constraining authority of the poster child.

Throughout the project, young people were able to mobilize the innocent poster child image to pursue many other ‘illicit’ ends. In the following vignettes, Zachary and Isabella literally embodied and enlivened their parodic references about innocence.

Vignette: The most sexist thing I’ve ever done!

By the end of the third workshop series, Zach had clearly emerged as a promising artist in his own right. He had been invited to show his work at The Salon, hosted by the Academy Award-winning film director, Atom Egoyan. His video had been included in several juried gallery showings, as had his photographs. The Trinity Square Video staff were delighted by his success since it garnered attention for their organization. They were eager to support Zachary where more formal personal assistance schemes hesitated. For instance, Zachary had created a photography series for a Toronto photography exhibition. His images entailed sneaking onto a 400 series highway, in order to achieve his desired shots. Not surprisingly, he had been unable to obtain support through any of the attendant care services in the city, nor had he succeeded in his attempts to “pay off” any individual worker. His proposed activity was illegal, unsafe, and most certainly contravened occupational health and safety conditions for personal support…or any other work. In contrast, a TSV staffer jumped at the opportunity.

No one was surprised then when Liam, a staff member at TSV, agreed to accompany him on a shoot for a new video about activism. Among the planned sequences were to be some footage of the ‘Dyke March’ held in Toronto each summer as part of the larger Lesbian and Gay Pride celebrations. However, when an anguished Liam called me about a week after the march, I was surprised by the turn of events. According to the staff member, he and Zachary had situated themselves on Yonge Street in order to get a ‘good shot’ of the march. Liam said he had tried many times to pin Zach down about the exact content of the shots, but never had a clear sense of these until Zach began to direct him. Liam quickly found himself in a distressing dilemma. Workshop support workers and I had emphasized the importance of following a disabled person’s direction when providing support. Liam had taken this to heart, but grew more

In the end however, the pair opted to sneak into an abandoned building overlooking a highway to secure the needed shots.
uncomfortable as Zachary directed him to shoot one topless woman after another. Liam tried to protest, stating that he knew many women who were present. Zach deftly responded by disclaiming any ulterior motives to his selection of shots. Liam now wondered – a week later – if maybe Zach’s motives were “not so innocent”. He asked if I thought Zach’s innocence had been feigned? When I next worked with Zachary, he could barely contain his delight about having garnered Liam’s assistance with the shots.

Isabella described a less lewd, but equally strategic use of innocence to meet her needs.

Vignette: Visiting Rosie O’Donnell

Isabella recounted how as a young teen, she dreamed of visiting New York and meeting Rosie O’Donnell before she finished high school. Her mother’s response was to laugh and instruct Isabella to accept her fate: she had no money and her support requirements were too high to travel. Her mother told her that disabled people could not harbour such hopes for themselves. Refusing to accept this dim view of her future, Isabella wielded an image of innocence to her advantage.

She set herself to the task of getting to New York. The inspiration came when she saw a billboard promoting the Children’s Wish Foundation75. She contacted the organization to inquire about whose wishes could be met. She learned that the Foundation only fulfilled the wishes of children who had terminal conditions. Isabella, whose cerebral palsy is not terminal, was undaunted. In her application letter to the Foundation, she depicted her chronic respiratory condition as placing her under threat of death, an exaggeration allowing her to claim eligibility.

I wrote them the most tragic stuff. I just poured on the innocent little victim routine. I swear I almost made myself cry when I read it over.

Her letter was convincing. At seventeen, just three months shy of ‘aging out’ of the Foundation’s criteria, Isabella’s wish to fly to New York City and meet Rosie O’Donnell was granted. The ‘wish’ included travel accommodation and extra personal support so her mother could go shopping while Isabella attended the show’s taping76. Isabella told this story many times

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75 The Children’s Wish Foundation is a charity that provides funding so that children with terminal illnesses may be able to fulfill a special dream or goal (e.g. meeting a famous sports figure, visiting Disneyland, traveling to a foreign country, attending the ballet, etc.).
76 Her tale did not end there. Isabella and her mother did travel to New York and were in the studio audience for the taping of the Rosie O’Donnell show. But that particular day, Ms. O’Donnell’s son was in a soccer tournament, so
throughout the course of the project. Each time she would conclude with a satisfied sigh: “It was totally Jerry Lewis, but it was worth it”.

Isabella’s closing comment clearly points to her working of the poster child image. She seems conscious of the text at work; her phrase ‘totally Jerry Lewis’ indicates that she counts on people understanding her actions and words within the context of charitable disability images. Similarly, Zach (likely) opportunistically infused innocence associated with young disability with his own suspect intentions. Both participants counted on people recognizing them as honest, deserving of support and innocent of any ulterior motive. Their gamble paid off. In each instance, both the Foundation and Liam had an obligation to mobilize a set of legal discourses. For instance, as a TSV staffer, Liam was required to encourage Zach to seek permission from the subjects of his video, but had neglected to do so. I believe this happened in part because it was widely assumed among TSV staff that the Poster Child participants would not exploit the images. I also found it surprising that the Foundation did not require medical certification from Isabella prior to granting her wish. A plausible explanation might be that because participants are disabled and young, their requests for support are assumed to be completely transparent and honourable.

In fact, Zach and Isabella replicate the poster child in their actions, feigning naïve innocence, highlighting, even exaggerating physical deficits, all the while remaining outwardly polite, respectful and pleasant. However, their responses are not passive acceptance, but add new dimensions to the poster child discourse. Both subversively re-cast the ‘innocent poster child, as they put it in conversation, with their own aspirations, views of themselves and of disabled people. By covering over the underlying intent of their actions with a veneer of innocence, young people remained the recipients of charitable interventions, dependent on others not challenging their actions, and subsequently not held to account in the same ways as their peers.

she wasn’t able to stay after the show taping and meet the audience. Isabella was incensed. She called the Children’s Wish Foundation contact in Toronto and as she described “Put on a real show”. Apparently through sobs she explained how her wish was not fulfilled. Within the hour, the Foundation had arranged for her, along with a small cadre of disabled children, to meet Rosie O’Donnell.

TSV filmmakers were to make every effort to secure image permission, but we all acknowledged that this was sometimes difficult to achieve. There was an informal code that filmmakers would do everything possible to get permission, but that in the end, filmmakers needed to exercise respect and treat the images they captured in video with dignity.
For their own part, Zach and Isabella actively imagined and pursued their futures. Zach and Isabella’s desires were not unreasonable for young people. Seventeen-year-old high school students often have school trips – for instance, March Break vacations – to warm-weather destinations. Such trips are first forays into greater independence and freedom from adult supervision. Similarly, Zach is certainly not the first young man to film the Dyke March for any purpose whether lofty or dubious. Even if we were to take the most cynical view that Zachary’s intentions were not artistic but voyeuristic, surely his actions must be viewed as an attempt to participate in adult, (heteronormative) activities.

As I argued in Chapter 6, assuming innocence allows young people’s requests for support to be viewed as benign and even deserved. Taking care that one’s actions are above reproach maintains the image of innocence. Drawing in the text of the innocent disabled person allows others to see them as someone whose request is deserved or can be met. In turn, parodying innocence shapes the actions of those providing supports to disabled young people. Zach and Isabella, mobilize innocence to concert support provided by others. In a sense, doing innocence allows those supporting them to act in particular ways (like taking video footage at the disabled person’s direction; eschew permission forms, neglect medical certification, etc.). Innocence makes these support activities okay; it justifies and possibly even compels workers to provide supports.

Parodying innocence could backfire; it could inadvertently reinforce neoliberal concerns that recipients of social and benevolent assistance may be undeserving abusers of others’ goodwill. In the two scenarios described above, some might suggest that disabled young people were undeserving of both the support they illicitly secured and the future supports they may request. As I have tried to indicate, parodying innocence was often aimed at obtaining experiences that were on par with their peers through restricted or unsanctioned support resources. Parodying innocence may have been one of the few sequences of activities that they could pursue to access such resources. As I have noted in previous chapters, the authority of the poster child discourse precluded rights-claims or other recourses to citizenship. In fact in the above instances, both young people parody innocence in order to secure extra ‘philanthropic’ or benevolent supports. While the source of support does not mitigate the ‘illicit’ nature of their activities, it does point to the limited extent of their citizenship.
Dialogizing deferral: “Making them wait for me”

Up to this point, my focus has been on participants’ work that broadly mobilized deference. I now turn to different dimensions of the poster child discourse. In this section, I examine how disabled young people brought deferral and deficit into dialogue. Specifically I examine how disabled young participants relied on the discourse of the poster child in their efforts to resist waiting. As I pointed out in Chapter 6, disabled young people deferred activities, putting off everything from their basic physiological needs to their life aspirations in part to accommodate others and in part because required supports were inadequate and unavailable. By waiting, participants reproduced the view of disabled people as futureless; in fact at the same time they participated in constraining and putting off their futures in deference to the demands of individuals and broader systems of support provision. In this section, I provide an illustration of how participants were able to draw in the discourse of the poster child to make others – in this instance Wheeltrans – wait for them and to challenge the futurelessness of the poster child.

Transportation seems at first, to be beyond the realm of support. However, accessible transportation not only was an important form of everyday support for participants; it concerted in various ways with the personal supports young people were able to secure and maintain. The transportation system entailed its own set of documentary procedures which young people mobilized in co-ordination with the image of the poster child. With the exception of Graham who lived in a small community outside of Toronto, and Gerry, Bernard and Joanne who used the mainstream Toronto transit system (with an attendant), participants mainly relied on an alternative public transportation system. During the course of the project, the mainstream Toronto Transit Commission became more accessible, installing elevators at several of its subway stations and launching a fleet of wheelchair accessible buses. Despite these changes, most participants travelled around the city on Wheeltrans, a system of wheelchair accessible vans which can only be booked before 9 am on the day prior to planned travel.

The problems with the Wheeltrans system are well documented (Henderson, 2007; Kontos et al., 2007). Among these problems are the system’s temporal demands and the punitive repercussions on passengers when user rules are not met. The first of these demands was ‘the pick-up window’: the period of time in which a disabled person was expected to wait at a pre-determined location for a Wheeltrans bus. According to Wheeltrans policies, passengers needed
to be available, on the street, no matter what the weather, for a twenty-minute window\textsuperscript{78}. Buses were often late and young people were often left waiting. But, just as frequently, and without warning, buses arrived at the beginning of the pick-up window, or earlier. Young people in the project complained bitterly when they were ‘yellow-carded’ for being late for a Wheeltrans pick-up. An accumulation of 3 or more ‘yellow-cards’ within a month resulted in a suspension of Wheeltrans services, in effect confining potential commuters to their homes. These rules are likely necessary, since passenger lateness might lead to delays in the overall system and cause others to wait. However, participants were indignant since there were no consequences when a ride was late for them or did not arrive at all. Participants lamented the many opportunities missed because they were “waiting for the bus”.

Another transportation challenge disabled commuters faced was the inception of ‘common pick-ups’. An alternative to door-to-door service, these pick-ups were regularly scheduled ‘Wheeltrans’ stops at several sites commonly used by disabled people: Variety Village, Holland-Bloorview Kids Rehabilitation Hospital; West Park Hospital, the Anne Johnson Health Station and so forth. A form of institutional rationalization, transportation service to these stops were infrequent and entailed long waits for passengers. Young people trying to juggle school, voluntary work and social schedules, found themselves dedicating large periods of their day to waiting.

The temporal demands produced by Wheeltrans significantly shaped young people’s everyday lives. It influenced when a young person got up in the morning, when he or she came home at night and his or her social opportunities in between. It became impossible for young participants to plan to attend both the project workshop session and a dance or other social event the same evening. Booking two separate return trips in one day was difficult to communicate to the Wheeltrans dispatcher. The unpredictability of Wheeltrans pick-ups and drop offs meant that there was no guarantee that participants would make it to the second pick-up site at the scheduled time. Furthermore, Wheeltrans schedules were very difficult to co-ordinate with personal support workers’ schedules, whose activities were similarly coordinated by public transit schedules and routes. On many occasions, disabled participants scrambled to re-organize a

\textsuperscript{78} In other situations I witnessed how individual drivers were inclined to be more lenient around these rules. They sometimes go into the foyer of buildings in search of passengers. For instance, one gatekeeper described how her wheelchair broke down in her apartment. Stranded with no cell-phone in her hallway, she was eventually discovered 80 minutes later when a Wheeltrans driver called her superintendent worried about why she had not shown up for her pick-up.
booking as they realized their Wheeltrans ride was either very early or very late. Six times during the course of the project, disabled young people who were helping out with the project (often as actors) missed a personal support booking. On several of these occasions Nas or I tried to arrive at the young person’s home ahead of Wheeltrans in order to let them into his or her home because they required support to get in.

All these little delays and deferrals could conspire to restrict disabled young people from participating in informal rites of passage, such as dating, going to dances or other recreational events, clubbing, dining out and so forth. These activities typically help young people develop a social network and forge a social identity as a member of his or her community. Indeed, although disabled young people in this study participated in many extracurricular events – the actual events tended to be defined by what was possible through Wheeltrans common destinations, rather than through a broader engagement with the city. As a result, disabled young participants remained isolated within the very narrow sector of disability youth services.

While disabled people have been vocal in their criticisms about Wheeltrans, in the present study I focus on what participants did in response to its imposed institutional order. Despite making many compromises in other parts of their lives, their conversations about Wheeltrans descended sharply into collective anger. Participants were furious about abandoned or lost job interviews, volunteer opportunities, classes, movies and so forth because of delays and misses with transportation. Over the course of the research project, I watched them develop strategies in which they used deference and deficit to stretch the system to their advantage.

Disabled participants fought back against the Wheeltrans pick-up window, by drawing upon their impairment related support requirements. Participants sent out a personal assistant to inform the bus driver that the rider was delayed in some way. They often fabricated excuses that were so connected with impairment (e.g. they were in the washroom, waiting for a slow elevator, the only working elevator was at the other end of the building) that it was impossible for the driver to leave. Impairment-related excuses were commonly understood as legitimate, and as such could override the driver’s obligation to maintain his schedule. Not unlike ‘doing innocence’, young people used these little strategies as an alternative to interminable waiting. It is noteworthy that this form of ‘transgression’, relied heavily on having a good relationship with workers, since it entailed a worker doing the waiting for the disabled young person – definitely beyond their job description.
Similarly, in order to escape the long waits and inconvenient schedules of ‘common pick-ups’, young people deliberately gave different addresses to Wheeltrans. Participants had learned the street addresses of all the businesses surrounding common-pick-up stops and used these when booking rides. They learned quickly to never give the name of a large institution, but the exact building address and intersection of their destination. For instance, requesting a ride to Ryerson University inevitably meant that passengers were dropped off at an entrance that was locked on weekends and impassable after a snowfall. Asking for a drive to 350 Victoria Avenue however, meant the rider was dropped off at a more accessible, and more populated entrance. These strategies meant participants wilfully and repeatedly lied to the dispatcher. Participants often were acquainted with the dispatcher, and were in the awkward position of having to ‘forget’ that common pick-ups existed. As Elena, one of the peripheral participants noted: “it’s so awkward! The dispatcher always asks now if I’m sure I want the pick-up at the Second Cup? I think she’s thinking ‘You idiot. The common pick-up is across the street at 3 (at the local CHC). But I have to be…all ditzy. Like ooh yes, I’m just having a latte with friends”’. Over and over participants had to feign innocence and lack of knowledge in order to gain a greater measure of control over their lives.

My argument here relies less on what participants say, but more about how they bring their utterances into dialogue with the authoritative and established ‘policy texts’ of Wheeltrans. By bringing in the voice of the ‘innocent and deficient disabled young person’ into their interactions with Wheeltrans they do several things. First, they parody and subvert the authority of the poster child discourse, by using its authority in ways that are inconsistent with its origins and anticipate their unique preferred responses. Second, they deflate the authority of the Wheeltrans pick-up policies, by illuminating some of its flaws. The policies (and punishments) literally lost authority, as drivers were compelled to wait for disabled riders. Finally, participants were able to infuse these spoken and written utterances with their own purposes. These strategies stretched the time available for disabled participants to lead their young lives, however, they carried an element of risk. If caught bending the rules in this way, young people jeopardized their transportation access. Periodically, young people would fall out of favour with Wheeltrans and lose their right to use its service for a brief time. Participants found themselves in an odd two steps forward, one step back situation. They could never entirely escape the centralizing

79 One of the workshop settings was at Ryerson University.
force of authoritative discourses. Indeed this reflects the character of dialogue: the utterances that go back and forth between speakers, never escape their historically and socially situated origins. Therefore, anything that is ever spoken or written still tastes of its authority and will unify and constrain the dialogue itself. As such, bringing the poster child discourse into dialogue is never a process with a clear and definitive endpoint.

Towards the next chapter

In this chapter I have presented the sequences of activities through which participants brought the poster child discourse into dialogue. Like any utterance within a dialogue, it was anticipated, voiced, responded to, and re-articulated in myriad ways. Participants wavered between assimilating, rejecting and dialogizing the poster child discourse in their efforts to secure support – their work with it was never entirely finished. Rather they worked and re-worked the discourse sometimes pulling it into dialogue, sometimes letting it go in order to get, keep and stretch their support resources.

In the next and final chapter, I review how disabled young people work very hard to accomplish relatively thin or marginal citizenship. Like other citizens, they find themselves eschewing claims for rights, in favour of working with the views and values associated with the poster child that enable them to carry out the practices of citizenship. However, I also suggest that dialogue offers young people hope for something different. Some of the activities presented in this chapter teeter on the edge of transgression, placing young people’s integrity and support in jeopardy, potentially constraining their citizenship. However, young people’s dialogical work also exposed and reversed the authority of the poster child. Young people find ways to potentially re-write or re-thematicize the poster child, such that its utterances create new intersubjective and interindividual spaces – not unlike those that are formed between workers and disabled young people described above – and expanding the ways in which participants may live citizenship.
CHAPTER 9

Discussion: Fragile support, dialogical work and strengthening citizenship

In this final chapter I summarize the findings and analysis. In the first section I review the fragile and skeletal nature of the supports received by participants. I note that the supports secured by the disabled young participants in this study were likely superior to those received in other jurisdictions in Canada and Ontario. Nevertheless, they were scarce, inconsistent and always somewhat under threat. As a specialized formal social right, these fragile supports could not allow a lived citizenship in which participants could engage in meaningful activities of their choosing in the broader community. Indeed in order to maintain supports, the participants frequently had to engage in considerable work. In the second section of this chapter I summarize and examine this work more closely. Participants’ work entailed mobilizing the poster child discourse in their own self-interest and protection, but not always or completely to their advantage. The major work practices are assimilating and echoing, resisting and ignoring, and dialogizing of the poster child’s view. Regardless of how well they are done, their labours result in fragile citizenship. In the third section of this chapter I examine the constraints on how disabled young participants lived citizenship. Finally, I speculate about how in defusing the philanthropic underpinnings of the poster child discourse, participants pry open hopeful spaces in which they may live citizenship more fully.

Introduction

The purpose of this study was to characterize the work done by disabled young people to accomplish citizenship. I used support provision and receipt as an empirical social arena to allow me to discover how participants actively engage in the practices of citizenship. Support was uniquely suited to this purpose since as a formal social citizenship entitlement, it enabled disabled young people to actually carry out the lived activities of citizenship – particularly as they related to self-determination, participation and contribution. Throughout the study, I focused on the activities young people performed as they negotiated, secured and maintained support.

80 My thanks to Dr. Kathryn Church for this phrasing.
Much of the data presented in the preceding chapters was gathered in the context of a media arts workshop in which participants made videos about their experiences of support. I was able to witness participants’ talk and efforts to secure support as they created their videos. The process often led participants and the research team out of the confines of the workshop setting into their homes, their neighbourhoods and other public and private spaces - sites in which citizenship was lived through the activities that take place within them.

The workshops also afforded me the unique opportunity to see citizenship as lived on different, often interrelated levels. For instance, participants used the videos to make public statements and claims about their inclusion and exclusion, rights and responsibilities and relationships in their everyday worlds. These could be regarded as formal claims to citizenship that offered insight into the more intimate private activities in which formal citizenship status takes on meaning and substance in people’s lives. I was able to observe participants live citizenship as they routinely negotiated and actively maintained support both in the workshop and throughout the entire process of making their videos.

**Fragile Support**

In *Chapter 4*, I presented the different forms of supports disabled young people described throughout the project. Although the general themes and categories disabled participants developed bore a tangential resemblance to the administrative categorization of support, the supports participants described had been in their family homes with parents, siblings and other relatives. These supports not only reflected practical requirements for assistance, but also mapped onto different sites and occasions of activity. School attendance, public participation, adolescent rebellion and special occasions brought about requirements for support that went far beyond those of daily domestic life. Participants highlighted these (I imagine there were many other areas as well that they could have addressed), delineating the supports family members, especially parents provided. In my discussion I also gestured to the way supports provided by family enabled and limited how disabled young people might substantively exercise their rights.

I met most participants in this study as they were preparing to move from their childhood homes into more independent living arrangements. Consequently the supports families offered up to that point were no longer consistently or immediately available. Instead, participants had to acquaint themselves with the organization of formal support provision. The public system of
support provision has been deemed strained and underfunded by workers, disability rights advocates and family members (Church et al., 2004; Lilly, 2008; PSNO, 2010; OCSA, 2008). In Ontario, support is not a universal entitlement, but subject to medical assessment, general competency and age eligibility criteria. Support resources are scarce, poorly geographically distributed and of variable quality. Supports are often agency administered, separating the interests of providers from recipients.

On the surface, participants seemed to be relatively privileged with respect to support provision. Throughout the course of the project, it was evident that participants had the basic supports for daily living. They had support with hygiene, eating, administration of medications, other aspects of personal care and the basic maintenance of their living space. These were largely provided through SSLUs, attendant outreach services and community-based developmental support workers. Moreover, participants had access to the local Centre for Independent Living that provided up-to-date referrals for attendant services, alternatives to conventional attendant care/personal support services, training and support around the management of personal support workers and advocacy. Perhaps most significant for this group of participants, they could access transitions programs designed to facilitate the development of skills for independent living. Not unlike living in a university or college residence, or sharing one’s first apartment with friends, transitions programs provided disabled young people with the chance to practice living on one’s own, while buffering some of the consequences that inevitably accompany such endeavours. Once disabled young people had passed through such programs, the pool of support workers, while insufficient, was larger than in smaller communities. As such, disabled people in this study may have stood a better chance of securing desired supports by preferred providers than in other communities.

By virtue of living in a large urban centre, participants had additional complementary resources that arguably decreased their requirements for personal assistance. For instance, they had access to a system of adapted public transportation, access to community events and agencies that provided attendant care, accessible community recreation centres, ‘barrier free’ housing options, retail, worship, community health and other civic institutions and services. While these community resources could be considerably improved upon in order to accommodate greater numbers and a more diverse group of disabled individuals, participants in
this study were keenly aware of their greater opportunities for community participation, work and other activities because of their residence in Toronto.

Their opportunities for finding other complementary forms of support were also enhanced. Participants could subscribe to a range of supported employment programs, career and job-entry programs and pursue a range of educational alternatives in which they might be accommodated. This too could diminish requirements to secure personal support. In ideal situations, participants might be able to look forward to personal assistance provided through an employer.

Participants appeared to enjoy many of the entitlements of the status of social citizenship. However, as I have indicated throughout the previous chapters, the system of support was fragile and skeletal. In many ways these supports were inadequate. They were formally in place, but not to an extent that allowed for lived citizenship. Below I highlight several limitations to formal support provision.

Form of support

For the duration of this project, all except one participant accessed publicly-funded supports through supportive housing, attendant outreach services, day programs and possibly through CCACs. The remaining participant secured direct-funding for supports, considered to be the ideal form of publicly funded personal support arrangement (Kafka, 2003; Priestley, 1998). In part, this reflects the oversubscription and long waiting lists for direct funding program approvals. However, the very limited use of direct-funding among participants may also speak to the challenges of demonstrating self management skills, employee management skills and judgment in directing their own assistance. The participants had few opportunities to develop and demonstrate such skills prior to moving away from their parents’ home in which the negotiation of everyday assistance had long since become taken for granted.

Availability

Participants could not rely on supports to be readily available. Because the supply of support workers was small, agencies rationalized worker services across numerous disabled individuals. Nor could participants expect that support services be well-coordinated with other community resources such as accessible public transit. Participants’ requirements for support were prioritized by agencies. Not surprisingly, disabled people’s requirements frequently
overlapped and conflicted with another, forcing individuals to receive support at inconvenient times or forego some forms of support altogether.

Another limit to availability is the eligibility criteria for personal support services. In Ontario, consumer-directed attendant care and developmental support services rhetorically promise the greatest opportunities for autonomy and the least imposition of supervision. However, in these services, disabled individuals must be able to articulate and direct support interactions. For at least two participants in the project, this ability was in question. For example, one young woman experienced frequent seizures followed by long periods in which she appeared disoriented and unable to direct her own support. Each of the participants who could not reliably meet the criteria for consumer-directed support eventually went on to live in independent living arrangements that embraced an intentional community philosophy. These settings promote mutual relationality, a form of interdependent autonomy in which individuals’ dignity and unique gifts are celebrated (Cushing & Lewis, 2002). It could be argued that intentional communities may enable a more fulsome accomplishment of citizenship than the liberal philosophy underpinning consumer-directed care, since such citizenship hinges on living in fellowship with others (Isin & Nielson 2008; Lanoix 2007; Nussbaum, 2006). However, these are not widely available and in practice may only be open to the most acquiescent and ‘workable’ of disabled people. Disabled people whose activities, interactions and movements are not easily contained are not easily accommodated in either consumer-directed or intentional support arrangements. Instead, aggressive, non-social, ‘difficult’ disabled people may find themselves subject to more custodial or carceral ‘care’. Even disabled people who are more quiescent, such as those with profound physical and cognitive impairments may not be able to access intentional or alternative supports since space is extremely limited and the supply of community members who sustain such support provision is on the decline (Cushing, 2007). These limits to consumer-directed support, considered to be a marker and means to full citizenship for disabled people, raise serious questions about the potential citizenship of those who cannot or will not direct their own care.

Another problem with supports was the degree to which they were outside of participants’ control and direction. In formal settings such as SSLUs, participants’ comments suggested that both they (and workers) were subject to surveillance, monitoring, and reprisals, acting as an external control on how disabled young people requested, directed and evaluated
support services. There was strong awareness among participants that they could not challenge any perceived inadequacy with support services without consequences. Although at no point did anyone tell me that services would be completely withdrawn, participants worried that future supports would be cursory – providing the bare essentials without sociability, attention to their personal preferences, convenience or even need. Nor could they easily demand more services without having to give up other future supports. Although participants often initially attributed these consequences to workers’ personalities, other comments and their activities demonstrated that they were conscious of the limits imposed by the larger structure of support services. A related issue was participants’ lack of control over who provided their support. As noted above, I believe that relying on agency administered funding lent a peculiar fragility to participants’ support services. Participants could not be guaranteed assistance from a worker with whom they had good rapport, nor could they easily avoid workers with whom they simply could not abide. The same of course could be said for workers’ ability to avoid certain ‘clients’. One’s home, the place where we might expect to act as we wish, indulge in whatever idiosyncrasies or moods take hold of us, became a site of restraint, compromise and submission. In short, supports were subject to agency fiscal and organizational demands, rather than the concerns of either disabled people or support workers.

The rationalization of support workers’ time and labour within support provider agencies meant that by default the actual supports provided were often utilitarian. Although I witnessed rich interactions between disabled participants and workers, often by necessity many supports were simply the most basic of services. These guaranteed supports were often instrumental, time-limited and contractual, neglecting the emotional investment that allowed a person (disabled individual or worker) to push through demanding tasks. They did not allow participants to exercise choice and control around the most basic activities like when or what to eat, when to brush their teeth or when to begin or end their day. Support workers were hands and feet – or when working with someone with a developmental disability – an external brain, part of a fragile skeleton of support that made the disabled person ‘whole’ for short periods.

Members of the disability rights movement have decried the concept of ‘care’, arguing that to speak of care in the context of disability is to reproduce relations of disabled people as passive recipients of state or individual benevolence. Jenny Morris (1997, 2004), Paul Hunt (1979) and Mike Oliver (1990) have strenuously argued that the concept of ‘care’ should be
replaced by the word ‘help’. In their view, help denotes practical, utilitarian labour that supports the disabled person in carrying out everyday activities. Help is a right, and its exercise is delivered by paid workers at the direction of disabled people. This position has been critiqued from both within and outside of the Disability Rights Movement (Beckett, 2007; Hughes et al., 2005; Kroger, 2009; Shakespeare, 2006). Feminist and post-structuralist critiques have pointed to this position as a mere reversal of the power relations of care. Where traditional notions of care posit care-providers as in control and having power over disabled people, disability rights models of support have called for the empowerment of disabled people with little regard to workers’ rights. Critics charge that the disability rights model has reproduced gender, race and class relations for workers – transforming workers themselves into little more than “the help” (Rivas, 2002; Wolkowitz, 2006). As I reviewed in Chapter 2, the philosophical underpinnings of these support arrangements fail to account for human interdependency and the extent to which we are all dependent (Kittay, 2002; McRuer, 2007; Smith, S., 2001). Utilitarian models of help, with their emphasis on consumer-direction, exclude those who cannot articulate or direct their own care, abandoning them to traditional modes of support delivery.

In the preceding chapters, supports that appeared to enable disabled participants to pursue their desires, achieve a dignified public presence and voice and make contributions to others were those that went far beyond utilitarian, contractual arrangements. Ideal supports were those in which mutual relational bonds existed – in which there was some semblance of recognition that both parties in the support interaction had gifts that needed to be nurtured.

**The future**

There is every indication that supports will remain fragile for disabled individuals. Funding increases to assistive living and attendant care programs have not kept pace with inflation and there are significant increases in operating costs. For instance, personal assistance providers have lost 23% of their spending power in the past decade (OCSA, 2008). These providers also face financial barriers in recruiting and retaining staff. The wage and benefits gap between those working in hospitals and in other residential care settings and personal support workers has recently grown larger, particularly with a successful bid by developmental support workers for an increase in their hourly wage. Personal support workers earn on average $15.50 per hour and often as low as $11.50 per hour (PSNO, 2011). Disability advocacy groups, fearing
a siphoning of workers into the higher waged employment alternatives, have anticipated an increase in waiting lists for support services as demand increases with the aging demographic and attendant services decrease (OCSA, 2008). Currently, many personal support workers are recruited from the ranks of the most disenfranchised (newcomers, people with very mild intellectual impairment, students), placing people in labour conditions that may further their sense of material marginalization with potential consequences for the support provided to disabled people.

I began this section by noting the unique privilege of the participants in the present study. Despite this privilege, there were a number of constraints on the supports disabled young people were able to access. This raises questions about the availability and adequacy of supports in other, typically less resourced communities (e.g. the North, rural Ontario, urban neighbourhoods without public transit access or considered unsafe). In the next section I discuss the work participants did to maintain and strengthen their fragile supports.

**Dialogical Work**

Participants worked very hard to secure and maintain support. Throughout the dissertation I employed Dorothy Smith’s generous conception of work. Work entails a whole range of everyday/evverynight activities that extend to anything that individuals do that takes time, involves effort, that is intentional and done under “definite conditions and with whatever means and tools and that they may have to think about” (Smith, 2005: 151-2). Work includes the silent, unpaid and often invisible ‘doings’ or everyday activities that sustain and coordinate with the activities of others in different places and times. This work can include waiting, being patient, remaining silent, complying and other activities that are not typically viewed as active.

Throughout the workshops it was evident that participants’ work was organized by texts as wide-ranging as Wheeltrans schedules, worker timetables, labour guidelines (legislation, agency policies and procedures) and public health, community and social services policies. Over the course of the three plus years, participants became more cognizant of the texts that organized their work. Had this been a traditional institutional ethnography, I could have mapped how the joint work sequences of securing support and citizenship were organized by any one or combination of these texts. Instead I looked to utterances as a ‘spoken or written’ micro-text that shapes and co-ordinates social relations in the way Smith’s material texts do. As speakers we
hold utterances in common as we speak to one another, creating and re-creating an interindivudual territory grounded on shared and reciprocal meanings, concepts, ideologies and thoughts. Utterances as micro-texts are integral to ongoing co-ordination of people’s subjectivities and doings. As I outlined in Chapter 5, the utterances of interest were those associated with the poster child. Throughout my findings I traced utterances which literally and figuratively originated with or evoked the poster child, focusing on three ideological dimensions: the view of disability as futureless, deficient and the value of deference. I traced how the poster child discourse was activated through three separate work sequences, or coordinated courses of activities which I named ‘reproducing the poster child’, ‘resisting the poster child’ and ‘dialogizing the poster child’.

Reproducing and resisting the poster child was comprised of ‘doings’ in reaction to both the authority of the poster child discourse and the organization of support services. Although their reaction to poster child utterances might be considered passive – in that they diffused into or through their activities and talk – participants themselves were not passive. Instead they engaged in a range of work activities that I present in Chapters 6 and 7. These include the work of waiting, compromising, deferring, restraining, submitting, acquiescing, resigning oneself to one’s circumstances and other activities that enlivened and embodied deference and the view of disabled young people as deficient and futureless. Participants absorbed the shortcomings of the support services, containing their activities, requests, plans and aspirations to maintain their available supports. These two work sequences lessened the demands participants made for support as they put aside, delayed, postponed and abandoned their own requirements or desires around assistance in order to accommodate and favour the needs and preferences of others.

Poster child utterances were not immediately answerable. Participants did not easily or immediately draw in the utterance in a way in which they might evaluate, challenge or re-signify the views and values it encompassed. For instance, in resisting the poster child, participants pursued activities that were in many ways at odds with its views and values, but never articulated as overt challenges. The authoritative poster child discourse then activated ‘resistance activities’ such as positioning oneself as a worker, but never really challenged the way participants were excluded from adult paid employment.

In Chapter 8, I presented a third work sequence in which participants played with or dialogized the poster child discourse. Dialogical work responds to the fragile nature of formal
supports and the poster child utterance that organizes support use and provision. Dialogical work offers a rejoinder or responds to the views and values underpinning the poster child, and anticipates novel and preferred responses from others. It is important to note that dialogizing the poster child does not mark a clean turn to rights or other alternate discourse, but instead mixes the poster child utterances with others to challenge and shift their meanings. Dialogical work enables participants to find alternate ways to enhance and strengthen their existing fragile supports.

Dialogical work could appear consciously calculated. As I noted in Chapter 8, participants could leverage their material resources in order to re-direct the views and values of the poster child to their own purpose. For instance, I discussed how participants used their homes, food, electronic equipment and other resources not only as active deference, but as means to hold the personal support worker’s attention and time to secure enhanced and unsanctioned supports. Dialogizing the poster child discourse in this way actively mitigated workers’ labour conditions, bartered material resources for assistance, fostered sociability, lent dignity to what is often considered low-status work, while all the while widening available supports. These activities could seem patently self-interested in that participants did not put aside their own preferences or acquiesce to the needs and desires of others. However, I suggest that by dialogizing deference, the poster child discourse becomes ‘two-sided’. On one side, participants anticipated its rejoinder, relying on their dialogical work to be ‘answered’ by workers through preferred, timely and increased support. On the other side, participants recognized and answered the needs of workers for dignity, respect, rest and nurturance – making support work doable. Thus participants’ dialogical work is not necessarily or solely motivated by submission to disabling ideologies, self-interest, institutional constraints, or the difficult and unjust labour conditions of workers – but a hybrid or interplay of all these reasons.

Given that participants’ work sequences are always coordinated with another’s, advancing their own interests inevitably involves altering the work of others. The work they do to secure support is always at once their own and someone else’s. Participants’ activities respond to the social, material and cultural conditions of those providing support, evening out the pain and gain of the support interaction. In their activities participants try to mitigate these conditions – in a sense absorbing and remedying the shortcomings of the larger system. Participants’ dialogical work when directed to support providers, attempts to achieve a balance of their values
and interests. While this balance is not necessarily achievable, it does work against the organization of formal support arrangements that may set up the interests of disabled people against those of workers. Throughout the project there seemed to be some effort among participants to foster solidarity with one another, workers and occasionally family members who provided support.

Dialogical work also unmasks some of the sclerotic authority in poster child discourses by drawing attention to the resources that must be deployed in order to secure support. As I noted above and in the previous chapter, participants leveraged their material and social resources in order to foster greater connections and extract more assistance from support providers. This raises questions about the capacity of those without these resources to secure or enhance supports. Disabled young people who lacked only material goods could at least rely on social graces, such as hospitality, a pleasant demeanour or expression of interest in order to create mutually congenial support environments. However, there are disabled young people who cannot easily act deferentially, let alone subvert or assume its appearance. How then can they exercise, let alone enhance their entitlement to support?

Dialogical work also suggests that individuals possess a number of cognitive resources, including the ability to evaluate the material and micro-texts that organize their work and draw in others that allow (or require) different courses of activities. An example of this is the ‘double-crossing’ of Wheeltrans drivers in which disabled young people activated poster child discourses together with the policy texts of the transit system in order to stretch pick-up times without penalty. Such strategies require that disabled young people be aware of the existence and content of transit policies and creatively subvert them. Dialogical work of any kind may require an awareness of various texts, languages, utterances and the effect of their parody, dissent, hybridization and juxtaposition. This sort of textual work may be complicated for people with profound impairments with whom we cannot easily communicate. However, Antelius’ (2009) ethnographic study of communication partnerships between group home workers and severely disabled workers suggests that we can look beyond the privileged status of verbal communication to consider the salience of non-verbal expressions. Taking the body as a field of expression, Antelius suggests we can identify the body as having desires, and these desires can transform the social order. Antelius supports her argument by noting that routines and schedules are frequently used to take away control and deny self-determination in group-home and other
in institutional settings. However, in her observations, severely disabled residents used their bodies (banging tables, laying on the floor, blocking doorways or otherwise positioning their bodies in space to express what they want, or not) to disrupt group home routines and schedules. Group home residents non-verbally communicated their desires and intentions. Antelius’ work suggests that what counts as an utterance can be expanded to include these physical movements or positionings. Those who have significant levels of physical and cognitive impairment may sometimes carry out dialogical work – evaluating, dissenting from and challenging the authoritative ‘account’ of institutional life.

Dialogical work has the potential to expose the views and values encompassed in the poster child discourse. For instance, participants’ playful and transgressive work with innocence explored the common philanthropic roots to both the poster child discourse and support provision. Frequent targets of unsolicited acts of benevolence on the street, participants regaled one another with accounts of having money dropped on their laps or in their coffee cups by passers-by. Some had long since given up trying to return this money, choosing instead to keep the spoils – a price calculated against those who were motivated by ‘poster child ideology’. Anticipating similar benevolence, participants capitalized on the view of disabled people as helpless and needy. They simultaneously relied upon, fostered and undermined their imputed innocence as they sought unsanctioned support or other privileges. They hoped that others would understand their requests and actions as truthful and without ulterior motivations. While their activities were clearly directed at securing supports, they also highlighted the specific views of disability underpinning acts of assistance.

It is noteworthy that these activities carried an element of risk for participants. The implicit critique and transgression of the poster child discourse could potentially threaten or weaken supports rather than enhance them. For instance, in the example of dialogising innocence, others could easily construe participants’ activities as fraudulent, casting doubt not only on future requests by the specific individual, but others who request support. However, as I will discuss more fully below, participants had limited alternate discourses that they could draw in that might be co-ordinated with the activities of those providing supports. If anything, the riskiness of these activities highlights the diminished salience of rights discourses. While their activities may not be prudent, they may be one of the few options available.
Dialogical work was creative. Participants shifted the meanings and force of the poster child utterances by stylizing, parodying, challenging, hybridizing and infusing them with their own intentions. This happens as individuals infuse and contextualize utterances with different and competing views, values and standpoints. Their dialogical work shifted the interindividual space produced by the poster child utterances. In turn, this changed how the poster child utterances coordinated the activities of personal support workers, charity representatives, Wheeltrans drivers and friends. In doing so, participants challenged the socio-hierarchical arrangements which are sustained by textual reality that holds disabled people as futureless, deferential and deficient is destabilized and re-created.

Fragile citizenship

In the opening chapters of this dissertation I noted the paradoxical relationship between support and citizenship. On one hand, support, a formal right is dialectically related to the lived practices of citizenship in that supports enabled disabled people to exercise choice and control over their everyday lives, take part in and have a presence in community life and contribute in domestic or private spheres. Sectors of the disability rights movement, such as Independent Living proponents, have emphasized this linkage between lived and legislated citizenship. Working within normative understandings of citizenship as the competent, rational, decision-making worker, support potentially ‘remedies’ impairment, paving the way for a ‘whole’ or full citizenship.

However, support is also a ‘special’ social right, historically afforded only to those who are deemed deserving because of their incapacity for self-management, self-sufficiency and contribution to the economic and social health of their communities (Barnes & Mercer, 2005; Kittay, 2002). Those who receive support have been commonly understood as the passive recipients of welfare benefit. They have been cast in political and popular discourse as an economic and physical burden on others. Tragic victims who cannot be cured, disabled people are the deserving targets of care.

Perhaps the more significant conclusion from this study is that its findings empirically reveal how normative formal citizenship rights provided limited aid in the accomplishment of citizenship. Supports provided through formal social rights were fragile, based on a stretched and rationalized system. Like the findings of other studies, this can leave disabled young people
with only their most basic needs met – and even these were often inadequately met (Hagglund et al., 2004b; Brooks et al., 2008; Power, 2006). Throughout the preceding chapters I have noted the instances in which these have limited or constrained the ways in which disabled young people may live citizenship.

Disabled participants had constrained self-determination over most aspects of their lives. Despite the claim of many attendant care services to honour consumer choice and control, disabled young people had restrictions around how they could exercise their rights to support and their lived citizenship. They could not select how or when support would be provided. Participants compromised on almost every aspect of their lives, from what they ate and drank to their career choices. They made these compromises in order to maintain insufficient supports. It could be argued that all Canadian young people are faced with making some similar compromises. For instance, North American parents will tell their children they can do anything, however, many young people will not be able to fulfill their educational and career aspirations due to social, material or individual circumstances. What is of significance here is that the participants in this study made compromises primarily due to a lack of assistance. Assistance ideally should be available for disabled young people to ‘try and fail’ as much as to ‘try and succeed’. False starts, circuitous education paths, experimentation and practice help all people define their location and contribution within their communities and the polity as a whole. Without assistance, disabled young people cannot even try. I would argue that the young people in this study had to make compromises over a much wider array of life spheres and made physiological concessions around eating, drinking and voiding that might lead to negative health consequences.

Although this was not the focus of this research, it is also noteworthy that family and workers’ lives were taken up by ‘disablement’ as much as those of disabled participants. There was a tension throughout the project that in order for disabled young people to exercise choice and control in their lives, someone – either family members or workers – correspondingly needed to give up choice and control.

Participants also struggled to secure formal assistance that would allow them to participate and achieve a public presence in their communities. Consequently they tended to pursue activities in a limited number of spheres. They strategically sought out activities in which attendant services would be present for anyone who required them. This generally meant that
participants attended events hosted by disability services, charities or pediatric health-care facilities, which kept them ‘segregated’ within disability-related settings. It could be argued that the participants in the present study were content with this arrangement. These spaces may have been familiar and comfortable. Participants may have been free from discrimination, unwelcome attention and could have their requirements for assistance safely met (Milner & Kelly, 2009). However, I suggest that relying solely on such spaces for public participation, limits the public presence of disabled people generally, doing little to foster wider acknowledgement of their membership in a range of communities. Segregated or restricted participation of this sort keeps disabled young people at a social and physical distance from their fellow citizens. Further, disabled young people are restricted in the opportunities for social networks, civic engagement or other benefits that may result in diminished contact and fellowship with other citizens. Perhaps significantly, given the focus on the ‘poster child’ in the preceding chapters, participants’ confinement to disability-related and pediatric settings, promotes the view of them as deficient and childlike.

Despite the limitations to their supports, participants strove to make a contribution to the broader community. Some activities were quite conventional such as pursuing education, paid work or volunteering. At the close of the project, all but one participant was receiving ODSP. From my contacts with participants over the intervening years, I believe that only one other participant has secured paid employment. The rest, however, have continued their many marginally or unpaid activities in the community, working primarily in supported employment arrangements. This form of labour has a marginal place in our current political economy, for it does little to fulfill the consumer desires of others and does not strengthen one’s consumer capacity through money. Consequently, disabled young people may find themselves living a marginal citizenship in which their relationship to the labour market is economically and socially fragile (Nash, 2009).

However, these same efforts can also be understood as valuable contributions to communities. Eva Feder Kittay (2002) suggests that disabled people who do not meet normative definitions of the citizen worker, may still make any number of contributions that slip by unnoticed. For instance, workers who run such programs depend on the participation of disabled people’s requirements for support for their livelihood. Non-disabled people’s lives are enriched through interaction with disabled people as friends, neighbours or acquaintances (see also
Cushing & Lewis, 2002). Although not paid labour contributions, these activities represent ‘work’ in both the Smithian and moral sense.

Much of the work participants carried out in order to secure and maintain support also involved contribution activities including self-containment or self-management. These activities were in line with the achievement of individual independence and productivity (Hindess, 2002; Miller & Rose, 2008). Such efforts are troubling for disabled people who cannot achieve this level of self-sustainability without significant support. Under neoliberal political economic rationalities that generate and depend upon such technologies, these supports are particularly precarious.

While participants might not be able to fashion themselves into the self-sustaining citizen, they can pursue some aspects of active citizenship. Contemporary notions of active citizenship mitigate the entrepreneurial individualism that underpins neoliberal rationalities (Dowse, 2009; Lister, 2005). Typically, active citizenship enables the promotion of community values and social responsibilities while continuing the pursuit of self-interest. Citizens do not look first to the state to take responsibility for their communities through the distribution of resources. Instead citizenship is accomplished through taking responsibility for one’s own community and the vulnerable within it through voluntary, charitable and civic-minded actions (Lister & Bennet, 2010). Participants accomplished this sort of active citizenship in two ways. First, they dedicated large amounts of their time to ‘give back’ or ‘help out’. While these activities were in part about positioning themselves as citizen-workers, they also bolstered a system in which disabled young people were active partners in carrying out a governance strategy that undermined their own social welfare. Second, participants contribute to the active citizenship of others. Drawing in the poster child discourse, participants appeal to the moral sensibilities of others, enabling them to carry out the activities associated with providing support. Workers rely in part, on the shared understanding that disabled people are innocent and needy for their labour to be identified as the fulfillment of community responsibility and benevolence.

While much of my focus has been on disabled young people themselves, it is important to consider how their activities enhance the ‘active’ citizenship of others. Creating the conditions of active citizenship raised the moral worth of support workers’ labour, transforming it from menial to “unalienated” work (Kittay, 2002). This potential re-casting of support work may have made
support provision more ‘doable’, thus indirectly securing greater assistance for disabled young people.

This last contribution highlights the degree to which benevolence and charity shape the work disabled people must do to accomplish citizenship. In some important ways the participants in this study were not representative of disabled youth in Canada. All, as I mentioned were affiliated with charities or medical philanthropy. All had been involved with some form of public social marketing activity for these organizations with the intertwined aims of generating donor funds and public awareness about a specific condition. They worked in a range of capacities, they had offered success stories, served as living medical models, appeared on telethons, acted as spokespeople or most frequently, posed as ‘poster children’. All were conventionally attractive, even those with significant facial differences and visible markers of impairment. In fact, these physical attributes may have been assets since they identified participants as members of the charity’s constituency. In most instances, although not all, they also had personal charisma, which may speak to their comfort with public interactions. There was a degree of media savvy in the group which likely attracted them to the project and facilitated their perseverance over its many months to completion.

These experiences also suggest that their capacity to pull in poster child utterances to coordinate their work may have been enhanced. The disabled young people in this study may have been better positioned than many of their peers to realize the potency of evoking the poster child in order to secure assistance. Their accounts of modeling as poster children in the past illuminated the importance of appearing deficient, childlike, innocent and deferential. However, participants went far beyond assuming certain appearances.

I suggest participants appreciated and practiced a certain self-objectification. They knew how to transform their attributes – perhaps especially their young age and their impairment – into an object for consumption by others. My argument here is that with relatively little economic or material resource power, participants ‘marketized’ their disability in order to secure precious supports. I would suggest that by drawing in the poster child, whether with unproblematic assimilation or dialogical parody, participants assume its views and values so that others may consume that good feeling that comes from caring under capitalism (Bellah, 1996). Thus support is not something that people provide on the basis of community membership, a sense of fellowship, mutual sacrifice for the good of others or even a response to an articulated need.
Rather support is an investment on which the giver expects some emotional return. In order to secure and maintain support then, disabled young people work these consumption relations to secure and negotiate assistance.

It is noteworthy that drawing in the poster child was not limited to the core participants but extended to parents and other gatekeepers of support as I noted in Chapter 5. As I also noted in the preceding chapters, many of the peripheral participants were apt to draw in the poster child to organize their talk and efforts to negotiate support. Not all these disabled young people had the same experiences with charities as core participants. This suggests that poster child utterances have a salience over and above that of personal experience. It is possible that the pervasive presence of charities in the lives of disabled people shaped the extent to which it coordinated disabled young people’s activities. I did not meet one disabled young person or family whose lives were untouched by philanthropy.

In recent years charity has taken on increased salience under conditions of neo-liberal state restructuring – filling in the increasing gaps of publicly funded supports. As charities take on a greater role in social and community life, they begin to infiltrate more of disabled people’s lives, offering opportunities for social inclusion, participation in civic society and consumption that were not always, or ever, possible through publicly funded services.

Throughout their efforts to secure support, participants drew in philanthropic texts that promoted views and values firmly established as demeaning if not outright oppressive to disabled people. Over the course of the project, I wondered why participants were not activating rights discourses instead. Although participants made passing references to rights and citizenship they rarely evoked them when trying to negotiate and secure support. Youth reticence around rights is consistent with the findings of other studies (Hall and Williams, 1998; Lister et al., 2005; Nash, 2009)

There seemed to be several reasons for this absence of utterances of rights in their talk. First, throughout the project there were very few mentions of rights from anyone in young people’s lives. Only one gatekeeper and no family members made any reference to rights in interviews and other conversations. This is not to say that no one involved with the study was aware of rights, but that rights were never raised with respect to discussions about support, and certainly never evoked as a first resort by participants. Second, publically funded supports were rarely viewed as entitlements, but privileges only afforded to those able to meet obligations –
deference and deferral. For instance, participants with intellectual impairments never turned to rights, instead they spoke at length of feminized concerns with the affective aspects of support (e.g. love, reciprocity, respect) or with the obligations that usually are associated with ‘citizen-workers’ that tend to characterize both the DRM and neoliberal welfare policies. Third, even when they received publicly funded resources, participants tended to understand them as acts of benevolence. This was captured best in a comment by Rochelle as she cynically reflected on the Canada Council Grant that funded the third workshop series.

Esther and Roy… had to make an issue of the fact that disabled youth were in this project in order to get money from the government. And you must believe that some bureaucrat sat in an office looked at the application and thought “oh those poor disabled people’ – let them make their little films”.

The strong presence of philanthropy in resourcing supports was underscored by the fact that some of the attendant care services used by participants had their roots in medical or religious philanthropy. Over the years these providers have received public funds to deliver attendant care services to the community. It was not always clear to participants or even their families that they were receiving publicly funded services\(^{81}\) that were in fact, a social citizenship entitlement.

It was noteworthy that rights eluded the conversation of those providing support as well. I rarely heard attendants speak of labour rights (safe working conditions, length of work day, freedom from harassment, fair pay). Similarly, family caregivers never raised the issue of their children’s rights with respect to support, but they never raised their own rights as caregivers. Instead support was framed as a matter of familial, moral or economic obligation.

Finally, participants may not have activated rights to negotiate and secure supports because of the normative assumptions inherent within their conventional form. As I suggested in Chapter 2, the image of the ideal citizen reflects the interests of dominant groups. Despite efforts towards social equity and pluralism, in Canada the dominant group remains comprised of non-disabled, middle-class employed, non racialized men with educational achievements (Beckett 2005; Meekosha & Dowse, 1997). As Helen Meekosha and Leeann Dowse (1997) state “hegemonic normalcy invests the very language and imagery of citizenship. We speak of upright and upstanding citizens, we stand to attention to the singing of the national anthem” (p. 52). As

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\(^{81}\) Supported living arrangements directed to individuals with physical impairments received funding from the Ministry of Health and Long Term Care. Supportive housing directed to individuals with developmental impairments received funding from the Ministry of Community Services.
such it is unsurprising that disabled people, and perhaps those whose lives are implicated with
disability, do not immediately invoke the language of citizenship rights. Traditionally rights have
and continue to be formally denied to disabled people. For instance, there continue to be
prohibitions against disabled people to immigrate, hold certain occupations, participate in new
reproductive technologies, serve in the military or control their personal finances. Despite the
rights rhetoric that permeates everything from the disability rights movement to medical facilities
to government policies to small disability services agencies, citizenship rights may reflect a
failed and irrelevant promise for the participants in this study.

To further explicate this last argument I now turn to a reflection on the structure of the
video project itself. The Poster Child Shoots Back project was intended to use PAR techniques
to bring a ‘disabled youth’ voice to public policy discussions pertaining to support. As they
participated in video-making workshops, disabled young people were to arrive at a set of key
themes to guide future policy discussion and development. These themes would form the basis of
and be disseminated through a video, documenting disabled young people’s experiences of
support. I believe that these workshops did generate stories and participant analyses that
contribute to discussions about formal support provision in the community. The project also
illuminated some of the shortcomings of accomplishing citizenship through the appeal to formal
status entitlements. However, the project surfaced unanticipated ways in which participants
could accomplish citizenship.

**Dialogizing and strengthening citizenship**

The participatory foundations of the project meant that I was able to witness some of the
challenges in young people’s efforts to enter into the balanced dialogue imagined by both
Freirian PAR practitioners and cultural citizenship theorists such as Iris Marion Young (1990;
2000). I initially assumed that participants would reach consensus about their requirements for
support. However, as a cross-disability group comprised of individuals with an array of physical,
cognitive and affective impairments, finding commonalities with respect to support proved
challenging for several reasons. First, each participant wanted to highlight their unique story.
This is not surprising given the emphasis on individual over collective interests that characterize
contemporary life. Telling and documenting one story is an expression of autonomy and self-
determination, not easily obtained by disabled young people. Second, there were hierarchical
divisions among disabled young people. Although I had trouble distinguishing which impairments occupied the upper ranks of this hierarchy, it was evident that participants with cognitive impairments occupied the lowest. Participants without (identified) intellectual impairments explicitly distanced themselves from their labeled peers, unwilling to collaborate on collective narratives of support. In part this distance reflected the different supports available to impairment groups and the consequences these had for their everyday lives. More troubling, participants feared they would share the stigma of intellectual impairment.

In response, Nas and I abandoned the initial plan to produce a single collective video documenting the shared experiences of the group. Although this seemed like an abandonment of the universalist vision of citizenship and participatory projects of any kind, it exposed some of the limits of both. First, had we continued with a single documentary, we would have risked masking some of the differences and divisions within the group. As small sub groups’ or even simply an individual’s experience may have dominated the apparently collective product. Other, less powerful voices would inevitably have been subsumed. This would have raised questions about whose interpretations, values, viewpoints or interests had shaped the ‘disabled youth voice’ ostensibly captured in a collective work. In contrast, the turn to individual videos allowed otherwise muted voices to come to the fore. Personal accounts and interpretations surfaced the unique intersecting socially structured positions in which each participant understood and experienced support.

As I noted in Chapter 3, I entered the project believing that videos would be a form of political capital for participants based on several lines of theorizing. Disability Studies’ attention to the relationship between the personal and the political has amplified the significance of mass and alternative media representations (e.g. Corker, 1999; McRuer, 2006; Siebers, 2008). They allow disabled (and other marginalized) people to enter their ostensibly private everyday concerns into broader public debate, potentially shaping their recognition and the distribution of resources that may address or mitigate these concerns (e.g. Beckett, 2005; Fraser, 1997; Kershaw, 2010; Young, 2000). Bringing one’s personal, local concerns into the public sphere transforms how we might collectively conceive of and live citizenship. The videos could be understood as an opportunity for participants to accomplish citizenship by re-signifying and re-thematizing their concerns within the public sphere. Participants might be able to achieved
institutional/material supports and recognition through advancing a cultural critique and offering instead their own cultural, social and material claims.

Although the focus of this dissertation was not on the videos themselves, in other places I have suggested that digital videos allowed participants to edit together, thereby juxtaposing differing voices and ideas, exposing exclusionary social barriers and practices. A number of the participants may not have been self-consciously engaged in cultural critique, but their video art, particularly the ways in which they layered music, images, text and voice gently allowed the audience to witness a self-determining, public, cultural contribution even as they were confronted with stories of exclusion. For instance, Joanne’s video consisted of many sharply edited shots of a competitive pool. Her voice-over, simple and hesitating, suggested her cognitive impairment. Her dialogue, incisively revealed her awareness that as a disabled person she was tokenized through charity swim meets. Similarly Caterina’s video juxtaposed the story of her parents’ response to her medically fragile infancy, with shots of her powerful strokes as she swam the lengths of a pool. Both these videos dialogized ideas about disability and competence, reading them against one another to understand each afresh.

In my view, dialogizing the poster child utterance was like embarking on small projects of cultural critique. Many disabled people experience their different bodies and minds as radically separate from others and radically out of sync with the demands on self-managing, empowered individualism that characterizes contemporary citizenship (see for example Gilbert et al., 2005; Rogers, 2009). A call for social justice that begins in dialogue and cultural challenge rather than a claim for status or rights offers a perspective that does not begin from a relatively privileged non-disabled embodiment that underpins the very notion of citizenship. In dialogizing the poster child, participants began from their immediate practical, material and symbolic contexts. They began in the sites and activities of exclusion, exploitation and oppression, focusing on the common everyday occurrence. But in their dialogizing, parody, play and dissent, participants shifted these oppressive and demeaning utterances into cultural critique.

Dialogue does not guarantee the transcendence or the transformation of inequality, difference or exclusion. However, through dialogue, forms of objectified privilege and authority are called out and addressed as they come into experience. In the end, participants pry open small windows into a world in which all are aware at all times of the “histories, practices and
imaginations that have shaped it, and collaborate in addressing exclusion.” (Kuppers, 2009, personal communication).

**Implications and future directions**

Many years have passed since the data for this study were collected, however, I am still in contact with many participants from the project. For most, day-to-day life has changed very little: their supports are still thin and fragile; their work still wavers between deference and deferral; they still move in and out of the shadows of citizenship.

Perhaps the most significant implication of this study is the need to acknowledge the continuing and increasing role of philanthropy in providing disability services. In most countries in the global North, state restructuring, economic recession and the entrenchment of neoliberal capitalism has increased the salience of charities and philanthropy in the lives of all citizens (Galvin, 2004; Lister & Bennett, 2010). Disabled people have had a long and ambivalent history with charity. Some might argue that disability and medical philanthropic organizations have significantly improved the quality of life for many disabled people (Fleischer & Zames, 2001; McRuer, 2006). Yet the Disabled People’s Movements formed in large part as a critique of the dominant and oppressive role of charity in individuals’ lives. The participants in this study lived out this tension – as much as they were engaged in citizenship relations, they were living out charitable relations. Given that there is little chance that the role of charities is likely to decrease, in contrast there is every indication that it is on the rise, it may be important to explicate the complicated relationship between disability, citizenship and philanthropy. How are these charities promoting their work and the need to fund that work? What views about disabled people are they promoting? Given the manner in which disabled young people’s talk was steeped in the views of disability charity, almost to the exclusion of rights, it may be useful to think about how philanthropy and rights may co-exist.

There are several questions that could be posed about the poster child utterance itself, particularly with respect to it socio-historical specific dimensions. The data from this study were collected between 2002 and 2005. While young people were still actively participating in philanthropic organizations during this period, it could be argued that the dimensions of the poster child utterances they mobilized reflected philanthropic campaigns of the late 1980s and 1990s when they were children. Philanthropic campaigns may have changed in recent years.
Today they may seek to resist or deconstruct disability stereotypes, or actively engage with rights discourse. Contemporary depictions of disability may point to the built, economic and social barriers still faced by disabled people, highlighting systemic injustice rather than pathos. Disabled people may be presented as ‘like everyone else’, accomplished, talented and skillful, leading lives that are at once valued and ordinary. While these changes may still be subject to critique, they will likely have a somewhat different organizing effect on the everyday practices of those who mobilize their messages. What texts are currently available to disabled young people? How are those texts being mobilized and how are they organizing young people’s work of accomplishing citizenship? What alternative texts are available to young people?

A challenge however, is that a Bakhtian analysis would explore the ways in which these contemporary portrayals respond to texts and utterances articulated in the past. From this perspective contemporary philanthropic depictions might be seen as progressive or empowering by virtue of their contrast to earlier negative or demeaning representations of disability, that is, through recalling and reiterating the authoritative poster child utterances of disability as deficient, deferential and futureless. More practically, progressive campaigns in which disabled people are positioned as ‘ordinary’ or valued fellow citizens may give the impression that the philanthropic organization’s constituency no longer requires ‘special’ or extra support. Charities, and the disabled people who rely on their resources, may find themselves facing donor fatigue and lagging donations. The changing portrayal of disability in philanthropic and other social marketing campaigns and the impact of these changes on both disabled people and the charity/service is an important area for future research.

Although I did not study charities, the findings highlight a number of dilemmas inherent in philanthropy. While the findings of this study draw attention to the ways in which participants’ activation of poster child utterances results in a qualified or fragile citizenship, charitable images of all kinds generate positive outcomes for disabled individuals. For example, organizations like the March of Dimes or Easter Seals have garnered important resources that contribute to the material betterment of the lives of many disabled people, such as grants for housing renovations, wheelchairs, recreational activities or personal support services (Fleischer & Zames, 2001). Professionals involved in such campaigns, may be aware of the disabling potential of representations they reproduce and perpetuate. I have encountered many professionals in other arenas who champion disability and youth rights, who have a critical
analysis of philanthropy, who struggle with both the opportunities and pitfalls of involving their own disabled children in charitable campaigns and concertedly bring this critique to their own social and charitable marketing campaigns in their own agencies. However, materially, these representations are one among many strategies to supplement a fragile formal support system in the only way possible under neoliberal economic conditions. Some further exploration about the interplay between the figurative and material dimension of disability charity fundraising campaigns could explore these tensions.

The theoretical orientations and findings of this study raise questions about the relevance and impact of this research for people with profound physical and cognitive impairments. Citizenship as a formal legislated status is bestowed on the members of a political community. In this sense, all people who are part of a community are citizens to some degree. However, lived citizenship assumes that citizens are reflexive, can voice claims and concerns and otherwise act within the boundaries of their legislated status. If we argue that citizenship is lived, then our attention turns to how we form relationships, pursue community activities or make choices that follow our desires and aspirations. It thus could be argued that discussions of citizenship as lived excludes those who have profound physical and cognitive impairments. Certainly, without a way to apprehend the desires, aspirations, and reflexivity of individuals with profound impairments there may be little way for us to appreciate how they live citizenship. Moreover my argument in the preceding chapters is that participants’ lived citizenship can be apprehended through their dialogical work. This too suggests that those who cannot engage in this communicative labour may not accomplish citizenship. Given that individuals with profound physical and cognitive impairments have been denied citizenship throughout different historical periods, leading to their systematic neglect and abuse (Linton, 1999), such exclusion is troubling.

As I noted earlier in this chapter, philosophers, such as Eva Feder Kittay, Jean Vanier and Michel Berube, argue that it is always possible to apprehend the personhood – subjectivity, desires, intentions – of those with profound physical and cognitive impairments when we live in moral relation or community with them. These authors contend that although people with profound impairments may not be understood as communicative by biomedical standards, there are moral and relational ways of knowing others. Kittay (2011) has recently returned to this argument noting the many innate ways she and her daughter Sesha communicate. In the future, it may be interesting to use the work of these philosophers to consider if and how concepts like
citizenship and dialogical work can include those with profound physical and cognitive impairments.

My intentions, as I stated throughout this study, were to question the notion of disabled young people as passive recipients of welfare benefits. In brief, perhaps not unlike feminist care theorists, I worked from the assumption that receiving support entailed deliberate work. The problem with such an assumption is that it may seem as if disabled people who have profound physical and cognitive impairments do not work and therefore cannot accomplish citizenship. In order to address such concerns, I employed as much as possible a generous conception of work. I believe that ‘waiting’, ‘being patient’ or ‘staying silent’ are activities that concert with those of others allowing them to carry out their jobs or social roles. In my view, these ostensibly passive ‘states’ are work, whether or not they are conscious. Again, it would be interesting to explore this notion of work in light of the writings of philosophers Kittay, Vanier or Berube. Could this work, although not conventionally reflexive or intentional, concert with and enable the support work of others?

The study raises practice-related questions about the preparation of disabled young people for independence, adulthood and citizenship itself. Specifically, the findings raise questions about the ways in which disabled young people are prepared to secure and manage supports. While transition to independence is promoted and perhaps even valourized for all young people (Jones, 2009; Pascall & Henley, 2007; Priestley, 2003), there seemed to be few opportunities for disabled young people in this study to assume and practice independence prior to their first forays to adult citizenship. While many transitions programs exist for disabled young people, there seemed to be little systematic examination of what is taught in these programs and if the curriculum matches disabled young people’s stated and felt needs. Transitions programs seemed organized around teaching young people a set of practical and interpersonal skills. No doubt these are valuable, however, at the time of data collection it was not clear that disabled young people were being taught to recognize, let alone negotiate the intimate and complex power relations between themselves and workers. As well, disabled young people were not able to ‘ease’ into citizenship in the same way as their non-disabled peers. Rather than move in and out of independence, participants seemed to lack this flexibility. In a sense they had to learn how to work with supports ‘on the job’, with little chance of returning home if things did not work out. A practical implication from this study is to consider
introducing formal supports to disabled people at younger ages. For instance, disabled young people could be involved in the hiring of educational assistants or respite care providers or other support workers.

An obvious implication from this study is that disabled people would benefit from a stronger system of publicly funded supports, staffed by well-paid workers. Here I would echo consumer groups, family groups, disability advocates and disabled people who have been calling for enhanced consumer directed attended services. As I have detailed above, these services are critical if disabled people are to enjoy the dignity of personhood, let alone the privileges of citizenship.

The findings also raise questions about the alternatives to support provision through human labour. Technology, for instance, could have resolved some challenges confronted by the participants. Cell phones, laptop computers, call buttons, environmental controls (e.g. voice-operated locks, lighting, temperature control) would have eased the demands for home and personal support by bridging participants’ unmet needs. Technological innovations to assist with mundane tasks might lend spontaneity, autonomy and simplicity to individuals’ lives, particularly in their homes. However, technology can only be part of the solution since it is limited and subject to error and failure in ways that require human interventions. Moreover, disabled individuals, indeed all persons, will have support requirements that involve human feeling and judgment.

Finally, there were a number of methodological implications from the study. Many of these arose around the use of participatory methods in a cross-disability group. For instance, one of the first challenges I encountered in the study was the absence of an organized youth advocacy or social action group. This raises questions about the capacity of disabled young people to organize around their own concerns. As I mentioned in Chapter 1 and Chapter 3, I approached a number of youth action groups in Toronto. Many of these were concerned with the interests of marginalized groups and have effectively inserted a youth voice in policy making and the political process. However, none of these groups were able to identify disabled young people among their members. I suspect these groups did have disabled members, but they were not identified because disability was not viewed as a social, cultural or political concern. This speaks to the need to highlight disability as a social difference that structures the lives of young people on par with class, race, gender or sexual orientation.
The study was also a rare example of research that brings together people with physical and intellectual impairments. By including people with intellectual or developmental disabilities in the project, the research design contributes to a growing body of work that explores their concerns from their own perspective or standpoint. Using visual techniques in particular allowed these young people to position themselves as speaking subjects who could exercise their political and cultural voices. That said, stigma surrounding intellectual impairment may have served as a barrier to the sustainability of the group for future political and cultural work. The tensions between ‘impairment constituencies’ in the workshops most definitely led to fundamental changes in the direction of the media workshops, shifting them from a classic participatory trajectory. In time, participants with physical impairments became more willing to work alongside those with intellectual impairments in the workshops. However, participants with physical impairments were unwilling to form closer or more collaborative relationships. Once the workshops were over, the ‘impairment groups’ went their separate ways. Although the group may have disbanded regardless of its internal differences, the tensions from almost its inception raise questions about the hierarchies within the disability community and how these detract from a broader project of disability rights. More practically, this study presents one model for how cross-disability groups may move forward on collective endeavours, but clearly there is a need for more examples.

Conclusion

I set out in this study to explore disabled young people’s experiences of negotiating, securing and maintaining support, with the goal of developing a collective citizenship claim related to their concerns. I ended up tracing the largely invisible work disabled young people did to accomplish a fragile and marginal citizenship that their supports enabled and demanded. Beginning from a standpoint in disability, this study broadens the conventional view of citizenship as formal status bestowed upon individuals; rather it is accomplished through work that concerts with the work of others. For disabled young people this work is dialogic in nature.


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Want To Make A Video?

Intensive media arts workshop in which you will:
• Make your own short video around themes of support and living with a disability.
• Receive training in using a video camera and the logistics of video making. All equipment will be provided.
• Present your work publicly.
• Workshops are FREE!

When: Saturdays 10 to 2, Oct. to Feb.
Who: Youth, 15 to 25 yrs, living with a physical disability or chronic illness.
Where: Ryerson University, 350 Victoria St.

Contact
Esther Ignagni
(416) 351-3800 Ext. 2762
esther.ignagni@utoronto.ca

Community support: Spina Bifida and Hydrocephalus Association of Ontario, Variety Village, Young Women’s Action Group and Bloordview MacMillan Children’s Centre.

This workshop is part of a larger participatory research project about the role of support in the lives of people with disabilities, conducted under the auspices of the School of Disability Studies, Ryerson University. Funded by the Hospital for Sick Children’s Foundation, the Canadian Institute for Health Research and Social Sciences and Humanities Research Council.
APPENDIX B – Community Screening Flyer

The Poster Child Shoots Back

Community Video Première
Featuring Videos Produced and Directed by Youth with Disabilities

Saturday March 6, 2004
7:00-10:00 pm

Olive Baker Lounge
Jorgenson Hall, Ryerson University
380 Victoria Street (Gerrard & Yonge)

For information or to RSVP: 416-351-3800 ext. 2762
theposterchildshootsback@rogers.com

Attendant care & light refreshments provided
APPENDIX C – Ethics Protocol for the University of Toronto

1. Background, Purpose, Objectives of the Study

One of the key arguments for the shift in the care of young people with disabilities from institutions to the community, is that young people deserve the chance to take part in all aspects of community life. Meaningful participation in home and school life, however, often requires specialized support. Yet, since the mid 1990s, the Ontario government has passed a wide array of legislative reforms that have dramatically affected the ways in which young people with disabilities receive this support. Most significant among these are the reforms to home care and education. The implementation of The Long Term Care Act altered the funding and infrastructure of home care to a system that is now regionalized and marketized. Early reports suggest that these changes have disrupted continuity of care, and have limited the quantity, scope and quality of care.

There is little research that focuses specifically on the experiences of children and youth with disabilities with home support; and none that explores children’s and youth’s perceptions of how home support influences their ability to participate as “full members” of their communities. Although the amount of data is small, children and youth with disabilities speak to their curtailed involvement in home, school and extra-curricular life, and to the difficulty of securing and maintaining formalized support in carrying out “regular” activities. These findings suggest that children and youth with disabilities are at risk of social isolation, a condition recently linked to many health problems among Canadian young people with disabilities.

The proposed study is both exploratory and developmental in nature, intended to provide initial direction about children’s and youths’ participation in managing disruptions and gaps in their support. The goal of the overall research is to develop a participatory policy review of home care policies in Ontario based on the experience of children and youth with disabilities. A secondary objective of this study to undertake and complete an institutional ethnography of the role of home and community support in the everyday lives of children and youth with disabilities. This is intended to enhance understanding of those with an interest in the participatory policy analysis process, particularly as it relates to children and youth, and people with disabilities, in that the ethnographic component of the work will highlight children and youth’s everyday experiences with home care and support, illuminating the policies that seem to shape the social and material conditions of their lives. Finally, the research also intends to develop the use of media-based or visual methods as a way of enabling the participation of children and youth with disabilities in the research process.

Research Methodology

The following project components comprise the focus of this review:
Youth advocacy focus groups
Gatekeeper interviews;
Media-arts workshops;
Project wrap-up interviews with individual participants of each media-arts group.
Field notes created and maintained by myself throughout the research process;

Forms and a listing of the topic areas for interviews are provided in the attached appendix.

a) Youth Advocacy Group Meetings:
I will meet with four youth advocacy groups to 1) gather feedback about the project, 2) explore issues around home support and personal assistance, and 3) explore issues around community participation and integration. Issues that arise out of these meetings will be used to develop guidelines for the media-arts workshops (e.g. strategies for ensuring egalitarian participation within workshops, data collection guidelines). An agenda for discussion will be distributed at the beginning of the meeting and members of the youth group will be invited to make any amendments.

Two additional meetings will be planned with the advocacy groups. One will be at the “half-way mark” of the project. In this meeting, results, analysis and media pieces developed to that point will be presented to the group. Results and analysis from other parts of the project will also be presented. Groups will be asked to provide feedback on the material, noting what they feel captured well in the research to date, and what needs improvement. Their feedback will be used to shape the remaining media arts workshops.

The final meeting will involve a presentation of the completed media products. Groups will be asked to comment on the set of media presentations.

All meetings will be tape recorded, with permission of the group members, and transcribed for further analysis in accordance with the consent and anonymity procedures described below.

b) Gatekeeper interviews:
These interviews have several purposes. First they will be used to sensitize the researcher to issues currently believed to be relevant to children and youth with disabilities in Ontario. They will also be used to identify potential participants and recruitment sites for the media arts workshops. It is expected that these interviews will also help me anticipate some of the practical considerations of working with children and youth with disabilities. As well, these interviews will provide insight into the material and non-material practices pertaining to community participation/integration/inclusion for children and youth with disabilities.

Interviews will last approximately 45 minutes and address several broad themes including 1) their impressions of the integration and participation of children with disabilities in their communities; 2) their assessment of the extent and manner to which the issues pertaining to young people with disabilities are represented in the policy process; 3) material resources and institutional access issues (home care) that impact the opportunities young people with disabilities have for community membership and participation and 4) their awareness of advocacy initiatives led by youth with disabilities.

All interviews will be tape recorded, with permission of the group members, and transcribed for further analysis in accordance with the consent and anonymity procedures described below.

c) Media Arts Workshops:
Children and youth with disabilities will be invited to participate in a 12 week-long creative arts workshop to develop a media-based report about home care based on their experiences. In workshops, children and youth with disabilities will be provided with cameras, operational instructions and a brief overview of the types of data to gather (i.e. activities of a typical day, activities/situations in which personal support is negotiated). The degree to which direction will be provided at this point will be determined in collaboration with the youth advocacy groups.

In subsequent sessions children and youth will begin to develop individual narratives, using the photographs or videos they have taken. As a group, workshop participants will identify major themes addressed in individual narratives and reflect on how they relate to home care policy. A larger group narrative will be formed and recorded in a form agreed upon by the group (e.g. video, photo-essay, popular education theatre, etc.). Workshop participants and myself will develop a plan to disseminate the media ‘products’ to health and home care advocates and practitioners, educators,
policy makers, disability networks and child and youth networks. The implementation of this dissemination plan will be undertaken through a separate research project.

d) Summary Interviews
Exit interviews will be conducted, with individual members of the media-arts workshops, about their experience of participating in the project. These will be conducted in order to learn more about this method with the participants and to help with the design and implementation of subsequent workshops and similar future projects. The interviews will focus on several key themes including 1) the process of participating in the workshops; 2) reaction to the final “product”; 3) further thoughts on community participation; 4) further thoughts on home care in Ontario; and 5) possible impacts on their lives (see the Appendix for the interview guide.

e) Field Notes
Field notes will be maintained throughout the course of the project. The field notes will be taken after project management meetings, Youth Advocacy Group meetings, gatekeeper interviews and the media arts workshops. These notes will be helpful in documenting the progression of the project, recording methodological insights and developments, and serving as a means of refining and recording conceptual insights (e.g. evolution of research themes in the media arts workshops, insights about what constitutes “participation” for young people with disabilities, conflicts between participants, observations about the influences of structural influences such as race, gender, ‘generation’, etc.).

Analysis:
Data will be analyzed in two ways throughout this project: participatory analysis and ethnographic analysis. Participatory analysis will take place within the media arts workshops. Through a set of interactive exercises, all workshop participants will take part in analysis of individual visual narratives. Participants will examine the narratives for major descriptive themes, particularly around issues of home care, personal support/assistance and community participation. As mentioned this analysis will form the basis of the media products that are created in the workshops.

An ethnographic analysis of the individual narratives, group narrative or final workshop product, the workshop process will be conducted by myself. The content and process of the workshops, as well as the transcripts of the group review meetings and gatekeeper interviews, and the field notes will be analyzed using qualitative methods. These data will be examined for what kinds of things are said about participation, community integration, childhood, citizenship (in both the deliberative and institutional sense), formal and informal support, and how each of these issues are talked about by different groups of participants.

Participants
Describe who the participants are and why they were selected.
This study will involve several groups of participants.
Gatekeepers/Key informants:
These participants are selected on the basis of their experience with children and youth with disabilities. Their experience reflects direct non-clinical community work with children and youth. Special effort will be made to speak to gatekeepers/informants who have worked with youth in providing advocacy around community integration/inclusion issues; or who have worked with youth in a community setting (e.g. recreational programs). Interviewees will also be asked to identify potential recruitment sites for media arts workshops participants and for other individuals they perceive to be gatekeepers.

Youth Advocacy Groups:
Three youth advocacy groups have been identified to potentially participate in the group review process. These groups have been selected on the basis on their past advocacy work on behalf of
other youth with disabilities around issues of community integration, citizenship and/or health care access. Group representatives have been contacted over the telephone by me and introduced briefly to the project. These groups have expressed an interest in exploring the possibility of collaborating in this research once ethical approval has been received. All the members of these groups have a disability, defined as a ‘youth’ and are 17 years of age and above.

**Media Arts Workshop Participants:**
Children and youth with disabilities between the ages of 9 to 18 years will be invited to participate. This age range represents an age group that typically participates in their community with increasing independence. This is the most common age range of participants in other studies about childhood, citizenship and the policy. “Disability” is defined broadly in this study, so there will be no effort to recruit participants of any specific disability group. Rather, participants must receive (or believe they are eligible for) home support or specialized support for some part of their daily activities.

**State the proposed sample size.**
It is expected that 10 individuals will be interviewed for the gatekeeper interviews representing the key organizations working with children and youth with disabilities in the Toronto area. As indicated above, focus groups with 3 youth advocacy groups will be conducted.

A maximum of five media arts workshops will be conducted. It is anticipated that the first workshop will serve as a pilot; subsequent workshop series will integrate knowledge gained from this piloting work. Each workshop will have a maximum of 7 participants. In cases where participants require higher levels of personal assistance, the number of participants per workshops may be further limited. Also unlike other participatory research projects, the participants in this study are likely to be less “organized”. Holding several series of workshops may allow members of the youth with disabilities community to clarify what they wish the study to achieve, and ultimately take greater ownership of the research process.

**Recruitment**
Describe how and by whom participants will be approached and recruited.

**Gatekeeper Interviews:**
Potential participants will be selected using “snowballing” techniques. They will be contacted over the telephone by myself and briefly informed about the project. They will be asked if they are interested in receiving some written information in the event that they wish to participate in an interview. In the interview, gatekeepers will be asked to recommend other individuals who might be interested in participating in the research.

**Youth Advocacy Groups** have been easily identified because of their small number within the Toronto area. They are currently aware of the project and are considering possible participation once the ethical review process is complete.

**Media Arts Workshops**
Participants will be recruited through recreational and summer programs that are targeted at children and youth with disabilities. Potential sites include the youth and recreation programs at Bloorview-MacMillan, Sunnyview School, the Muki Baum Centre, Erin Oak, Grandview, the Spina Bifida and Hydrocephalus Association and Variety Village. Members of the youth advocacy groups will also be invited to participate in the workshops. Information letters will be sent to families. Families will receive a brief overview of the project and its goals and consent forms. Families will be asked to contact the researcher if interested in participating in the workshops or to return an interest form with their registration information (in the latter instance, the researcher will respond with a telephone conversation). In the telephone conversation, the researcher will explain the project in more detail.
and make arrangements to meet with the family at a time and place of their convenience. At this meeting, the researcher will review the project, and its potential benefits and harms to the family once again. Informed consent will be obtained from parents or guardians in cases where participants under the age of 16. Informed assent will be obtained from participants under the age of 16. Informed consent will be obtained from participants over the age of 16.

**Provide a statement of the investigator's relationship, if any, to the participants (e.g., treating physician, teacher).**

The researcher will have no relationship to the participant beyond the parameters of the study.

**Risks and benefits:** List the anticipated risks and benefits to participants.

The study potentially offers participants several benefits. Workshop participants may learn research skills, rudimentary photography and video techniques, and other media skills. Participants may also learn more about the policy process in Ontario and Canada and develop leadership skills in the areas of youth and disability issues. At minimum, they develop links with other young people with disabilities.

There are also several potential risks associated with this study. Group workshops may not be appropriate for all participants, and their self-esteem may be negatively affected if group interactions are not always amicable. Every effort will be made to create a variety of roles through which young people may participate in a more independent fashion, while still contributing to the final research product.

It is possible that conflicts may arise within the group. The research team will provide group interaction guidelines in the first workshop. Conflict mediation resource people have been (or will be) identified within each setting where the workshops will take place (e.g. peer counselors at Variety Village, child and youth life staff at Bloorview-MacMillan Centre, etc.).

A clearer understanding of barriers to full participation within their communities may also produce negative feelings for young people. The researcher design’s emphasis on collective participation will hopefully balance this. In instances where individual experiences of discrimination and exclusion are revealed, participants will be directed to appropriate advocacy organizations. Where appropriate the workshop group may choose to frame their policy analysis around that incident.

Finally, young people may attract negative attention and criticism as they attempt to document their surroundings through photography and video. For example, it is possible that others may become angered if young people attempt to photograph them. To address this, the first session in each workshop series will address issues of privacy and power in documenting others. Participants will be instructed to ask permission before they photograph or videotape any individual and to ask these individuals to sign a release form. Participants will also be instructed stop photographing or videotaping if others are uncomfortable or angry.

**Privacy and confidentiality**

_**Provide a description of how privacy and confidentiality will be protected.**_

In order to protect the anonymity of study participants, each will be assigned an identification number and pseudonym at the time of recruitment. They will be referred to by this number in all aspects of data handling. Identifying information will be kept under lock and key in a separate location. Any unique characteristics that could lead to the identification of the participants will not be reported. Examples may include rare diseases or specific details of an accident that led to the disability or the name of an organization in the case of gatekeeper interviews and review groups. Field notes, transcripts, computer disks, film, video tapes and audio-tapes will be held in a secure
location and only be accessible by myself and members of my advisory committee. Because in this study, participants are viewed as co-owners of the data, workshop participants may also have access to this data – however, they will not have access to data that compromises the confidentiality of any participant.

Transcripts of the gatekeeper interviews, summary interviews and group reviews will be reviewed for any identifying information. This information and along with the names of individuals will be removed from the transcripts. Participants in each of these study components will be given a pseudonym, and will be referred to by this name in all aspects of the project, including further transcription, data analysis, reports and publications.

The media samples, any copies and or negatives will be returned to the participant and or the family. Information presented in final reports will not be attached to any one participant. The group narratives that form the basis of these reports may arise from individual stories or images, however, every effort will be made to remove identifying information from these data. In instances in which this too difficult to accomplish participants will be asked if they can create a “staged” re-enactment of their data. Alternatively, images may be technologically altered to obscure identifying information in images, such as voice or appearance.

As a further measure anonymity, participants and their families will be asked to review any photographs and video-tapes of themselves. At any point, they may ask to have any image excluded from further analysis. Field notes, computer disks, film, video tapes and audio-tapes will be kept for six years after the project is completed. This is in accordance with UTRS policy.

Finally, a clause will be inserted into appropriate consent and assent forms stating the expectation that participants will not repeat or discuss what is said in the focus groups or the media arts workshops with anyone outside the groups.

**Implications of Research**
Final reports will be distributed to families and participating institutions/programs, as well as policy-makers and health, youth and disability advocacy groups. These reports will be helpful for those interested in how home care, health and disability policy affect young people’s everyday lives. The findings may be helpful in the development and evaluation of these policies. The findings may also be helpful in community/home health and social care planning and delivery for young people with disabilities. The study will also be instructive for future participatory research projects with young people.

**Compensation**
Describe any reimbursements, remuneration or other compensation that will be provided to the participants, and the terms of this compensation.
Not applicable.

**Conflicts of interest**
Provide information relevant to actual or potential conflicts of interest (to allow the Review Committee to assess whether participants require information for informed consent).
Not applicable

**Informed Consent Process**
Provide a description of the procedures that will be followed to obtain informed consent (consult the Tri Council Policy, Section 2 for detailed information on informed consent).

Where written informed consent is not being obtained, explain why (see Tri Council...
Policy, Section 2)
See attached

Where minors are to be included as participants, provide a copy of the assent script to be used.
See attached

Scholarly review
If the research poses greater than minimal risk, provide sufficient information to allow the Review Committee to determine whether the design of the project is capable of addressing the questions being asked in the research.

Not applicable

Additional ethics reviews
The Board of Education, Sunnyview and Bloorview-MacMillan all have their own review processes. Reviews are being submitted concurrent with the University of Toronto Review.
APPENDIX D – Gatekeeper Interview Consent Form

<table>
<thead>
<tr>
<th>Title of Research:</th>
<th>Negotiating Community Care and Participation: A Participatory Policy Review of Home and Community Care with Young People Living With Disabilities and Chronic Illnesses.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Investigator:</td>
<td>Esther Ignagni, M.Sc., Ph.D. (candidate)</td>
</tr>
<tr>
<td>Telephone:</td>
<td>(416) 351-3800 ext. 2762</td>
</tr>
<tr>
<td>Funding Source:</td>
<td>Hospital for Sick Children Foundation</td>
</tr>
</tbody>
</table>
| Supervisor:        | Dr. Heather Maclean  
Public Health Sciences, Faculty of Medicine, University of Toronto  
Director, Centre for Research in Women’s Health |

Dear

My name is Esther Ignagni and I am a graduate student in the Department of Public Health Sciences at the University of Toronto. I am conducting a study under the supervision of Dr. Heather Maclean. I would like to invite you to take part in a study designed to learn about children’s and youths’ experiences of living in the community with a disability or chronic health condition.

You have experience working with children and youth with disabilities and we are interested in hearing about your insights. I am speaking to individuals with similar experiences as yourself to learn more about the integration and participation of children and youth with disabilities in their communities. I am particularly interested in what you think are important influences in children’s and youth’s access to formal and informal support. I am also interested in your thoughts as to how issues relevant to children’s and youth’s lives are reflected in the policy process. I will also be speaking to young people with disabilities about these issues.

In order to carry out my research, I would like to interview you for approximately 30 to 45 minutes; and I can conduct this interview at a time and place of your convenience. If you participate in the study you will be given an identification number that will be used throughout the study. Although, the interviews will be audio-taped so that I can accurately record what you say, your name will not be used on the tape. These tapes will be kept in a secure location, accessible to only myself and members of my thesis committee. These tapes will be kept for six years, at which point they will be destroyed.

Because this is a qualitative study, select quotations of our interviews might be used in reports. However, your name will not be used in any report from this study. Information that would link quotations with you will be removed – for example, the name or description of your organization or group will not be used in connection with quotations.

You have the right to refuse to answer any particular question throughout the interview and to stop
the interview at any time.

Participating in this study is not risky to you; however, participating in this study will likely not be of any direct benefit to you.

If you have questions or concerns about the study, please feel free to call me at 351-3800 ext. 2762. You may also email me at esther.ignagni@utoronto.ca.

I have read and understand all of the information given above. All of my questions have been answered. I agree to participate in this research project entitled "Negotiating Community Care and Participation".

Name: ________________________________________

Date: _________________________________________

Witnessed: _____________________________________
APPENDIX E - Gatekeeper Interview Schedule

Gatekeeper/Key Informant Interviews

Can you tell me about your work with disabled children and youth.

What have been important social issues to young people with disabilities? Why are these issues in particular important to young people?

In general terms, how do you think home care policy in Ontario affects children’s opportunities to integrate into their communities (e.g. attend school, participate in recreational programs, take part in family life)? What works well about the policies? What needs improvement? Are there aspects of community life that children are missing because of current home care services?

What, if any, concerns have young people expressed about the home care services they receive? If they haven’t raised concerns, why do you think that is? (e.g. no problems, don’t know how to articulate problems, etc.).

Can you tell me about times that young people with disabilities have been able to express their concerns about the personal support they receive? To whom did they express these concerns? What do you think enabled them to express their concerns? Did they confront any barriers to expressing their concerns?

What other resources do young people use to supplement home care? In your opinion what works well in these other resources? What needs improvement?

Can you tell me about the work young people do to secure home care or alternative means of personal support? What works well about this? What needs improvement?
APPENDIX F - Youth Advocacy Focus Group Form

CONSENT FORM FOR FOCUS GROUP PARTICIPATION

<table>
<thead>
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<td></td>
<td>Canadian Institute for Health Research (K.S. Krogh)</td>
</tr>
<tr>
<td>Supervisor:</td>
<td>Dr. Heather Maclean</td>
</tr>
<tr>
<td></td>
<td>Public Health Sciences, Faculty of Medicine, University of Toronto Director, Centre for Research in Women’s Health</td>
</tr>
</tbody>
</table>

I agree to participate in a focus group about children and youth’s perspectives on obtaining and managing support for taking part in community life. I understand that a “focus group” is a type of group interview. Members of a focus group are asked questions about a specific topic by a researcher. Members of the focus group take turns answering the questions and commenting on other members’ answers. The point of a focus group is to see how people from similar backgrounds talk about specific topics together. As a member of (group name) I will take part in a group discussion led by Esther Ignagni, on three different occasions.

Meeting one: I will participate in a discussion about the following topics: home care, informal support, community integration for children and youth with disabilities. At this meeting Esther Ignagni will describe her research and as a member of the focus group I will share my ideas about how children and youth with disabilities can be involved in this project and what kinds of research might be most interesting and useful to children and youth with disabilities.

Meeting Two: Once the project is underway, Esther Ignagni will show my group what has happened in the project so far. I will share my reaction about the information she presents. I will be asked if I think the project is relevant to children and youth with disabilities and accurately represents some of the issues we deal with in our lives.

Meeting Three: When the media arts workshops are over, Esther Ignagni will present several media products to my group. We will be asked to share our reactions to these presentations. This feedback will be included in the final report.

I understand that our meetings will be audio-taped so that what we say maybe recorded more accurately. I understand that although quotations from the meetings will be used in reports about
this study, my name will not be used in relation to these quotations.

I agree that I will not repeat what other focus group members say in the group to anyone else.

I understand that taking part in this study is voluntary. I can tell Esther Ignagni if I do not want to be in the focus groups anymore.

I understand that tapes from this study will be stored under lock and key for 6 years following the study. At that point, all the materials will be destroyed.

I understand that I will not have any direct benefit or good things happen from being in the study. I may feel awkward or uncomfortable about taking part in group activities. If this happens I may leave the group discussion. This will not affect my membership in (name of group) in any way.

I understand that this study might help other children and youth like me because health care professionals will learn things that will help them care for these children better.

I am signing two copies of this form. I will keep one copy, and the other will be kept by Esther Ignagni.

Participant’s Signature:

Date:

I consent to having my child (name of child) participate in the study described above.

Date:
APPENDIX G - Interview Schedule for Youth Advocacy Focus Groups

Meeting 1 (Summer 2002):

Tell me about your group. What sorts of advocacy issues has your group addressed? Who are the young people you represent?

What do you think are the most important issues affecting the young people you represent? Why are those issues important? How are those issues being addressed by (the government, schools, health care practitioners, etc.)

What do you think community participation/integration means for young people with disabilities? What enables community participation/integration? What are the barriers to community participation/integration?

How well do you think current home care/personal assistance programs support young people with disabilities? What’s good about the current programs? What do you think needs to be changed?

In general terms, how do you think home care policy in Ontario affects children’s opportunities to integrate into their communities (e.g. attend school, participate in recreational programs, take part in family life)? What works well about the policies? What needs improvement? Are there aspects of community life that children are missing because of current home care policies (e.g. as a result of service delivery gaps or structures)?

What, if any, concerns have young people expressed about the home care services they receive? If they haven’t raised concerns, why do you think that is? (e.g. no problems, don’t know how to articulate problems, etc.).

Can you tell me about times that young people with disabilities have been able to express their concerns about the personal support they receive? To whom did they express these concerns? What do you think enabled them to express their concerns? Did they confront any barriers to expressing their concerns?

What other resources do young people use to supplement home care? In your opinion what works well in these other resources? What needs improvement?

Can you tell me about the work young people do to secure home care or alternative means of personal support? What works well about this? What needs improvement?

Is there anything else you think is important for me to know?

Groups will be presented with an overview of the media arts workshops and be asked to provide feedback (e.g. reactions, suggestions for change).

Meeting Two (Late Fall 2002/Early Winter 2003):

Groups will be provided with a project update and preliminary analysis. Groups will be asked to provide feedback and offer suggestions for change.

Meeting Three (Fall 2003):
Groups will be informed as to how suggestions were incorporated into the project. Final media products and an overview of group process will be presented. Feedback and suggestions for change will be solicited.

* Each meeting will last approximately 2 ½ hours.
APPENDIX H - Information Sheet for Parents regarding Media Arts Workshop

Information Sheet for Parent(s) or Guardian(s)

My name is Esther Ignagni and I am a graduate student in the Department of Public Health Sciences at the University of Toronto. I am conducting a study under the supervision of Dr. Heather Maclean. The purpose of this study is to investigate children’s and youths’ perspectives on living in the community with a disability or chronic health condition. More specifically, this study will focus on children’s and youth’s perspectives on how they access, solicit and negotiate formal and informal support in their efforts to participate as full members of their community.

The study will consist of a series of six 1/2 day media arts workshops in which children and youth will create a group media product. Children and youth will be taught media arts and research skills. For example, they may learn how to use a digital camera, how to create a script for a video, or how to analyze research data. Your child may also be taught about home care and youth policies in Ontario. Your child, if s/he chooses to participate in these workshops, will be asked to record “a day in the life of my community”, with photographs, video-tapes or stories. In other sessions young people will be asked to comment on the types of images they obtained. By the end of the five sessions, each group will create a single media “product” (e.g. a short video, a newspaper article, a photo-essay, a play etc.) that reflects what they feel is important to say about home and community support services for children and youth with disabilities. This media product will be integral to the public reporting of this project. This means that the final “group media product” will be shown publicly (e.g. to policymakers, other young people with disabilities, community groups, in further research, etc.).

Because I would like the research process to be as participatory as possible, it is impossible for me to fully inform your family at this time as to what issues will be raised and addressed in the workshops. However, together with workshop participants, I will provide brief ongoing reports of each session, so that your family will remain informed about the process. Once the workshop series is over, I will meet with your child individually to see how s/he felt about participating in the workshops, what s/he thought was good and bad about the workshops and to see if there is anything else s/he would like me to know.

I would like to invite your child to participate in this study. His/her experience living with a disability means s/he will have a lot of valuable insight to offer the research project. This would involve your child’s attendance at these workshops. These workshops will take place at the same time as (recreation program) so this means that s/he will not be attending the usual program. I will speak to you before your child attends the first workshop session to find out what sort of special support they need. Each workshop will have six or seven other participants. There will be four members of the research team, including myself and although all of us have experience working with children with complex care needs, we do need to speak to you and your child about any specialized support s/he may require and make appropriate arrangements. In general, we cannot provide personal assistance for your child, therefore people who usually provide that for your child must be available.

Everything your child contributes to the workshops will be kept confidential, except in those circumstances in which the law requires otherwise, such as suspected child abuse. Your child’s name or any other information that would identify him or her will not appear attached to information your child provided. Identifying information and field notes will be kept in separate locked locations. Only myself and my supervisors will have access to this information. When the
study has been completed, all identifying information about your child will be destroyed. However, I will keep my field notes, computer disks, audio-tapes, videotapes, film and final group projects, which will not contain any identifying information about your child for six years.

You and your child are free to stop participating in the project at any time, either temporarily or permanently. You are also free to withdraw from the study at any point and ask me not to include any information about your child in my study. Asking me to stop will not affect your service from (the study site) or (recruitment site).

There is a risk that your child may become distressed or uncomfortable about participating in the workshops. If this occurs, we provide alternative activities or modify the activity they are engaged in at the time. If your child has difficulty communicating, I will ask you about what I should look for to figure out if he or she is unhappy about my presence. If I think he or she does not want to take part in the project any longer, I will provide your child with alternative activities and let you know. Then you and your child can decide together whether you both would like the study to continue.

Your child will be able to review any photographs/videos taken in your home. If he or she is uncomfortable with any of these images, you and your child may remove them.

There will be two options for how your child can do this. Your child may return the camera to me once s/he has taken the photographs. I will develop the film and return the package to your child unopened. They can take the photos away to view on their own and remove any they don’t want anyone else to see. Another option is that you and your child develop them on your own and I will reimburse you.

Although your child may learn some new skills and meet peers, participation in the study may not be of direct benefit to your child or yourself. However, your child’s participation may help others like him or her because learning about his or her experience will help health professionals provide better care and support.

If you have any further questions or concerns, I will be pleased to answer them. You can reach me at home at 416-425-7854 or at my office at 416-351-3800 ext. 2762. If you and your child wish to participate in the workshops, I will ask you to sign a consent form.

Esther Ignagni
APPENDIX I - Consent Form for Media Arts Workshop

Consent Form for Parent(s) and Guardian(s)

Title of Research: Negotiating Community Care and Participation: A Participatory Policy Review of Home and Community Care with Young People Living With Disabilities and Chronic Illnesses.

Investigator: Esther Ignagni, M.Sc., Ph.D. (candidate)

Telephone: (416) 351-3800 ext. 2762

Funding Source: Hospital for Sick Children Foundation (E. Ignagni) Canadian Institute for Health Research (K.S. Krogh)

Supervisor: Dr. Heather Maclean Public Health Sciences, Faculty of Medicine, University of Toronto Director, Centre for Research in Women’s Health

I have been asked to give consent for my child to participate in a study exploring the perspectives of children and youth with disabilities on living in their communities and how they obtain and manage home care support. It has been explained to me that participation in the study involves the following:

My child will attend a series of six ½ day media arts workshops. As part of these workshops my child will be asked to photograph “a typical day”. My child will be asked to comment on the photographs she or he has taken, eventually creating a story about a day in their lives. My child will be asked to reflect on how her or his story, and the stories of other workshop participants relate to home care policy in Ontario. Together with other participants from the workshop, my child will be part of creating a “media-based report” about living in their communities with a disability and about the support children and youth receive from home care services. This final media-based report will be shown publicly (e.g. to policymakers, in other research, to community groups, etc.).

During the time of the workshops either myself or my child can ask to no longer participate either temporarily or permanently, or withdraw from the study at any time.

I understand that both my child and I may review the photographs and videos my child takes. We may ask to have specific photographs or video segments removed from the study.

Any decision regarding my child’s participation in the study will in no way affect the services my child is currently receiving through (name of site).

Everything Esther Ignagni observes or is told will be kept confidential, except when otherwise
required by law, such as in suspected child abuse. This means that at no time will any names with personal identifying information of my child or anyone else my child is in contact with be used in any reports that may be written about this study. For example, quotations from discussions with my child may be used in reports, but my child’s name and identifying information will be removed from them.

Tapes, photographs and films from this study will be stored under lock and key for 6 years following the study. At that point, all the materials will be destroyed.

I understand that there is a risk that my child may feel uncomfortable or distressed by group interactions or the information discussed in workshops. I will advise Esther Ignagni about how to assess this with my child and will provide alternative activities for my child if this occurs.

I understand that my child may not directly benefit from the study. However, the information may be useful in helping other children and families in similar circumstances.

The days and times of the workshops will be as follows (TBA)

I am signing two copies of this consent form. One will be kept by myself and the other will be kept by Esther Ignagni in a secure location.

I hereby consent to having my child Participate in the study describe above.

Signature
Date
APPENDIX J - Information and Assent Form for Media Arts Workshop

Assent Form for Media Arts Workshop Participants Under 16 years

I agree to participate in a study about getting and managing support for taking part in community life. I will take part in a media arts program in which I will do as many activities as I choose. This may include collecting information, listening to each group members’ stories and looking at their photographs and videos, looking for important and common themes in these stories and creating a final media report with my fellow group members. (Details of workshop to be included).

I understand that some of the things I say and do in the workshops may be used in reports about this study, but my name or a description of me will not be used in any reports of this study.

I understand that I will not repeat other group members’ stories or things they say with anyone outside the group. I will not describe their pictures or videos to other people.

I understand that I will have a chance to review my photographs and videos before anyone else in the workshops sees them. I can ask that any of my photograph or video segments be destroyed or not used in the workshops. I can share any problem or concerns I have about the group video with other participants in the workshop. We will work as a group to resolve any problems or differences in opinion. I understand that taking part in this study is voluntary. I can tell Esther Ignagni if I do not want to be in the workshops anymore.

I understand that tapes, photographs and films from this study will be stored under lock and key for 6 years following the study. At that point, all the materials will be destroyed.

I understand that I will not have any direct benefit or good things happen from being in the study. I may feel awkward or uncomfortable about taking part in group activities. If this happens Esther Ignagni will find other activities for me to do.

I understand that this study might help other children and youth like me because health care professionals will learn things that will help them care for these children better.

I am signing two copies of this form. I will keep one copy, and the other will be kept by Esther Ignagni.

Participant’s Signature:

Date:

I consent to having my child (name of child) participate in the study described above.

Parent’s or Guardian’s Signature:

Date:
### Title of Research:

**Negotiating Community Care and Participation: A Participatory Policy Review of Home and Community Care with Young People Living With Disabilities and Chronic Illnesses.**

### Investigator:

Esther Ignagni, M.Sc., Ph.D. (candidate)

### Telephone:

(416) 351-3800 ext. 2762

### Funding Source

- Hospital for Sick Children Foundation (E. Ignagni)
- Canadian Institute for Health Research (K.S. Krogh)

### Supervisor:

Dr. Heather Maclean
Public Health Sciences, Faculty of Medicine, University of Toronto
Director, Centre for Research in Women’s Health

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I have been asked to give my consent to participate in a study exploring the perspectives of children and youth with disabilities on living in their communities and how they obtain and manage home care support. It has been explained to me that participation in the study involves the following:

I will attend a series of six ½ day media arts workshops. As part of these workshops I will be asked to photograph “a typical day”. I will be asked to comment on the photographs I have taken, eventually creating a story about a day in my life. I will be asked to reflect on how my story and the stories of other workshop participants relate to home care policy in Ontario. Together with other participants from the workshop, I will be part of creating a “media-based report” about living in our communities with a disability and about the support children and youth receive from home care services. This final media-based report will be shown publicly (e.g. to policymakers, in other research, to community groups, etc.)

During the time of the workshops, I can ask to no longer participate either temporarily or permanently, or withdraw from the study at any time. Any decision regarding my participation in the study will in no way affect the services I am currently receiving through (name of site).

I understand that I may review my photographs and videos. I may ask to have specific photographs or video segments removed from the study. I can share any problem or concerns I have about the group video with other participants in the workshop. We will work as a group to resolve any problems or differences in opinion.

Although quotations from things I say in the workshops and my pictures may be used in reports
written about this study, at no time will any names, my description with my personal identifying information or anyone else I am in contact be used. Tapes, photographs and film used in this study will be kept under lock and key for six years. At that point they will be destroyed.

I agree that I will not repeat what other workshop members say and do in the group to anyone else.

I understand that there is a risk that I may feel uncomfortable or distressed by group interactions or the information discussed in workshops.

I understand that I may not directly benefit from the study. However, the information may be useful in helping other children and families in similar circumstances.

The days and times of the workshops will be as follows:

(TBA)

I am signing two copies of this consent form. One will be kept by myself, and the other will be kept by Esther Ignagni in a secure location.

I hereby consent to participate in the study described above.

Signature:

Date:
APPENDIX L – Media Arts Workshop Schedule

Media Arts Workshop Overview

**Session 1:**
Introductions of ourselves. Acknowledging and respecting differences.
Consensus building and collective decision-making.
Overview of privacy and power issues when taking photographs or videotaping other people.
Introduction to using cameras.
Informing others how to take photographs.
Distribution of cameras

**Session 2:**
Report back on weeks activities.
Introduction to digital video techniques.
Perspective in photography and videography
Thinking about participation and home care.

**Session 3:**
Creating a photoessay: A day in my life….
Reflections on one another’s stories/photoessays.

**Session 4**
Story analysis – identification of major themes in photoessays.
Introduction to story-boarding.

**Session 5:**
Story-boarding and scripting writing.
Envisioning a final product.

**Session 6:**
Mounting the media product.

**Follow-up Interview (at a time convenient to individual participants).**
What did you think about the workshops? What did you like? Was there anything you would change?
Do you think the final (script, video) we produced reflects your experience? Can you tell how it does (or does not)?
Is there anything else you would like to tell me about young people with disabilities and community integration?
Is there anything else you like to tell me about the support you have and need in carrying out your day to day activities?

**Note:**
Sessions 2 to 6 will begin with an ‘unfinished business’ section, so that may share any concerns or further insights that have arisen from the previous week’s session. As well, once the piloting session is complete, workshops will ‘pick up’ on what previous workshops have already produced. It is also possible for workshop participants to participate in more than one workshop session in order to refine their skills and to continue working on their project.