

**NARRATING RESISTANCE:
A B.C. MOTHER'S STORY OF DISABILITY RIGHTS
ACTIVISM**

by

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ABSTRACT

Though mothers have engaged in social activism to expand the citizenship rights of people with intellectual disabilities for the last 50 years, research in disability studies has been slow to examine what can be learned from their experience. Using a life story approach, this thesis explores how one activist mother, Jo Dickey, describes raising a son with intellectual disabilities and advocating for the social inclusion of people with disabilities and their families between 1955 and the present. Informed by ethnographic theories of performativity and intersubjectivity, I show how Jo performs resistance by recounting how she contested ideologies and systemic practices through everyday acts and collective action in the past and by simultaneously speaking to discourses and audiences in the present. Her storytelling challenges the limits imposed on people deemed to have intellectual disabilities, foregrounds her negotiations of disability and gender politics, and creates discursive space for an activist mother's perspective.

Keywords: life story; narrative ethnography; activist mothers; resistance; intellectual disabilities; community living; motherhood; family studies

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In memory of my brother, Alex

1947-1985

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PROLOGUE

I follow the detailed directions I've scribbled from Jo about how to get to her West Vancouver condo. I find the "island" in the road, the winding drive, take a right, then a left, and pull in at the front of a long modern building nestled high on the mountain slopes, with three storeys of balconied units overlooking English Bay. She buzzes me in and I take the elevator to the second floor, emerging onto a lobby with a panoramic southern view of the city of Vancouver, Georgia Strait, Vancouver Island, the San Juan Islands, and Mount Baker hovering faintly in the distance. After pausing to take it in, I head down an outdoor hall at the back of the building, sheltered by Ponderosa pines, to number 213. When I approach the apartment's alcove, I'm startled to find the door open and Jo's figure standing there in the shadows, quietly waiting. Despite her small, light-boned frame, she is stately and dignified, with a shock of white shoulder-length hair, black penciled eyebrows and deep brown eyes. She wears an outfit of sweater, pants and boots that are entirely black.

She gives me a warm greeting and we head down a hall to enter an immaculate living room with light beige carpeting, elegant antique furniture and a chandelier hanging above a formal dining table. She shows me the stunning view from a generous patio off the living room and says, "Oh, wait till you see the view from upstairs!" It is in the second floor loft, the den she calls her lair, where we settle into the comfortable armchairs and couch, surrounded by family photographs, magazines, books and a desk piled with papers, and we embark on the narrative journey we will share over several

months to come. Later, the journey takes us north to Jo's lakeside family cottage in the Cariboo, where conversations and memories weave through swims, walks, meals and tea on the porch, or morning coffee around a woodstove, as the ever-shifting colours of lake and sky flicker in the background.

In her book of short stories, *Birds of America: Stories*, Lorrie Moore comments on the limitations and "tidying up" function of narrative:

The trip and the story of the trip are always two different things.... One cannot go to a place and speak of it; one cannot both see and say, not really. One can go, and upon returning make a lot of hand motions and indications with the arms. The mouth itself, working at the speed of light, at the eye's instructions, is necessarily stuck still... All that unsayable life! That's where the narrator comes in. The narrator comes with her kisses and mimicry and tidying up (Moore 1998, p. 237).

This observation is as true of the research process as it is of the stories that are the subject of research. Within such limitations then, this thesis tells a story of some of the paths followed on a narrative journey with Jo Dickey through memories of mothering and disability activism.

CHAPTER 1: INTRODUCTION

Under the radar – mothers’ disability activism

In the last half of the 20th century, North America has seen a period of significant change in social attitudes and policies towards people with disabilities. Many of these changes came about during the 1970s and 1980s as a result of the activism of disabled people themselves who redefined and laid claim to citizenship within a human rights framework. However, for people with intellectual disabilities, who had been dehumanized by eugenics discourse and socially excluded by segregationist policies of institutionalization, the shift in attitudes began mid-century with the activism of parents – mainly mothers – who envisioned a different life for their children, one that emphasized capabilities, citizenship rights, and acceptance and participation in communities. During the 1950s and 1960s, these mothers became the founders of an activist social movement now referred to in Canada as the “community living movement.” They were joined in the 1970s by a “self advocacy movement” of people who had been labeled with intellectual disabilities, advocating on their own behalf.

This thesis explores the life story of one activist mother, Jo Dickey, who raised a son with intellectual disabilities (Drew) born in 1955, and participated over the next five decades in a variety of actions and campaigns to expand the rights and social inclusion of people with disabilities and their families. While parent activism is widely recognized as a founding and sustaining principle within the grass-roots community living movement in Canada, it has garnered relatively little attention in academic literature until recently (see

Panitch 2008, Ryan & Runswick-Cole 2008, Schwartzberg 2005, Jones 2004, Castles 2004).

Disability studies and mothers

When the interdisciplinary field of disability studies emerged in the early 1980s alongside disability activism, its emphasis was on challenging the medicalized understanding of disability and articulating an analysis of disability as a social construction that oppressed a wide range of people who failed to satisfy a normative ideal of personhood (Burch & Sutherland 2006). The “social model of disability” uncoupled individual characteristics (impairments) from their social labels and cultural interpretations (disability) and effectively turned the gaze from individuals diagnosed as “defective” and in need of “fixing” back onto social and cultural systems that produced disability as a category and excluded people within the category from participation in society (see Shakespeare 2006, Oliver 1996). Further, it suggested possibilities for addressing exclusion and dehumanization through social activism and reform rather than individual rehabilitation. Disability activism and research focused on collective “disability” experience, building solidarity and pride among people with the label, and critiquing the processes and authorities that created barriers to social and economic participation. But with the attention on empowering people with disabilities, disability discourse overlooked or actively dismissed the activism of non-disabled parents that had preceded it by two decades (Ryan & Runswick-Cole 2008, Shakespeare 2006). In addition, as Kittay (2001) has argued, disability activism focused on achieving the inclusion of people with physical disabilities and neglected the interests of those with intellectual disabilities.

Despite embracing the initial emancipatory potential offered by the social model of disability, disability scholars and activists have challenged the model's universalizing tendencies and its emphasis on collective experience and identity. Critiques from a variety of disciplines – notably feminist, queer, antiracist and cultural studies, as well as philosophy, anthropology, and history (Dossa 2005, Watson 2003, Clare 2001, Kittay 2001, Wendell 1997) – argue that by focusing on social structures and processes, the social model has neglected or downplayed the importance of individual agency and the diversity of embodied experiences of people living with impairments, thereby producing a new form of disability oppression:

The social construction imposes its own set of meanings on Disability that affect the lived experience of the Disabled; it is also a limited and prejudiced understanding of what a Disabled life can or cannot be, one that must be challenged and broadened by the lived experience (Burch & Sutherland 2006, p. 129).

Strowger argues that the social model, while unsettling fixed biomedical views of “disability,” can also entrench an understanding of “barriers as things that make one either ‘able’ or ‘unable’ to keep up with life” and a definition of disability that has come to mean “a body that cannot survive its culture – a person that is an icon of what *not* to be” (Strowger 2008, p. 1).

These critiques inspired a variety of new approaches to disability studies, including ethnographic and life story research (see Dossa 2005, Angrosino 1998, Zola 1982), which have not only deepened the critique of disabling systems but have also shed light on the embodied experience of “disability” from various subject positions. Linking the personal and the political, they address not only systemic effects upon individuals but the ways that individuals negotiate, deploy, resist and influence systemic processes from

a variety of social locations. Indeed, Gabel & Peters (2004) suggest that the concept of “resistance” operates as a common thread connecting the many facets that now make up the diverse theoretical matrix of “social models of disability.” Further, French & Swain (2006) emphasize the value of life stories that contribute to ongoing resistance and a politics of hope. I return to this idea of resistance in my framing of Jo Dickey’s story of activism.

Though these critical approaches opened up new perspectives on disability from the point of view of those living with impairments, the experience of family members, and particularly mothers, as early activists for rights and social inclusion has remained relatively unexplored (Ryan & Runswick-Cole 2008). In *Disability Rights and Wrongs* (2006), Shakespeare argues that disability activists have viewed non-disabled parents (and the nuclear family) as obstacles to self-determination and autonomy rather than as potential allies. I suggest that this distancing has also relegated historical and anthropological research into family experience to the margins of disability studies. Furthermore, scholarly literature that does address parent activism prior to the 1980s tends to regard it as tainted by conservative ideals of family domesticity that prevailed during the postwar years and by parental motives to avoid the stigma of disability by redefining the parameters of “normality” (Jones 2004, Castles 2004). Only recently have scholars such as Schwartzberg (2005) and Panitch (2008) begun to research family stories (and, in the case of Schwartzberg, family photographs and memorabilia) to shed light on the diverse experiences and circumstances that give rise to parent activism.

Feminist studies and mothers

Feminist theories, meanwhile, have challenged the social construction of gender that designates mothers as the “natural” providers of unpaid care and have attempted to redistribute caregiving responsibilities either within the family or within society. Until recently, there has been minimal research interest in mothers who perform what appears to be a traditional caregiving role for their children with disabilities (but see Panitch 2008, Castles 2004, Jones 2004, Rapp & Ginsburg 2001, Landsman 1999, Traustadottir 1995, O’Connor 1995). However, both feminist and critical disability approaches tend to oversimplify the complexity of caregiving and parental relationships, particularly where intellectual disabilities are involved. As Jones (2004) suggests, intellectual disability “has always been more than an issue for the experts or a problem for the individual. It has also posed a unique dilemma for the families of children diagnosed with developmental disabilities” (p. 323). Scholars who are also parents of children with intellectual disabilities have productively explored this “dilemma” through their own experience. Ryan & Runswick-Cole (2008) describe their liminal role as parents and researchers this way: “we are neither disabled nor non-disabled” (p. 199), and argue for greater scholarly attention to the activist role of parents. Kittay (2001) draws on her parenting role to examine the ideological roots of our understanding of personhood and points to the failure of disability activism and discourse to address the status and rights of people with intellectual disabilities (such as her daughter) who require extensive lifelong care.

Rapp and Ginsburg (2001) suggest that when families have a child with disabilities, they must revise their kinship narrative and practice to accommodate the notion of difference that such a child brings to the family’s identity. This reconfiguring

involves extending the boundaries of the nuclear family to a broader support network and incorporating an understanding of interdependence into their daily survival strategies and efforts to provide quality care. The authors argue that narratives from such families are critical for re-imagining kinship, integrating disability into everyday life and expanding inclusion and notions of citizenship. I suggest that activist mothers have been engaged in this re-imagining since they first began to contest segregation and exclusion in the mid-20th century. Anthropological research into their complex negotiations of traditional female roles, mothering, securing care, and public activism have the potential to offer valuable knowledge to the fields of disability, family and feminist studies.

Research purpose and questions

Rooted in these suggestive openings in disability discourse, the purpose of my research was to explore a mother's account of activism for the human rights and social inclusion of people with intellectual disabilities during the last half of the 20th century. This would focus attention on four areas of interest to disability studies that were under-represented in my review of the literature: 1) foregrounding the participation of mothers in Canadian disability activism in the mid-20th century and beyond, 2) exploring a mother's lived experience of "disabling" social processes and power dynamics in British Columbia, 3) describing a mother's interventions in those social processes through resistance and activism, and 4) examining how storytelling could extend activism and contribute to contemporary knowledge and disability politics.

Using a collaborative approach to narrative ethnography, I sought to investigate how Jo Dickey represented her life as an activist mother, how she experienced constructions of intellectual disability and how she intervened in social processes to

assert her son's and others' humanity and rights. Three broad questions guided my research:

1. How does Jo describe the experience of raising her son with intellectual disabilities in the Vancouver area from 1955 onward?
2. How does she describe negotiating care, support and social inclusion for Drew within and outside the family?
3. How does she describe and explain her engagement in disability activism?

An additional question focused on how a life story emerges through a performative, intersubjective process and operates as a discursive form of social action:

4. How does Jo's "performance" of her life story constitute social action?

Definitions

Intellectual disability

Throughout this thesis I use the term "intellectual disability" to refer to a wide range of cognitive "differences" that have been categorized as deviating significantly from the "average" intellectual capacity of human beings. While medical and educational professionals have debated a variety of wordings, diagnostic criteria, and assessment methods for defining "intellectual disability" (see Scheerenberger 1987), I rely on a slightly modified version of a "plain language" definition adopted by the BC Association for Community Living that understands intellectual disability as:

a cognitive impairment of developmental origin that results in a person having difficulty or limitations in understanding concepts, communicating, or managing daily tasks of living, or taking longer than most people to learn or to carry out tasks (BCACL 2006).

Despite the apparently unifying implications of the label, impairments falling within the domain of intellectual disability vary widely in type, severity and impact on daily life, and they have widely divergent functional and social consequences depending on their context. Having an intellectual disability does not exclude a person from being able to learn, from having social relationships, or from having active preferences, interests, abilities and talents. Other terms currently used in the English-speaking Western world to refer to this constellation of impairments include developmental disabilities (Canada), learning disabilities or learning difficulties (U.K.), mental retardation (U.S.) and mental handicap. Historical terms for the category (e.g., feeble-minded, mentally unfit, idiot, imbecile, moron, mental defective) have generally been discarded in contemporary discourse due to their pejorative connotations.

Defining any “disability” necessarily invokes a large body of critical literature that has challenged biomedical definitions of disability in favour of an understanding of disability as socially constructed. Even from the working definition above, it is apparent that “intellectual disability” has meaning only as a relative term that marks people as different from an average or norm, thereby producing and reinforcing both “difference” and “normality” as apparently stable social categories (see Davis 2006, Trent 1994). In addition to deconstructing the biomedical model of disability, historians have traced the emergence of disability categories (alongside other categories of social “difference”) to broad social and economic changes that accompanied the development of Enlightenment philosophy and industrial capitalism (Stainton 2004, 2001, Noll & Trent 2004, Stiker 1999, Trent 1994). Critiques of what has come to be called the “social model of disability” have taken issue with its universalizing focus on collective identity and

disabling social processes at the expense of examining embodied experience, individual agency and diverse perspectives. Further, some disability studies scholars have debated the value of utilizing, and thereby reproducing, “disability” as a collective identity category at all, even for emancipatory goals (Strowger 2008, Shakespeare 2007, Watson 2003, Wendell 1997). For example, many activists with intellectual disabilities (e.g. People First of Canada) have rejected terms that emphasize *disability*, in favour of terms like “self advocate” that affirm abilities and agency. Strowger (2008) suggests that the dilemma of categories and labels may be unresolvable, as indeed is the case for various collectivities opposing oppression (women, racialized groups, etc.). Strowger suggests a provisional use of disability categories that recognizes their inherent contradictions as both enabling resistance and reinscribing hegemony: “In rethinking disability as something livable – and even desirable – disability must conditionally inhabit its oppressive stereotypes” (p. 4).

As a mother who resisted categorizing her son, Drew, yet became an activist for the inclusion and rights of “people with intellectual disabilities,” Jo Dickey echoes the same concern about categorizing. Commenting on the challenge of resisting labels to focus on abilities and personhood while also advocating for human rights and access to supports, she adopts a cautious but pragmatic flexibility:

For Drew and other people like him, they never knew how much he understood. Back then, they fell between the cracks. Now it’s wrapped up as a package. Naming it gave people some money – at least they had a label. But I’m still not sold on labels. With a label, it’s “This is what you get.” But that soon turns into “This is what you are.” Labels are not true. Well, it’s not that what a label represents isn’t true, but it puts you into a slot and there you stay for life. People would deny other attributes. They wanted to ignore people because they were “crazy” or an “imbecile.” The *label* got the attention instead of getting the *Drew* going.

Jo also articulates here the tensions between acknowledging specific impairments while at the same time addressing socially “disabling” processes and resisting the perception of disability as an individual, private “problem” requiring an individual “therapeutic” solution.

In this thesis, therefore, I use the term “people with intellectual disabilities” provisionally as a way to refer to a group of people who have historically been categorized based on a particular set of characteristics and whose placement in that category is likely to have resulted (though not always) in some form of stigma, social exclusion or oppression.

Citizenship

Throughout this thesis, there are references to activism that sought to affirm and establish the *citizenship rights* of people with intellectual disabilities. While the concept of citizenship is embedded in much of disability studies literature, I began by grounding my understanding of it in the multiple aspects of citizenship that Jo articulated in relation to her son and other people with intellectual disabilities. These included, most fundamentally, being considered a human being entitled to basic human freedoms of life and liberty, in the context of eugenics discourse which had designated people with intellectual disabilities as a manifestation of evolutionary regression and therefore not fully human. She also addressed access for people with intellectual impairments to public services available to other citizens (such as health care, education, social services), participation in the social and economic life of the community, having opportunities to speak out and participate in political life, choosing where and with whom to live, being free from discrimination and harm, being able to engage in relationships (including

sexual), access to employment, and equal access and entitlement to the rights and protections available to others under the law.

These aspects correspond to some degree with Oliver's (1996) more formal articulation of citizenship as it pertains to disability politics, with the exception that Oliver foregrounds access to employment (and the enforced poverty that results from its absence) as an important aspect of citizenship for people with disabilities. As Oliver suggests, citizenship is an evolving and complex concept that serves as a "shorthand device to consider the relationship between individuals and society" (p. 49). He identifies three dimensions of citizen rights that have characterized that relationship in the last century – political, social and civil. Political rights manifest in the right to vote (enfranchisement) and participate in the political domain. Social rights emerged in the post-World War II welfare state and include "the right not to be poor or live in fear of poverty, to use social facilities in the same way as everyone else and to have a standard of living or lifestyle compatible with current social expectations" (p. 47). Civil rights incorporate the concept of legal rights (property and contract rights) but also include freedom of speech and thought, religion, assembly and association (p. 48). Oliver argues that despite Western states' claims of having achieved universal rights in the 20th century, "citizenship" defines precisely what has been denied to people with disabilities, as well as to many other oppressed groups.

Bach & Rioux (1996) argue that while the postwar welfare state offered social "security" to those who were accepted as being within a morally and socially constructed category of "worthy" poor (including the disabled), the form of security offered to people

with intellectual disabilities was conditional upon their designation as incompetent and the denial of their citizenship rights:

These systems segregated them from their families, educational institutions, labour markets, political participation, from the exercise of rights of self-determination and from their communities. The monuments to the “disabled but worthy” poor are the institutions, special schools, vocational workshops and segregated classrooms. The costs of being “worthy poor” have been high for people with disabilities (extremely high rates of unemployment, violence and abuse, illiteracy, poverty, illness, social isolation and discrimination) (p. 318).

In addition to addressing the rights of people with intellectual impairments in her understanding of citizenship, Jo also articulated the importance of public support for families and others who are raising or providing care to those with impairments. She understood this as a collective responsibility that flows from the recognition of disabled people as citizens, entitled to a reasonable quality of life and care.

Kittay (2001) takes up this issue in a discussion of the limitations of liberalism’s configuration of justice and citizenship for people with intellectual disabilities and their caregivers. She points out that the concept of “personhood” in Western philosophical tradition is inextricably wedded to the notion of a rationally competent, self-sufficient and productive individual. It is from this state of personhood that citizenship rights and entitlement to justice flow. Kittay argues that when people do not meet these criteria of citizenship, they are deemed ineligible for justice and are defined as existing outside the parameters of full humanity. So while intellectually disabled people deemed “worthy poor” may have access to the support of the state, as Bach & Rioux have suggested, this support is not offered within a broad framework of enshrined rights or justice, but rather, within a “charity” framework that calls for the forfeiture of rights and relegation to a non-

citizen class. Kittay takes disability activists to task for failing to challenge this liberal construction of personhood, failing to deconstruct the Western myth of independence, and opting instead to inscribe disabled people within the existing terms of citizenship. By reconfiguring people with disabilities as competent, employable, productive and self-sufficient individuals, disability activism has excluded people with intellectual disabilities, especially those who require substantial ongoing care or who cannot work, from disability discourse about citizenship and justice.

Further, she argues that the liberal construction of independent citizens masks the ways that all human being are interdependent and stigmatizes those forms of dependence that are most visible. As a parent and advocate for a daughter with intellectual disabilities, Kittay suggests that “the advocate for the severely retarded person needs to look beyond liberalism, while still respecting the values of autonomy and liberty propounded by liberal theory” (Kittay 2001, p. 562). She argues for a broader conceptualization of citizenship based on understanding the relational aspects of personhood, the necessity of interdependence, and the importance of valuing quality caregiving – both for the giver and for the receiver of care.

In our meetings and interviews, Jo articulated an understanding of citizenship as the portal to achieving substantive rights, and the importance of constructing citizenship in such a way that it included both her son and his relationships with others, without negating his difference or his need for support:

Fairness, that for me is the basic thing. We have things that protect us [Jo’s emphasis] so that we have a fair kick at the can, but people with disabilities – in the name of “support,” they have taken justice away. You don’t understand – this is a human being with rights. That’s why we fought for the Charter. It was that whole theme of justice for people like

my son who had been labeled. But also acceptance, and all the other things we want for our friends and family members.

Methodology

Narrative ethnography

I employed narrative ethnography as the methodology for this research, using interviews and participant observation to collaboratively create a life story with a single participant, Jo Dickey. My approach to this methodology was informed by an understanding of narrative as emerging through an intersubjective process in which both the narrator and the researcher are implicated (Chase 2005, Denzin 2001). Stories emerge in the particular context of their telling, influenced by the researcher's responses, questions, and interpretations as well as by the narrator's creative processes of selection, memory and interpretation. Denzin suggests that interviews should be understood as an interpretive practice rather than as a tool for "information gathering." They do not elicit an "objective" mirror image of the external world or reveal a deep internal world, but rather create a way of "writing the world, of bringing the world into play" (p. 25). Chase views storytelling as a retrospective act of making meaning, as verbal action that interprets, explains, intervenes and constructs both the narrator and social reality. And as Jackson (2002) argues, stories enable narrators to affirm a sense of agency by taking interpretive charge and positioning themselves at the centre of their story. Stories provide a way for narrators to transform their "experience of events by symbolically restructuring them" (p. 16).

Jackson also reminds us that stories both draw upon and emerge into an already existing web of discourses, dialogues and relationships. While they are inflected and

even, to some degree, co-authored by these discourses, stories also enable the narrator to challenge and intervene in hegemonic ideology. Drawing on the theories of Benjamin and Bakhtin, Cruikshank (1997) develops this argument to focus on the ways that storytelling works not just to reconstruct the narrator and the narrator's experience, but as a form of social action that can destabilize categories, confront ideology, reinterpret history and provoke dialogue. Thus, storytelling can be viewed as a performative process that does not simply interpret but transforms social experience: stories "are a kind of theatre where we collaborate in reinventing ourselves and authorising notions, both individual and collective, of who we are" (Jackson 2002, p 16).

To assist in my thinking about the research process, I also drew upon Castaneda's (2006) metaphor of ethnographic fieldwork as a form of "invisible theatre." Castaneda likens fieldwork research design to creating a "script" of activities (such as interviews with planned questions, or specific activities) that will engage both the researcher and participants as "actors" in an improvisational process that allows exploration of the research questions. This methodological approach makes explicit the aspects of ethnographic fieldwork that are unpredictable and uncontrollable. Further, it acknowledges the inherently collaborative intersubjective quality of ethnography: while research outcomes are influenced by the researcher's questions, position, perspective and involvement, the research cannot take place without the ongoing engagement and investment of participants who also come to the process with their own motives for participating. Castaneda proposes, therefore, a reconfiguration of ethnographic ethics to foreground the importance of creating a research process that, in and of itself, enables a

valuable – and potentially transformative – social experience for both participants and researcher.

Finally, my research approach is informed by the idea that stories from the local level have the potential to reveal the interrelationships between local and larger social structures and to expose how systemic patterns of exclusion and discrimination affect individual lives. At the same time, stories can operate to unsettle the socially constructed boundaries between private and public or the individual and society, and help us understand how individuals intervene as active agents, redefining both themselves and the systems within which they live (Dossa 2005). In the case of this study, narrative ethnography creates a discursive space for an activist mother to speak about her experience, represent her agency through acts of resistance, and introduce counter-hegemonic perspectives about the social categories of “normal” and “disabled.”

Selection of participant

For this study, I sought a mother who had extensive experience as an activist who could discuss her experience from the perspective of both a parent and an activist. I was familiar with Jo Dickey through my previous employment with the BC Association for Community Living, a provincial umbrella organization that advocates for the inclusion of people with intellectual disabilities and their families. I knew her by reputation as an activist mother who had dedicated much of her life to public advocacy in support of this goal.

I selected Jo as a research participant after conducting a preliminary interview with her in early 2007 that was part of a shorter research project. It was clear from this

interview that she framed her story not merely as personal, but rather as deeply linked to social forces and systems that have positioned people with intellectual disabilities outside the mainstream of society, indeed of humanity. Moreover, her story emphasized the strategies that she and other parents, especially mothers, had employed to resist “disabling” social forces and to intervene in the status quo. While terms like “resistance” and “social justice” were not a part of Jo’s vocabulary, her initial references to activism appeared to be informed by principles associated with these concepts. I suspected that her story would resonate with the experience of other mothers who lived through the same time period and would touch on areas of concern to the broader field of disability studies.

As I became aware of the absence of academic research on activist mothers, I felt even more compelled to select Jo as a participant because of her advancing age and a desire to explore her story while the opportunity was still available. Despite the fact that the activism of Canadian parents of children with intellectual disabilities has had a significant impact on social policy in British Columbia, Canada and even internationally, I was unable to locate academic literature that focused on the Canadian context. As my research drew to a close, Melanie Panitch (2008) made a significant contribution in this area with the publication of *Disability, Mothers, and Organization: Accidental Activists*, a feminist historical examination of the contributions of three mothers – including Jo Dickey – to the development and ongoing work of the Canadian Association for Community Living. My thesis uses narrative ethnography to explore Jo’s activism and examine how her performance of stories operates as a way of extending that activism.

Confidentiality and collaboration

Due to the involvement of only one participant in this research, neither anonymity nor confidentiality were conditions of the ethics approval. However, the formal ethics agreement (see Appendix A) did include a provision for Jo to exclude data that she did not want made public. I saw this as important to the collaborative process. In our initial discussion about informed consent, I also suggested the use of pseudonyms in the final report to protect her confidentiality at least to some degree. (This would have required altering some personal and narrative details.) We proceeded on this basis until well past the active research period, when I learned of the publication of Panitch's (2008) study that named Jo as a subject and included photographs of her. We subsequently agreed to abandon the use of pseudonyms. The names of all individuals other than Jo's immediate family members appear as pseudonyms, except for one political figure whose activities are a matter of public record.

I revisited the topic of consent with Jo on several occasions, knowing that participants may develop a different understanding of consent as the research proceeds. During taped interviews, I sometimes raised the issue simply by seeking verbal permission to use a particular segment, or Jo raised it by indicating "you have to take this part out." After reviewing transcripts and selecting excerpts I wanted to use in my thesis, I gave Jo an opportunity to review them and make deletions or revisions for the purposes of confidentiality. She made only a few requests to remove or reword transcript material.

While I informed Jo in general about my interpretive approach to the material, she did not engage or intervene in that aspect of the work, and my analysis is wholly my own.

In my discussion of the position of researcher and participant below, I return to the issue of collaboration.

My position as researcher

As a researcher I could describe my position as that of an uneasy “halfie,” (see Forsey 2004 and Abu-Lughod 1991), shifting from “insider” to “outsider” in relation to Jo’s activist community, while attempting to hover in the spaces in between. As an “insider” I have a ten-year history of involvement in advocacy for the social inclusion of people with intellectual disabilities and therefore share certain assumptions with Jo. My approach to the research incorporates a bias in favour of citizenship rights for people labeled with intellectual disabilities, a decided preference for community living over institutional living, a critical view of medical models of disability and a belief in the value of activism. My preferred methodological approach to this research, therefore, was collaborative. Further, like Jo, my gender identity is female, and despite our differences in age and personal histories, we share certain perspectives regarding the gendered construction of social life. We also are both “white”¹ and share some similarities in class background. Our overlapping locations and concerns offered definite advantages for creating trust and rapport during the research, as well as some shared interests for engaging in the research. However, in my discussion of limitations later in this chapter, I acknowledge the limitations that these shared perspectives may have embedded in my research.

¹ I use this problematic term here to designate a socially constructed category with historical implications, rather than to suggest an essential biological racial identity.

On the other hand, as someone who is neither a wife nor a mother, nor a family member of a person deemed to have intellectual disabilities, I occupy an “outsider” position in relation to Jo’s experience. She is a generation older than me, and I am a product of “the sixties” in that most of my adult life has been taken up with advocating for the rights of those falling outside of the masculine, “white,” heterosexual, middle-class construct of personhood and citizenship. Due to this background, I was acutely aware, upon taking up work in the community living movement, of its relative homogeneity with regard to typical social categories of gender (female), racial/ethnic background (“white”), class (middle), and family (nuclear and heterosexual) – as well as its single-issue focus and relative isolation from other social movements. There are numerous historical and socioeconomic reasons for the configuration of this activist community, which I briefly touch on later in this thesis, but they are not its main subject or concern. I raise the point to contextualize my initial wariness, upon encountering mothers like Jo, about what I perceived as a somewhat genteel form of activism with middle-class concerns.

Forsey (2004) suggests that ethnographers “committed to a politically engaged, critical anthropology” need to position ourselves in “in-between spaces, where support or otherwise for the various parties one encounters is continually challenged and complicated by the ambiguities and struggles of social life” (p. 66). As my research with Jo progressed, her journey of activism proved more nuanced than it first appeared and called into question my own preconceptions.

Who am I for Jo?

Rothenberg (1999) urges ethnographers not only to be self-reflexive about their position in relation to research subjects, but also to ask “Who are we for them?” and be prepared to adapt our research agenda according to the answers. In working with Jo, the answer to this question emerged gradually. When I approached her to participate in research, I was uncertain whether she would perceive my background with the BC Association for Community Living as favourable or not. Although she had invested many years in the organization in earlier decades, she had since grown critical of it for privileging, in her view, the interests of service providers over those of families. However, a combination of personal rapport and Jo’s perception of our shared perspectives regarding disability politics in general prompted her to agree to participate.

As she described it later:

Well I liked you the first time I met you, first of all. And secondly, I knew that you would understand what we’re trying to say – so, you know, when you talk to people, you don’t have to worry about them understanding what you’re saying, because they’re already there. And you were already there, from the first time I met you – I can’t even remember the first time I met you!

Having given her consent, Jo was by no means a passive participant in research. In our initial discussion, she emphasized repeatedly the importance to her of developing what she called a “family voice” to speak out and influence policy and services across the country:

All I’ve been dreaming of all my life is to have a family voice. We need an advocacy voice in this country, and it has to be independent from service providers. I’ve never parted from families – that’s my main motivator and I believe that’s where the big need is. I look at families and I grieve. We haven’t got a family road. It’s important that we recognize ourselves. I feel very strongly about this – you have to know where I’m coming from. I’m so definite about this and so upset about families not having the support.

As the research progressed, I came to understand different facets of this goal, and some of the ways Jo hoped I might contribute to it. We continue to discuss how to make this research more widely available.

Generating data

Jo's stories emerged through a series of semi-structured audiotaped interviews and open-ended dialogues conducted between February and December of 2007 (see Appendix B for Interview Schedule.) The interviews took place at Jo's condominium in West Vancouver and during a five-day research visit to her family's lakeside cottage near 100 Mile House. At Jo's home I was able to view a wall of family photographs that included images of Drew at different ages with other family members and also to look at family photo albums and various documents Jo referred to. Though I prepared questions for each interview, I often departed from these to pursue topics as they arose. Questions seeking further elaboration often led Jo to steer the dialogue in a new direction. Therefore, in each subsequent interview, I often devoted some time to picking up story threads that had been dropped in previous interviews.

In addition, Jo and I shared many conversations as I accompanied her to the opening ceremony of the Woodlands Memorial Garden, on a visit to her son Drew's former home where his roommates continue to live, on visits into the town of 100 Mile House from her summer cottage, and to the home of her surviving son Rod, Jr., near 100 Mile House. These activities usually involved driving together, sharing a meal or coffee and a chocolate bakery treat (of which Jo is particularly fond), going for walks, or simply "hanging around." During the research period, I also had informal conversations with

other parents of children with intellectual disabilities, and occasional conversations with acquaintances or former coworkers of Jo's. I kept field notes on these activities.

Due to the quantity of interview data, my transcription of interview tapes involved a two-stage process. I listened to all interviews and made notes on their content in a time log, and transcribed sections I considered relevant to the research questions. I then reviewed log notes, transcripts and field notes more closely to identify emerging themes. After further selecting excerpts from the transcripts, I organized them into three main topic areas related chronologically to Jo's life story:

1. Drew's infancy and early childhood
2. Drew's institutionalization
3. Jo's organized activism to close Woodlands and create community alternatives.

I then reviewed the selected transcript excerpts with Jo, explaining my focus on the concept of resistance as an organizing principle and giving her an opportunity to remove or reword material for confidentiality reasons. As Jo's reiterations of stories sometimes created conflicting or confusing inconsistencies, the transcript reviews also provided an opportunity to discuss details and apparent contradictions in the interview data. In some cases conflicting details or contradictory statements remain in the transcribed text. In others, Jo's clarifications resulted in a mutual agreement to amend the contradiction. With Jo's permission, I further edited the transcript material to ease reading and reduce unnecessary repetition.

I did not conduct extensive document research or secondary interviews for the purposes of triangulating or verifying "facts." This choice was based on a methodological

approach that understands storytelling as a performative process and a form of social action, rather than a source of “objective” historical data. I saw Jo’s stories as interpretations of memory that contributed to a narrative of resistance and activism. However, as Jo made no claim to accurately recalling dates, it was difficult to mentally construct even a rough chronology of events as she described them. Therefore, for the purposes of understanding the general chronology and context of Jo’s narrative, I compiled a timeline tracking significant events in Jo’s and Drew’s lives, along with relevant historical events. The timeline is attached as Appendix C and is provided as a rough guide only. Though I consulted other sources (Panitch 2008, BCACL 2008, 2006, Adolph 1996) to clarify dates provided by Jo, the timeline makes no claim to historical reliability.

Limitations of research

Though there are several mothers of Jo’s age range in B.C. whose lives have taken a similar turn to activism, I chose to focus on one participant in order to conduct an in-depth exploration of subjective experience and the narrative process. A perceived limitation of this type of narrative ethnography is that it cannot be generalized, though this may be viewed as a statement of methodological fact rather than a limitation. Indeed, Abu-Lughod (2006) suggests that producing ethnographies of the particular that avoid generalization can be a fruitful strategy for what she calls writing against culture, resisting anthropology’s historical tendency to presume or construct cultural homogeneity.

At the same time, as Jo herself claims, one person’s story is never one person’s story – “I’m not saying it was just me – it wasn’t. It was all these people.” And as

Jackson (2002) argues, “stories are neither the pure creations of autonomous individuals nor the unalloyed expressions of subjective views, but rather a result of ongoing dialogue and redaction within fields of intersubjectivity” (p. 22). While Jo presents her unique interpretation of experience, her story references a variety of discourses as well as the experiences of other families, activist mothers and allies who lived during the same period and experienced similar social conditions. A main feature of those conditions when Drew was born in 1955 was the widespread institutionalization of children and adults with intellectual disabilities. Well entrenched throughout Canada and the United States, it reached a peak in the 1960s (Adolph 1996). But by the 1950s, small groups of parents across the continent had begun to organize and advocate for greater social inclusion and rights (Panitch 2008, Castles 2004, Jones 2004). Jo was, therefore, part of a parental activist phenomenon that began mid-century and spanned several decades and countries. As French & Swain (2006) argue, storytelling from the perspective of individual lived experience, particularly voices “from an excluded past” (p. 395) offers an important form of social intervention. It contributes to a “politics of hope” by articulating experiences of survival and resistance, building a foundation of knowledge for further political action, validating the storyteller’s experience, and highlighting both the diversity and commonality within collective experience.

Nevertheless, narrative research can reflect the limits and biases of its social context. As I mentioned earlier, Jo and I share some common experience and interests that may limit the scope of my analysis in ways that elude me. Further, the subject of my research is an educated, heterosexual woman with professional training, who lived in relative economic comfort – though as a full-time mother of two, she depended for many

years on the income of her working husband. The scope of this research is therefore limited to examining activism as it emerged in her particular social and historical location and through her negotiations of both entitlement and marginalization.

Interpretation of findings – resistance

As I reviewed the research data, the theme that emerged from Jo's narrative was *resistance*. Maddox (1997) views resistance as a response to “transgression of boundaries of the body, the home, or the community by a dominant power” (p. 279). Responses may be well planned out and organized, or improvised on the spot, and may vary in degrees of effectiveness for achieving social change. Jo's accounts of her experience as an activist mother demonstrate a number of ways that she resisted the power of state authorities – though some strategies proved more effective than others. In addition, she describes interventions and actions in her daily life that can be understood as resisting dominant ideologies. And finally, as the discussion of narrative ethnography indicated earlier in this chapter, her storytelling can be viewed as a form of resistance in itself.

In relation to disabilities, Gabel & Peters (2004) offer an approach to resistance that acknowledges the social forces that oppress people with disabilities and illuminates responses to those forces, recognizing that individual agency and social structures are intrinsically linked. As they put it, “resistance functions as a way for people to push against dominance while also attempting to pull society into disabled people's way of seeing” (p. 594-95). Resistance operates as a dialectic process, requiring ongoing engagement by disabled people and their political allies in “critical, de/re/constructive conversations with those who actively or passively participate in disablement” (p. 595). Gabel & Peters view the social model of disability, for example, as a manifestation of

resistance to medical or eugenic theories of disability. They regard situated knowledge from diverse locations within disability studies as resistance to an overarching social model of disability. They argue that this last form of resistance is important to avoid producing a “dominant discourse on disability studies” that silences individuals who do not accept the “party line” but who have valid perspectives and share emancipatory goals for people with disabilities (p. 596). Jo’s stories reflect an understanding of the social construction of disability, they challenge disabling social processes and they offer the situated knowledge of an activist mother’s perspective.

In accounts of her activist experience, Jo focuses on actions she took to resist social attitudes in the community, to dispute agencies that sought to prescribe her behaviour as a mother and to challenge and confront social authorities that defined and confined her son, limiting his opportunities and denying his rights. She recounts successful efforts to organize families and create an alternative to institutions, to assist people with intellectual disabilities to organize, and to lobby the national government for inclusion of people with disabilities in Canada’s Charter of Rights and Freedoms. Further, through the action of storytelling, Jo implicates medical, educational, social service, health and legal authorities, retrospectively holding them to account. She creates resistance to “disabling” discourses and presents counter-narratives that require her audience to consider disability in a new light.

Structure of thesis

In the next three chapters, I address aspects of Jo’s story, arranged chronologically from Drew’s early childhood, to his institutionalization and Jo’s response to state intervention, and finally to Jo’s engagement in organized advocacy. In each of

these chapters I combine story fragments with analysis of issues raised in the stories and discussion of relevant historical and disability studies literature. The concluding chapter discusses findings, methodology, limitations and areas for further research.

CHAPTER 2: EARLY FAMILY LIFE WITH DREW

This chapter presents Jo Dickey's stories of mothering Drew as an infant and young child, and provides contextual background to situate her stories historically and ideologically. The chapter begins with a discussion of Jo as an activist and the conditions that gave rise to her activism. I then provide historical background on eugenics and institutionalization in British Columbia, in order to contextualize the stories that follow about Drew's infancy, Jo's encounters with the medical system and her responses to recommendations to institutionalize him. In the next section, Jo presents images of Drew's childhood that emphasize his learning potential and his value as a family member, while addressing the ways that the family accommodated or responded to his difference. This section also discusses ideological pressures regarding mothering and family roles that would have had an impact on Jo during this period. Finally the chapter ends with Jo's forays into acts of resistance in the social environment beyond her family and her first connection with other parents.

Through her stories about this period, Jo weaves a perspective that subverts dominant social practices that sought to dehumanize and exclude Drew and others with disabilities from society. She resists professional narratives about family pathology and disrupts the marginalization of activist mothers in disability studies by affirming her role as an advocate for her son. In describing her encounters with professionals, Jo validates alternative sources of knowledge and support, and affirms her authority to accept or reject "expert" advice based on her own experience, knowledge and needs. In telling caring and

often humorous stories about Drew, she affirms her role as a “good” but not “typical” mother and constructs Drew as a “different” but nonetheless equal member of the family and community. While she acknowledges the challenges Drew’s particular needs presented both to herself and to other family members, she focuses on ways that Drew’s presence enriched the family’s life. Despite an evidently gendered division of labour in the family and the bulk of responsibility for care falling on her shoulders as a mother, Jo’s accounts locate the challenges she and her son faced outside the family sphere – in disabling social processes that sought to exclude him and judge her as a mother. Finally, in sharing accounts of various forms of social intervention at the local level, she suggests possibilities for resistance and empowerment to parents in a contemporary context.

Favourable conditions for activism

Jo emerged as an activist on the leading edge of a period of widespread activism for human rights throughout North America and Europe during a postwar economic boom that saw the expansion of liberal ideology. The civil rights movement in the United States launched a challenge to segregationist notions of citizenship that entrenched racial inequality, while other activist movements contested limitations to freedom perpetrated by prison and asylum systems. The second wave of feminist activism emerged during the 1960s and 70s, alongside widespread anti-war protests in the U.S., while in Canada, aboriginal rights activists, students and Quebec nationalists were growing more vocal. Though perhaps not directly influenced by these movements, Jo took up activism at a time when the conditions were ripe for contesting hegemonic ideologies and the continent was poised to enter an “age of protest” that would ensue for two decades and establish human rights discourse as a feature of mainstream political and social policy debates.

Jo's anecdotes about her personal background also suggested that the seeds of activism had been sown early in her life. Panitch (2008) cites research by Kasnitz (2001) that identifies individual qualities and life conditions that foster or predispose a person to becoming an activist or leader. Among them are family background, prior involvement in community activity, previous experience of discrimination or exposure to injustice, and a major turning point event. Jo noted that, growing up in a small town in rural Saskatchewan, she had been the more independent of two sisters and had often played a role "more like a son" with her dad. Given that Jo is under five feet tall and slight in build, this suggests an early propensity to reject the notion of being limited by physical attributes or by gender.

Though she was unsure of her direction after high school, Jo recounts that she took the bold step of applying to enter the navy. When she presented herself ("all 98 pounds of me") at their recruitment office, they told her to "go home and grow up and do something with your life." After some clerical training, she then worked as a receptionist in a physiotherapy office, where she "didn't like the work, but got to help out the physiotherapists sometimes" and decided that this profession would suit her. She applied to McGill's physiotherapy program and was accepted, but when she arrived at the university, as she tells it, they took one look at her small frame and told her she couldn't possibly succeed. Her response was, in effect, "watch me" – suggesting an inclination to resist limitations imposed by authorities. Though she recalls they made every effort to get her to quit, she worked hard to prove that "size didn't matter," and sought help from a senior student who provided her with old exams to practice on – also demonstrating a recognition that seeking out others with expertise and experience would help her achieve

her goals. She graduated from the program and found employment in the city she had earlier set her sights on – Vancouver – where she met her future husband Rod. On looking back, she observed that though she didn't experience disability discrimination, she did understand discrimination based on characteristics over which one has no control, including both stature and gender. She recognized, without rancour, that gender roles meant that “back then, men were the head of everything.”

When pressed to explain how she came to her perspective on disability rights, Jo referred to a maternal grandmother who had had a close and long-standing relationship with a First Nations community near her home in Saskatchewan. Jo credited her grandmother with teaching her an attitude of respecting difference. Her later situation of social and economic privilege as the wife of a successful business man may also have enabled her to feel a sense of entitlement that parents living in poverty or less advantageous circumstances might not have readily shared. In addition, Jo's personal blend of focused passion, networking skills and soft-spoken persuasiveness lend themselves well to leadership. As one observer, who had met her only briefly, commented, “My impression is that whether Jo had had a son with disabilities or not, she would have been a leader of some kind. It was just a question of where.”

Turning now to social conditions related to children with disabilities, I examine the historical circumstances and intersecting ideologies that constrained Jo's family situation but also enabled her to intervene in the politics of “disablement.”

Institutions and the legacy of eugenics

When Drew was born in 1955, virtually the only state-supported “service” for parents of a child with intellectual disabilities was institutionalization. At that time, the province of British Columbia operated two large institutions – The Woodlands School, in New Westminster, and Essondale, a psychiatric hospital in Coquitlam (now known as Riverview). Originally opened as the Provincial Asylum for the Insane in 1878, Woodlands gradually took over responsibility for children and adults with intellectual disabilities after Essondale began accommodating psychiatric patients in 1913 (Adolph 1966). By 1954, the institution was known as The Woodlands School (its third name change) and had a resident population of approximately 1,200 children and adults, and a waiting list of 450² (Adolph 1996, p. 90). In 1968, the year Drew was institutionalized, Woodlands still housed over 1,200 residents and continued to sustain pressure to increase its capacity (Adolph 1966). That same year, psychiatrist Dr. Pauline Hughes became the first female physician to take up the position of Medical Superintendent of Woodlands (ibid.). Dr. Hughes would soon become for Jo the figure symbolizing the institution’s total authority over her son.

Inmates of The Woodlands School were deemed uneducable. The *Schools for Mental Defectives Act* of 1953 defined three categories of “mentally defective persons” who could be involuntarily admitted to Woodlands: idiots, imbeciles and morons. Though the three categories were defined by levels of capability, all were considered “incapable... of receiving benefit from instruction in schools” (*SMD Act* 1953, s. 2), and

² A third of these 450 were children under six. The opening of a second large institution in Kamloops in 1959 (Tranquille) did little to reduce the Woodlands population as public demand continued to grow for full-time residential care.

were therefore excluded from public school programs. While according to Adolph the 1950s saw a refocus at Woodlands on training and rehabilitation, this approach could not shed the legacy of a eugenics campaign that had gained widespread support throughout Canada between the 1920s and the 1940s, and in which Woodlands and Essondale were implicated. The eugenics movement warned the educated and productive classes of Canada that an alarming increase in the “mentally unfit” would dilute Canada’s superior Anglo-Saxon genetic stock and create an enormous economic burden the country could ill afford to support (McLaren 1995). In a context of increased immigration and rapidly changing social and economic conditions, eugenicists adopted hereditarian theories to explain a variety of “social ills,” including poverty, crime, prostitution and immorality (Brantlinger 1995, pp. 4-5), and devised solutions that focused on preventing the “unfit” from reproducing. Not only did they advocate segregation in institutions, but by 1933, they had persuaded the B.C. legislature to pass a statute permitting the sterilization of inmates of “any public mental hospital... or any school for mental defectives” (*Sexual Sterilization Act* 1936, s. 2). The legislation remained in effect until 1972. Though sterilizations of people considered mentally unfit were routinely carried out in several other provinces, B.C. and Alberta were the only Canadian provinces to formally legitimize them in law (McLaren 1995).

As McLaren indicates, advocates of eugenics laid considerable responsibility for “progressive” reproduction at the feet of parents. Leading geneticist and eugenics advocate Dr. Madge Macklin argued in 1927 not only that physicians had “an enormous responsibility to defend a child’s right to be born ‘free’ of defect” but also that parents should not have the “‘right’ to have abnormal children” (cited in McLaren 1995, p. 138).

Similarly, the editor of the *Canadian Medical Association Journal* A.G. Nichols wrote in 1930 that “to bring into the world another individual grievously handicapped for the struggle of life, one who may in addition prove a menace to his fellows, is as much to be depreciated as murder” (cited in McLaren 1995, p. 90).

Postwar family ideology

Following World War II and the exposure of eugenics policies under the Nazi regime, the term itself was dropped but eugenics ideas persisted, though in modified form. Castles (2004) asserts that while pre-war advocates of eugenics in the United States saw their mission as defending the white middle class from the degeneracy of “genetically flawed” lower classes, postwar eugenics ideas merged with psychological discourse and new ideologies of the family to reframe intellectual disability as a threat to the psychological health and “normality” of white, middle-class families. A disabled child would place an undue burden on the mother, weaken the marriage, and cause neglect and traumatic stigmatization of other children. As Jones (2004) points out, where pre-war eugenics discourse framed intellectual disability as a public threat to society’s health, postwar ideology reconfigured disability as a private “menace to family harmony” (p. 326), in effect reconfiguring disability from a “social virus” to a “family virus.” In either case, the burden of preserving “normality” fell disproportionately to women.

The postwar ideology of domesticity emphasized family togetherness, distinct gender roles and the happiness and success associated with raising “perfect” children (Jones 2004, p. 324-5). It constructed mothers as the idealized arbiters of the reproductive role of families. As Landsman (1999) points out, even in today’s context the first requirement in performing “ideal motherhood” is to ensure the production of a perfect,

healthy baby. When an infant is born with a “defect” or potential disability, the infant is devalued to a status of “less than a full person,” while parents face an associated stigma.

Landsman traces this pattern to postwar constructions of motherhood:

Since World War II the moral worth of motherhood has been reduced to its association with *valued* children. If indeed a mother’s moral value rests on her association with valued children, the cultural expectation of, and exclusive maternal responsibility for, attaining perfection in fetal outcome links the diminished personhood of the “defective” child with disabilities to an experience of diminished motherhood for the woman who nurtures it. In the United States, mothers of infants with disabilities are not seen as morally equivalent to mothers of normal children (p. 135, author’s emphasis).

As Jones (2004) suggests, for postwar middle-class parents who gave birth to children with intellectual disabilities, the experience was frequently shrouded in guilt, shame, and secrecy (p. 325). Institutionalization of these children offered the solution that would maintain family “normality” and protect families from the pathology that was deemed inevitable if they raised a disabled child at home. Records cited by Adolph (1996) suggest that many parents resorted to this option (whether willingly or not), as the resident population of Woodlands increased in the late 1950s to almost three times the pre-war population.

The option of institutionalization also played a role in relation to the postwar emergence of the welfare state. While the state acknowledged an expanded collective responsibility to provide security for the disadvantaged, people with disabilities and their families found themselves in an odd relationship to it. At a time when disability was predominantly perceived as individual pathology and family threat, institutionalization served as a mechanism for state intervention in population regulation. Parents of children with disabilities were encouraged not only to admit their children to institutions but were

often advised to play a minimal or non-existent role in their subsequent care. The “security” provided by the state, then, was aimed primarily at protecting state and family security rather than that of individuals with disabilities.

With these ideological and historical conditions shaping the context in which her son was born, Jo recounts her story of mothering Drew through infancy and early childhood.

Mother care and medical care

When Drew was born in 1955, Jo and her husband Rod, Sr., were living with their two-year-old son Rod, Jr., in a North Shore community, connected to the city of Vancouver by a busy bridge crossing. Drew was born in their local hospital, and Jo came home with a baby who was apparently healthy. She describes discovering a problem with Drew’s health as a result of her mother’s intervention, pointing from the outset to the limitations of medical knowledge:

My mum came into the bedroom, and Drew was lying on the bed. He used to put his head back – obviously he was trying to get oxygen, but I didn’t realize that’s what it was. But my mum said, “Jo, you’ve got to take this child in, because his earlobes are blue.” And I said, “What is that, Mum?” And she said, “That’s lack of oxygen.” So I remember getting up out of bed, throwing some clothes on him and getting him over to the doctor’s office.

Of course the minute they listened to his heart, they understood that he had a hole in his heart. It was between the two chambers. And he wasn’t getting enough oxygen. I knew there was something the matter, but they didn’t know there was a hole in his heart when he was born. They didn’t catch that, because they didn’t have the wherewithal to examine a person for that then. I don’t know whether you would call it “missed it” or whether you would just say they didn’t realize – it’s the same thing. But it was my mother that realized it.

Invoking the voice of her mother, Jo underscores her confidence in sources of knowledge beyond the medical profession, and particularly her mother's knowledge, which, in her view, saved Drew's life:

[My mum] just was somebody that knew things. She was fairly bright – she was a teacher. But she may have had, you know, earlier experience... We lived in a small community, and for all I know – I never did ask her how she knew. But I'll remember that forever. She was kind of a bit psychic about stuff like that. She was very good at health, I mean. I can't explain it. She'd have made a great nurse. She went into teaching instead, but she would have been a great nurse.

Interpreting her memories of events in retrospect, Jo is able to acknowledge some ways that medical professionals assisted the family with Drew while also pointing to the limitations of health care and the perils of hospital care:

They couldn't operate on him because he was a child. They were just starting to operate on adults to close that opening, but they wouldn't do it on a baby. After that, they did, of course, and that was wonderful, but it was too late for Drew. The damage was done – to his brain, you see, because he wasn't getting any oxygen, wasn't getting circulation.... It was going from one side of the heart to the other – leaking over to the other side.

Well, he started to deteriorate of course. But they couldn't really *do* anything and they really predicted that he wouldn't live very long. They gave him digitalis for hearts. That got him over a few bumps, but they never did fix it properly, never. But as your body grows, the actual separation starts to close a bit, or the hole stays the same, but your heart gets bigger....

We went to St. Paul's Hospital [in Vancouver] because they couldn't take him here at Lions Gate Hospital. I think my sister told me. Lions Gate did not have the equipment and they were a young hospital at that time.

And they were very good about it, the doctors. I was feeding at the time, so when Drew was in there – they had to keep him in there to give him oxygen and everything –they gave me a place where I could feed him. I went in there three times a day to feed him. And then he got that raging infection that started in hospitals – what's the name? Staph! It was really something. And he got it from the hospital. And so they didn't expect him to live.

Though Jo acknowledges some sense of loss (“it was too late for Drew”) and implies a normative standard when she asserts “the damage was done,” in this account she firmly establishes her role as Drew’s mother by emphasizing the actions of a “good” mother: taking her baby into Vancouver to secure the best possible health care and visiting the hospital three times a day to breastfeed him. Even in an anecdote acknowledging support from surprising quarters, Jo underscores her efforts as a mother:

And I don’t know how many times I went across that bridge with a blue baby but ...I always remember one time – we used to have to pay a quarter to go across the bridge. And I didn’t have a quarter on me. And so this man at the toll said, “Just go, just go.” I’ll never forget him. Because a quarter was not much money, but then, you know, I just didn’t have it.

Though Drew’s health condition intensified the demands upon her as a mother, her actions merely continued and extended the mothering role she was already performing with her first son, having given up her job as a physiotherapist to become a full-time homemaker while her husband worked outside the home to support the family financially.

Commenting on Drew’s health crisis, Jo notes that she resisted the pessimistic medical prognosis for him and takes particular pleasure in pointing out how he beat the odds: “We didn’t give up. And he beat it. And we brought him home, and he was okay.” She adds with a chuckle, “Lived another fifty years. Not quite fifty – but almost fifty.” Here again, Jo’s narrative focuses on her attachment to Drew, her optimism about his future and her enjoyment of the fact that he lived as long as he did, presenting a view of a parent that contrasts dramatically with the image of families tormented by guilt, shame and secrecy (Jones 2004).

While affirming her status as Drew's mother, Jo's narrative also acknowledges a gradual shift from mothering a sick child to coming to terms with an impaired child. The transition occurred over time:

It was more gradual because he was physically impaired first, you see. They told us that he would not last any longer than six months – and he would have been about four to six weeks old. Of course, I kind of knew that if the heart wasn't functioning properly it would affect the rest of his body, particularly the brain. But we didn't know what progress or degress (*sic*) the heart was having, and we just assumed that he would die. So we were prepared for that, as opposed to anything about what he could or couldn't do. So it was just discovering...

Here she contradicts her earlier statement that “we didn't give up,” demonstrating how different perspectives and details come forward with each telling of a story, depending on the point she wishes to emphasize. There are frequent contradictions of this nature in Jo's stories, reminding us that stories have a fluid life, evolving and changing with each retelling.

For many parents of a child with intellectual disabilities, the moment when they are first told of their child's impairment – usually by a medical professional – is marred by poor communication skills and negative attitudes of the professional (Stainton & Besser 1998). Jo did not describe such an experience, but noted she received little useful information from medical personnel:

They [doctors] had no answers. Absolutely didn't even *know* for the first six months. And even when they did know, they didn't tell me what to expect. I mean, I told you before, if it wasn't for my mother, Drew probably would have died right in front of me. Then when they find out that really, he cannot be “fixed,” well...You know, with Drew, all they could tell me was that he would probably die before he was five. That's not what I wanted to hear.

Rejecting institutions

As Drew's impairment became more evident, doctors recommended institutionalization:

They immediately wanted me to put him in the institution, you know, and that never failed. Every time I took him in there, he'd ask me, "When are you going to put him in Woodlands?" And this was a good doctor – our family doctor. They didn't realize what was going on then. It was: "Woodlands, oh yeah, wonderful place, wonderful place."

Jo and her family rejected the idea outright. She invokes two alternative sources of authority to resist the expertise of medical professionals on this issue. The first is her own experience as a physiotherapist and her first-hand observations of institutional life:

Well, my feeling about that was that that was the last place on earth he would go, because...I was a physio and I had some experience in hospitals... I had seen children. I just knew about institutions. And they were the last place in the world you would want your kid.

Secondly, her understanding of her mothering role and the role of the family enables her to refute the "logic" of segregation, rooted in the history of eugenics:

And I mean, he was our son, and we had another son. And so why would we ship one out and leave the other at home? It just didn't make any sense to me, and it still doesn't. It still doesn't. So there was absolutely no question, with any of us, the three of us. Absolutely no way. That was very clear, right from the very beginning.

Parents who opted for institutionalization did so for a variety of reasons. Some accepted the dominant ideology about the need for segregation, while others simply did not have the resources to care for a person with disabilities at home. Similarly, some of those who kept their children at home did so only due to lack of space in institutions, while others, like Jo, actively resisted medical advice and chose to raise their children at home despite the extra work, family stigma, and social and economic challenges that it may have involved. In fact, in British Columbia, a number of parents had already

organized nonprofit groups to provide education programs for children with intellectual disabilities they were raising at home who had been excluded from public schools. In 1955, seven of these parent-run groups formed a provincial society called the Association for Retarded Children of BC (ARC BC, the precursor to the current BC Association for Community Living), and secured provincial government funding to run these school programs (BCACL 2008).

What accounted for some parents actively rejecting the strong message to institutionalize their children? First, middle-class family ideology presented mothers with conflicting messages. On one hand, as Jones (2004) suggests, it required women to prioritize nurturing behaviour and surrender careers to devote themselves to their children and husband. In this context, a desire to work or volunteer outside the home amounted to a rejection of the children and “bad” mothering, not to mention a potential threat to the marriage. On the other hand, for the sake of the family, mothers were expected to withdraw their nurturing behaviour from children deemed “abnormal” and abandon them to institutions. As Jo states, for her and many others, this made no sense either at an emotional level or in terms of their constructed responsibility for care of the family.

By “naturalizing” her role as Drew’s mother, Jo retrospectively positions both her actions and her story as a challenge to eugenic ideology and the “normalized” practice of institutionalization.

Castles (2004) suggests that although some parents deployed idealized family rhetoric to justify the institutionalization of their child, others drew upon it to argue for less isolation, more services and an end to the shame that “crippled the family” (p. 358). Jones (2004) argues that parents sought to expand the meaning of family normality by

advocating for their children's inclusion in everyday childhood rituals such as attending school and summer camp (p. 326). Activist parents sought ways to reduce the family stigma they experienced and incorporate disabled children into their concept of family togetherness. Jones argues that this is what drove their efforts to advocate for public education and to change the image of mental retardation. However, in a photographic study of parent advocates in Washington state, Schwartzberg (2005) suggests that many parents became advocates for reasons related to their belief in their children's capabilities and their rights to citizenship and universal education.

Parents influenced the public image of intellectual disabilities through a number of communication strategies. An example cited by Jones is the bestseller by Dale Evans Rogers, *Angel Unawares* (1953). This hugely popular book offered a personal account of the Rogers' care for their daughter with Down syndrome at home until her death at the age of two. Though the parents had kept her existence secret, the account represented their daughter as innocent and blameless, refuting the construction of such children as dangerous to families. The American National Association for Retarded Children (NARC) also took up the theme of innocence in its public awareness activities, reshaping the image of mentally retarded children by arguing that fault lay not with the children, but in society's refusal to accept them. Castles' (2004) research indicates that NARC adopted a "nice, average American" profile that focused attention on mental retardation in "ordinary families," by which, she argues, they meant middle-class white families (p. 356). One of NARC's early leaders, Gunnar Dybwad, referred in 1963 to children with mental retardation as "displaced persons" due to the social rejection and isolation they experienced (ibid., p. 357). Dybwad was later to prove influential in British Columbia

during a term as a visiting professor at the University of British Columbia in 1976 (Panitch 2008). Panitch also points to President J.F. Kennedy's establishment of the President's Committee (*sic* – Panel) on Mental Retardation in 1961 as a major turning point that “brought unprecedented profile to the issue of intellectual disability” (p. 52).

Like increasing numbers of other mothers who refused to surrender their children to the state, Jo makes it clear that reconfiguring her family to include a son with a disability was preferable to complying with family ideals that demanded removal of all traces of “abnormality.” Her work experience enabled her to discern the gap between professional propaganda and the social reality of institutions. Her decision reflects how, though family ideology had supplanted prewar eugenics as the new method of disciplining social beings into normality, the attachments of mothers to their children with disabilities could subvert this agenda. The fissure between the experience of mothers and an ideological framework that denied that experience enabled mothers like Jo to resist and imagine something new.

Alternative sources of knowledge and support

Jo recalls that she soon began to seek information outside the medical system. She described this process years later in an article she wrote for *Canadian Family Physician* about what she wished doctors had told her when Drew was born (Dickey 1979). Though in that article she framed the initial realization of her son's disability as a “devastating, unexpected reality,” her strongest wish was that she had been given “an understanding of the overwhelming joy that would be ours as we came to know our child” (p. 1273). Instead, when her doctor “recommended an institution for our child, it was made to seem

our only viable option. For ourselves, and for the child, he said” (ibid.). What she wanted was for the doctor to have told her:

that my child is a child, as any other. That while his needs are greater than most, he should be treated as any normal child is, with love and affection and respect for his humanity. That his basic need for love and affection can best be met by his parents. That he is, more than anything else, a person (ibid.).

She writes that her need for information took her to the community, where she discovered other parents and a local association for the mentally retarded (later called community living associations). The article pointed, as did most of her stories, to the two-pronged strategy Jo employed to counter limiting professional discourses and to advance what she understood as the rights of her son: 1) portraying her son as a valued member of the family and as a full human being with potential and 2) connecting with other families to “build those services that were necessary but lacking in our community” (ibid.). In the following sections of this chapter, I address these strategies as they are represented through her stories.

Drew as a person and family member

By generally refusing to describe Drew in medicalized terms, Jo embeds in her narrative a recognition of the social construction of disability. While she acknowledged some limitations he might have had, she did not view these limitations as central to his identity nor as reasons for his social exclusion.

I had to go with the labels when I went to doctors or anything like that – you know what I mean – to tell people. But I didn’t like labels and made it pretty clear, and it just never – that wasn’t what Drew was, to me. Drew was Drew. He was funny, he was just like his dad, he had a great sense of humour and he had a lot of love to give, which he gave. And he was beautiful. He was beautiful. Right ’til the day he died.

I understood that he had a restriction, you know – I knew he wasn't going to be a genius. I knew he wasn't going to be a doctor, he wasn't going to be this, he wasn't going to be that. But it was my job to, to just make sure that his life was as, without any, you know ... that's why it was so terribly hard for me to have him go in there, in that place [the institution], you see.

Jo's persistence in seeing the full personhood of Drew in contrast to viewing him in terms of deficits has been shown to be a strategy often used by mothers of children labeled as intellectually disabled (Traustadottir 1995, O'Connor 1995). While some mothers may initially negotiate feelings of guilt or question their prenatal behaviour as a potential "cause" of the disability, through the process of actual mothering – experiencing love, and receiving unconditional love from their child – many reconfigure their initial perception of the child and their own motherhood (Landsman 1999). In their study of family perceptions of positive impacts of disability, Stainton & Besser (1998) found that parents report a wide variety of positive family effects of having a child with intellectual disabilities. Among them are: a source of joy and happiness, pleasure in seeing their child "beat the odds," an increased sense of purpose and sharpened focus in life, expanded personal and social networks and community involvement, increased spirituality, strengthening the marriage and family bond, source of personal growth and strength (often through developing advocacy skills), enhanced moral and social development of siblings, and impact on community awareness and tolerance. Many of these positive impacts are integrated into Jo's stories, providing a counterpoint to professional discourses that constructed disability as a tragic event with a negative family impact.

Stainton & Besser's (1998) findings from families contrast sharply with research prior to the 1980s which "generally assumed family dysfunction and pathological reactions were an inevitable result of having a child with an intellectual disability" (p.

57). This included a syndrome defined by Olshansky in 1962 as “chronic sorrow.” Further, “positive impacts were frequently dismissed as denial or as an attempt by parents to alleviate their guilt (Turnbull, 1985; Behr, 1990)” (ibid.). O’Connor’s (1995) study of families raising a child with disabilities shows how families construct themselves in positive ways by focusing on the family unit as a whole and emphasizing the child’s valuable qualities. Yet she observes that such strategies may be dismissed by professionals as a failure to come to grips with a child’s disability. O’Connor argues this professional perception is often related to family rejections of professional advice or their refusal to comply with system-based expectations of clients.

Jo’s narrative about Drew employs some of these strategies to resist negative constructions of children with disabilities and their families. She never refers to Drew’s birth as a “tragedy” or to caring for him as a “burden.” Speaking indirectly to theories of “chronic sorrow” and family dysfunction, she asserts: “I think I’m being honest – I never took it personally. I never felt abused by it, never felt sad. To this day I never regret having Drew. If anything, he’s been the motivator.” Jo also emphasizes Drew’s relationships in the family, though she readily acknowledges that his unusual way of being in the world sometimes brought unexpected excitement to family life. Her accounts acknowledge his “difference,” often pointing to the humorous side of it, while emphasizing his acceptance in the family. She retells a story that his brother Rod told at Drew’s funeral in 2004 to illustrate Drew’s mischievous sense of humour:

Drew was a terrible – he had that Dickey in him that was just a terrible tormenter, you know. And Rod, Jr., was very meticulous you see. He had all these soldiers that he would line up in a row. So Drew, when he got a little bit older, he watched this performance and when Rod, Jr., would go to school, he’d go and he’d just move them, just a little bit. Or take one off and put it in his pocket. One time he even chewed the head off one! And

Rod would come home and go into a tantrum – “Leave my stuff alone!” And Drew would do the “rain man dance,” you know, and just kill himself laughing.

And that was the kind of relationship between the two, because Drew was an absolute terrible tormenter. He would tease and tease. And Rod was very – to this day he’s very precise. (*Laughs.*) So they had their moments.

What is perhaps most noteworthy in this story is its portrayal of a very typical sibling relationship. (What older brother has not said to a younger sibling, “Leave my stuff alone!”?) Jo’s term, the “rain man dance” references the Oscar-winning 1988 Hollywood film, *Rain Man*, which became the first popular film to depict a main character with autism. In conversation with a younger parent of a child with autism, I was told that the film had served as a significant cultural watershed, providing a reference point for parents describing their own children. Jo would not have had access to the term during Drew’s childhood, but had incorporated it into her language as a way to refer to some of the ways that Drew expressed himself (“swaying back and forth”). As the younger parent pointed out to me, the film was a mixed blessing, as it emphasized “savant” abilities which appeal to the popular imagination but do not occur in all individuals who experience some form of autism.

In another story, Jo emphasizes Drew’s particular interests, his connections in the community, his humour and delight in the world, and again, the relationship between the two brothers:

Another story – oh Drew was a terrible tease, and he probably would have been just like his dad. He would’ve been somebody who people loved, just a bandit, you know what I mean? Anyway, Rod, Jr., was coming home from school and he was walking up the boulevard – it’s a long trip and we were up at the top at that time. And Drew used to go down and sit with this man and watch this man do mechanics. The man was just lovely to him, and he was always fixing his cars or somebody else’s cars.

So anyway, Rod was walking up at lunchtime and he sees his brother doing the “rain man” at the top of the hill, and what’s coming down but a great big truck tire! ... It was one of those really *big* truck tires. And if you know that boulevard, it’s a very long way down ... but it went rolling and rolling and rolling and all the cars had to pull over and get out of the way. And of course Rod’s looking up at his brother – you know, you can imagine! (*Laughs.*) Oh we had some – I tell you – some really incredible times with Drew and his sense of humour.

While Jo acknowledges a sense of loss in describing what Drew “would have been” (mostly poignantly in “somebody who people loved”), her accounts of these family events draw upon humour as a way to resist the socially prevalent “family tragedy” script, as well as to construct Drew as a unique person and an integral part of the family. She nevertheless acknowledges that the demands of parenting Drew meant that Rod, Jr., did not always receive as much attention as she would have liked. Jo also relied on Rod, Jr., to help with caring for Drew, but for the most part, she presents this as a positive factor that contributed to his maturity, rather than a deprivation, echoing Stainton & Besser’s findings about the benefits families perceive for siblings of a child with intellectual disabilities:

And Rod, Jr. – he was just miraculous. He just put up with my attention taken from him then – because he was only two, you know, when this was happening. Rod just got quiet, he just got quiet and stayed out of things and tried to help me. And I marvel at it, and I think that’s part of his character because he’s a very understanding young man. I understand he’s a fairly decent doctor. (*Laughs.*) So maybe that was the introduction. Well, I’m sure it was, you know...

And as time went on, it was really quite interesting to see Rod, Jr., maturing. I think he was much more mature than his years, just having this brother. And I think he learned so much from Drew. I know I did. You know, I always got in young men to sit with Drew when we went out, but Rod, Jr., always stayed home with him too, because the babysitters didn’t know what to do. Rod did, you see. He was very good. But it must have just frustrated the life out of him because Drew was such a tease.

Gender roles in the family

While viewing a child with disabilities within the family context can subvert the professional focus on “disability” and emphasize relationships, Traustadottir (1995) suggests that viewing benefits from the perspective of the whole family unit may obscure the extent to which mothers bear the brunt of accommodating a child with extra care needs. Her research into parent roles in two-parent heterosexual families found that mothers of children with intellectual disabilities carried the bulk of responsibility not just for family caregiving generally, but for researching programs and coordinating services related to the child with disabilities. Fathers were invested in work outside the home and their role as economic provider, placing less importance on caregiving activities. While some of the mothers had professional training, most did not have paid jobs outside the home. In addition, they expressed fear of abandonment by their husbands and took responsibility for ensuring the child’s disability did not disrupt “normal” family life or make the home undesirable for their husband. When describing family limitations related to having a child with disabilities, family members generally did not consider limitations on the mother’s life to be part of “family limitations.” Thus the extra work, skills, and negotiations required to maintain the family’s “normal” functioning were naturalized as part of a mother’s role and rendered invisible.

On the subject of her husband Rod, Sr., Jo was somewhat reluctant to comment. She described him as a sociable man with a mischievous sense of humour, who was well liked by others. However, he faced several health challenges and died at the relatively young age of 58. When asked directly how her husband had responded to Drew having an intellectual impairment, she initially responded briefly: “Well, he didn’t desert me... He

didn't know how to react, you know what I mean?" The response reflects a perspective expressed by several mothers of Jo's generation that "having a child with a disability seemed to be particularly hard on men" and fathers were known to leave home "because they could not take the emotional and physical demands" (Panitch 2008, p. 153). This also reflects, of course, an assumption that responsibility for the child falls primarily to the mother. Jo later elaborated on Rod's role as a father:

He was great with Drew. He didn't knock himself out with it or anything, but he never – I'm sure it was hard for him, but he never admitted that, never showed it. Never touched him in a negative way – you know, never disciplined him or anything like that. There was nothing of that rough house stuff with either of the kids, which was very good.

She suggests here that she had relatively modest expectations of Rod, Sr., in relation to Drew. By staying in the marriage, keeping his difficulties to himself, and refraining from aggressive forms of discipline with their sons, he performed his role as a father. Her comments about Rod, Sr., were framed by an acceptance of the gendered division of labour within the family and gendered social expectations. She indicated that his work meant that he was often away from the family and frequently socialized with business associates. The work of caring for the children and negotiating any special care for Drew fell to Jo, a division of labour that was consistent with Traustadottir's findings. As Panitch points out, this division of labour was reflected in the predominantly female (and middle-class) constituency of Canada's early parent activist groups. But it meant that home "became a site of delicate negotiation, where mothers balanced not only family life and activism but also the expectations of professionals who had their own view of what constituted a 'good' mother where disability was concerned (Traustadottir 1988; 1991)" (Panitch 2008, p. 153).

Jo acknowledged her sense that, for Rod, Sr., having a son perceived as “not normal” was difficult, and she understood this in gendered terms:

I felt badly for Rod – he had a son. It’s harder for fathers if it’s a son, a boy. He was overwhelmed with Drew, sad. I knew more. If it had been a daughter, maybe it wouldn’t have been so bad. For me it wasn’t about not having a normal child. But for him, it wasn’t normal, he had that taken away from him. I don’t think that fathers know what to do. But no one knew what to do. He learned, just as I learned and Rod, Jr., learned.

Jo was careful to emphasize that though he was not at home a lot, when her husband was home, he was good with the family, he was understanding and not judgmental with Drew, and Drew “adored his dad.” However, I noted the absence of Rod, Sr., from most of Jo’s narratives, though he appeared as a lively presence in many informal family photos.

In a different performance of resistance here, Jo attempted to protect Rod, Sr., from undue scrutiny with respect to Drew and to avert any critique of the gender roles adopted in her family. Yet as Jo later grew more involved in public advocacy, she stepped well beyond traditional gender roles, volunteering, working outside the home and travelling extensively as she took on greater responsibilities. It was her role as a mother that provided the springboard for these activities. As she put it: “I measured everything I did against what I wanted for Drew. I was just doing it for Drew” (Panitch 2008, p. 152).

While she addressed equality issues for people with disabilities, Jo did not overtly extend her concerns to women’s equality. This is perhaps because, though her family situation conformed to traditional gender roles, she herself did not construe her role as having limited her life, but rather as having enriched and expanded it. Further, her account of family life indicates that her first son Rod, Jr., was actively involved in Drew’s support and care (which she argues benefited him by contributing to his maturity and understanding), which complicates Traustadottir’s portrait of mothers invisibly

managing disability to minimize impact on other family members. While Traustadottir productively explores the dynamics of gender in families raising a child with disabilities, a tendency to view disability exclusively as a burden, and caregiving as a limitation, colours her conclusions. Her interpretation of the impact of disability does not fully coincide with Jo's representation of her experience of caregiving and advocacy. This gap suggests the risk of embedding dominant ideological assumptions about disability and caregiving when attempting to deconstruct mothering. Jo's accounts disrupt such tendencies and attest to the importance of exploring individual stories that resist generalization and speak to the complexity of negotiating intersecting social identities. Viewing such a mother's life through the lens of resistance can uncover new insights. As Jo's narratives demonstrate, grounding her activism in motherhood enabled her both to intervene in disabling social forces and to subvert the idealized confinement of motherhood to domestic space, linking personal experiences of disability with public policy, and unsettling the boundaries between "the space we call private and the space of the world" (Jackson 2002, p. 28).

Focus on Drew's abilities

In addition to constructing Drew as a valued family member, Jo's stories incorporate an attitude of curiosity and optimism regarding his abilities. In order to validate this perspective and invite listeners to consider it, she offers both her own observations and accounts of how she sought professional assessments of Drew's abilities. Through her observations, Jo admits that Drew surprised her by surpassing even her expectations:

When he was around six, we used to go up to the Shuswap, and we stayed in the same cabin every year. And about two years after we started going with Drew, he got out of the car when we arrived and went racing into this cabin that we had had for a couple of years before. I went in and looked all over for him and finally found him in the bedroom, struggling to get out from under the bed. So I helped him, and in his hand he had this tennis ball inside a sock. He had stashed it there when we were there before, and he remembered exactly where it was.... So you see, you never know, you never know with these children. You can't really sell them short. I mean, I know what autism is, and that was his autistic side – he never forgot that kind of stuff. He never read – never did any of that sort of stuff, but the seed of it was there.

Jo also described Drew's heightened ability to assess whether people would respond to him warmly or not:

Every time I went to the door at home, he would come with me – when he was at home with me – and he'd come up behind me and he'd be dancing the old "rain man dance." We'd get up to the door and he'd be oh, so excited that somebody was coming. I'd open the door to whoever was standing there. And Drew would look at me and then he'd either continue to dance or he'd come around behind me, grab me at the back of my legs and just stay there. And it worked out every time that if he had hidden behind me, the person on the other side of the door could no more manage understanding Drew than fly to the moon. He just knew it, just like that.

When Drew was five, Jo took him for an assessment at the University of British Columbia "to get a reading on where his intellect was, if indeed it was there" and no doubt to obtain guidance about how to support his development. Jo told this story on two different occasions, emphasizing different details, and they have been integrated into one version here:

There was a gentleman, a well-known doctor, out there. I went out to see him and he sat me down with a pencil and a piece of paper and he said, "I want you to write how many words you've heard him say." And Drew was, he'd just turned five, and I got up to 68 words [*later* - 86 words] without any trouble and could have gone further.

And this man said, "Lookit, just keep doing what you're doing – he's learning."

So he was learning. He might not have been learning like a typical five-year-old, but he was learning. He got some language. But later, you see,

he just lost and lost, and then he lost his language completely when he went out to Woodlands.

In this account Jo draws upon professional authority to affirm her perception of Drew's ability to learn. The narrative also serves to validate her decision to raise Drew at home. At the same time, she leaps forward in time to implicate the authorities who later institutionalized Drew, by describing his language learning potential as "lost" when Drew was sent to Woodlands.

Jo later undertook a second assessment of Drew at the urging of others. Her account of that experience affirms her prerogative as a mother to selectively deploy professional assessments and reject those that did not support her own views of the family's role in Drew's life:

You know, we took him out to this place where you were supposed to go with your kid and they did certain things on them, and everybody wanted me to take him out there. I didn't.... But anyway, we went out there and they kept (*laughs*) they kept asking me all about my marriage. In other words, they were kind of insinuating that – at least that's how I took it – that we kind of brought this on, you know. And they didn't want me to be with him when they talked to him or anything, you see, because they thought it was parental kind of pressure. So I never took him back. That was enough for me...

There was no help. That's why they sent me over to this other place, but they were just kind of blaming me. I took exception to it... No thank you! I don't need you guys.

Here Jo rejects an assessment – even though it may have opened the door to services – because of its insinuation of parental responsibility for disability or perhaps parental abuse. This "diagnostic" approach may have been drawing upon theories targeting emotionally withholding mothers as the "cause" of autistic behaviours (the "refrigerator mother" theory cited by Castles 2004) or otherwise pathologizing or blaming family relationships for a child's disability.

Resistance in the community

As she described gaining confidence and experience as Drew's mother, Jo also referred poignantly to both the joy and pain it brought. She voiced gratitude for the richness Drew brought to her life, a gratitude unfathomable to people who perceive disability as misfortune:

It's fascinating – when you live with somebody who's a little bit “off the mark” – it's a rich experience. For his sake, I wouldn't have him the way he was, because he was hurt many times. He knew when people rejected him – he knew instantly. But for my sake, it was just the richest experience.

She recalls the social rejection both she and Drew experienced in public: “Society would reject you. You could feel it walking down the street. Everyone knew he was ‘bonkers.’” She modestly describes her response: “I don't know whether people's prejudice made me angry. I just defied it. I don't know – I really never thought about it. I just knew it was happening.” Yet she offers the two following accounts of everyday encounters in which she intervened to challenge others' rejection of her son, demonstrating how witnessing prejudice directed at Drew pushed her to take action that asserted his value as a person.

At the department store

People couldn't help noticing Drew. For example, I was shopping at a department store with Drew one time. There was a family a few feet away looking at Drew and talking – you know, obviously noticing him. And he knew, of course, you'd see him backing off. He could read people. So I took Drew by the hand and took him over to the family and said, “Would you like to meet my son? His name is Drew.” You don't do it to be cruel, but you need to make them realize that what they're doing is hurtful.

Telling this story also provided Jo with a way to make a link between a personal experience and the larger social policy context surrounding it – the exclusion of children like her son from public schools. As she put it: “They were locked out of the

mainstream,” and she believed that experiences such as this would be less likely if the school system included children with disabilities, not just to support the rights of disabled children but to educate other children (and their parents) about including and valuing a diversity of people.

New neighbours

Another story also provided a way for Jo to link personal encounters with broader social issues:

This was when Drew was at home, before we “lost” him. He was a little boy and he’d go out in the garden. And he was different, he was weird (*laughs*), you know ... but then, so am I! But anyway, he was used to the neighbours next door and he would go and say hi to them and do his little dance. But then the house got sold. So Drew did this with the new people, but as far as they were concerned, he was weird. So the new owner came over one day and she said to me, “When are you going to put your son into a” – I don’t know what she called it – “a school?”

And I said, “What do you mean?”

She said, “Well, he really shouldn’t be living here, you know.” And I just froze. Just – I couldn’t believe someone could be so offending. It just baffled me. And it made me angry, that’s what it did. It made me angry.

She said, “When will it happen? We just bought this home!”

And I said, “It’s never going to happen. Forget it. He’s never going to leave home.”

Can you imagine? Going over to your neighbour and saying to your neighbour, “You’ve got to get rid of your child because it’s taking the value of my home down”?

Well it’s interesting, because the very next day, the For Sale sign went up – or almost immediately. We lived in a small section of the community and we knew most of the neighbours pretty well. (*Laughs.*) And it was really interesting, because so many people – well, a number of people – came to our door and said, “Would you thank Drew for us?”

And I said “For what?”

And they said, “We didn’t like those people, and he got rid of them for us, and that’s just great.” (*Laughs.*) I’ll never forget that. Isn’t that lovely though?

In addition to indicating some community support for the family and affirming her response to the neighbour, Jo’s story served as a bridge for her to speak to the policy of institutionalization and the public’s indifference and lack of awareness about its impact:

The ordinary man in the street thought it was just fine for people to be put into Woodlands. It was the public’s perception and the government’s perception that “it’s taken care of.” The neglect, the dying rate, the terrible time for families – they just shut out the bad part. It was invisible. They were out of sight, out of mind. Once people went there, nobody knew what was happening and everybody thought it was wonderful.

But people who worked in those places viewed the people as being less than citizens. It’s not across the board, you know, but it’s the society they grew up in, it’s the value process.

As she did many times, Jo invokes the concept here of citizenship as a way to challenge the systemic exclusion of people with intellectual disabilities from rights that are normally understood as universal. On the issue of institutionalization, she consistently linked struggles to close institutions in the past to struggles in the present day. Though Woodlands and other large institutions in B.C. are now closed, she noted that “There are still people in the back wards all across the country – in Alberta and Saskatchewan and Manitoba and Ontario. It drives me nuts!” The variation in the status of large institutions across Canada attests to the local differences in social and political circumstances that may have afforded greater opportunities in B.C. to close institutions than in other provinces. Jo was particularly incensed about a recent Manitoba government decision to invest \$40 million in refurbishing that province’s large institution.

Reaching out to other families

As Drew entered preschool age, Jo recalls that she realized the school system would not admit him to a regular kindergarten or school. This is when she made her first contact with other parents of children with intellectual disabilities:

When Drew was born, there was a lady down the street who had a son with Down syndrome. In their good nature and their love for their child, they had joined a group of parents who were starting a kindergarten. So she came to me – she saw what I was going through and saw Drew and what he was going through. And so anyway they started a kindergarten, and I took Drew to the kindergarten when he was about four. Before then, I stayed home with him – I couldn't leave him with anyone, because of his health, you see. But he did okay there, he got along pretty well, especially when his friend Walter was there.

That was my first introduction to the organization – it was through Drew. So I became a member and got involved in the organization. It was a really good experience for me. You know, I kind of went up, and before I knew it, I was the chair. And the rest of my life, you know, really, it was Drew who introduced me to it.

Drew went to kindergarten and then he went to school – but it was a separate school. As families, we had to prove that it was possible. If it wasn't for families, we wouldn't have any of these schools, we wouldn't have anything because certainly the system wasn't doing it. They still *aren't* doing it...

Through this somewhat understated account (“I kind of went up”), Jo marks a turning point that affected the rest of her life – her entry into organized advocacy by families to create the services that were lacking for children with intellectual disabilities. In this brief reference, she affirms not only the central role played by parents in building needed services but their influence in shifting perceptions about what their children were capable of achieving. The account also points to her rapid assumption of leadership roles in the advocacy she undertook.

Taken together, the stories presented in this chapter provide an account of a mother's gradual emergence as an advocate for her son through an accumulation of experiences – of both exclusion and inclusion, rejection and acceptance, success and failure. Panitch (2008) refers to such activism as “accidental” – arising out of pragmatic, everyday necessity, rather than from an ideological agenda. Ryan & Runswick-Cole (2008) describe parenting a child with intellectual disabilities as a journey into uncharted territory: “there are very few guidelines, simply a range of conflicting, contradictory and, more often than not, negative bullet points” (p. 203). Jo's stories certainly suggest the improvisational nature of parenting a son with disabilities and navigating the social challenges her situation presented. But as a retrospective narrator, Jo is no longer floundering in “uncharted territory.” Rather, her stories challenge others to enter the open waters she did as a young mother and invite us to consider with a new perspective the routes she chose.

In the next chapter, I explore Jo's narrative of the period when state systems intervened in Drew's life in a way that overrode her authority as a mother and her aspirations for her son. Despite the devastating results of these interventions, Jo uses storytelling in creative ways to reclaim her authority and hold state authorities accountable.

CHAPTER 3: A MOTHER’S RESPONSE TO STATE INTERVENTION

In this chapter, I present Jo’s account of the events that led, like a series of falling dominoes, to the institutionalization of her son Drew at age 13. The narrative is presented here as a continuous story, but has been compiled from several interviews and conversations, edited for readability. In telling this part of her story, Jo frequently expresses regret and speculates about how she might have resisted or challenged the decisions of others more effectively. Yet some of the options she considers – such as taking legal action against authorities – would likely have been unavailable. Indeed, they are choices that have emerged only as a result of activism such as hers that articulated and established a framework of human rights for people with intellectual disabilities. Nevertheless, her regret enables her to bring a contemporary lens of human rights to bear on her account of the past, highlighting the injustice of procedures considered “ordinary practice” at the time.

At the same time, Jo affirms her agency by recounting her efforts to advocate for her son and create opportunities for him, despite opposition from social agencies. Furthermore, in her stories, Jo “speaks” the voices of others, as an omniscient narrator, and is able to position them to serve her narrative purposes. By representing key decision-makers during these events, she retrospectively holds them accountable. And by giving voice to her son Drew, she is able to bring his personhood, his wishes, and his world into play, in a story that otherwise negates them. As Denzin (2001) has suggested

in his discussion of narrative performativity, she uses these voices and stories to bring *her* view of *her* world into play. In the process, she implicates the educational, medical, legal and social service systems – even the community organization of which she was a member – in the decisions that led to Drew’s involuntary committal and its aftermath.

Drew goes to school

Jo recalls how, as she gained experience in the local parent association, Drew gained confidence and experience attending a segregated elementary school:

Drew was in kindergarten with Walter, who turned out to be his best friend. He spent the rest of his life, when he finally got out of Woodlands, with Walter.

Then he got into school. It was a separate school, which the association ran in partnership with the school board. By then I was the chair of the association. For me, what was so unbelievable was that Drew was so happy in school. He was learning to talk, quite extensively. He was doing pottery, he was just having a lovely time. He was starting to mature and he also made friends there.

One time, the teachers at the school told me that Drew had a job. I said, “Oh does he really?” And they said, “Yeah, he’s teaching Walter.” Now Walter was six foot three or something and Drew – if he hit five feet he was doing well. And Walter, well this was a boy that people thought didn’t have any capacities at all. The story about Walter is that he was autistic – is autistic – and has all the advantages of being autistic as opposed to having the negative side of it. He’s got that savant ability. But back then, they didn’t really have a name for that kind of behaviour, they didn’t know what these people could do. Drew did many things that Walter did, but he didn’t have that savant part. But Walter still couldn’t do some ordinary things and didn’t talk very much. He *could* talk but he *didn’t* talk. But they were the best of friends these two, and they lived together until Drew died. Walter still lives in the house.

So anyway, at school, apparently Drew was teaching Walter how to go into all of the rooms and get the wastepaper basket and bring it out and empty it. It was just unbelievable to see him teaching Walter how to do this.

In the story above, Jo focuses on the growth Drew experienced at school, his enjoyment in participating in a variety of school activities, and his enduring friendship

with Walter which involved reciprocity and mutual support. As in most of her narrative about Drew, she emphasizes the capabilities of both Drew and Walter, even when referring to diagnostic categories of impairment.

End of Drew's school days

In the next story, Jo emphasizes her observation that school officials did not recognize what students were capable of achieving and that they may have lowered their expectations unnecessarily.

When Drew was 13, all of his friends in the class that he was in were taken to the carpentry workshop at school. But someone decided that it was too dangerous for my son to be in the workshop, and so they left him with the younger children. They didn't want him going into the workshop because he might get hurt – that's the *story*. I'm not *sure* that was the story, because the principal at that time had been away, and then he came back, and he and I kind of didn't get along too well. I don't know. I think there's more to it than that. I honestly have a sense that they didn't see Drew as being somebody they could train in a way that would have been considered to be "progress." But of course, when all of them got out of school there was no place for them.

Well, Drew was angry because he was separated from his good friends. And he was angry because he was put in with children. He was 13 and he didn't want to be left with children, away from his friends. And so he responded to that, and not very nicely I guess, but very normally. He let them know the only way he knew, and that was to let his displeasure come to the surface. And then he got in trouble, and so I had to take him out of the school. They wouldn't let him stay. The reason they gave was that he might harm the children. He never harmed them, he was angry at the teachers. But that was the reason they gave.

When I look back, I guess I didn't expect the system to respond as it did. My regret is that I didn't force the system to do something other than having him in with a group of children. Drew might not have been able to do what the other children were doing in the workshop, but they could've found something for him to do because he was so creative. And around home we never had to worry about him hurting himself with anything because he had the capacity to understand danger. He knew fear and he was very cautious. But for the school, that was the end of it.

My regret, when I think back, is that I should have done more at that time to distinguish the problem because that shouldn't happen to *any* child. I

didn't challenge the system about that. Today I would. Today I would. But at the time, I didn't think I would win. I thought it would just maybe spoil any opportunity he had other places – which he didn't have, of course, because there were none there.

In her account of Drew's exclusion from the carpentry workshop, Jo retrospectively challenges the validity of the school's decision, even while expressing regret that she did not do more to contest it at the time. She suggests that an underlying pressure to meet normative performance standards, even in this segregated school program, contributed to the exclusion of her son. Jo noted that this occurred at a time when administration of the school transferred from the parent association to the public education system, which may have triggered a shift to greater emphasis on performance, even though, as she points out, this bore no relationship to the opportunities available to students after completing school. In conversation with Melanie Panitch, Jo recounted that the school had performed an IQ test on Drew and she suspected the decision to move him into a younger classroom, with children who had little or no language skills, was based on the test results (Panitch 2008, p. 62). Jo clearly indicates here her resistance to professional assessments of her son, deviating from parents who allied with experts to bring their children under professional control. By interpreting Drew's anger about being placed with younger children as a reasonable response to a decision that negatively affected his enjoyment of school and contact with friends, she challenges how the school pathologized Drew's behaviour. Again, she makes a link between a particular experience of unfairness towards her son and injustices that other children might experience: "that shouldn't happen to *any* child."

Finally, Jo alludes to tensions between herself and the school principal. As the former chair of the association that had earlier run the school, she had already established

a reputation as an activist. She suggests that a factor in Drew's expulsion may have been the principal's response to her, rather than to Drew, pointing to the social costs for mothers – and sometimes the children for whom they advocated – of stepping outside accepted behaviour norms (Panitch 2008, Ryan & Runswick-Cole 2008).

Seeking alternative support

Jo described her efforts to find alternative care for Drew:

I had Drew at home after that. But then he thought that I was to blame for him not going to school and not being with his friends. He was very bitter, very unforgiving to me and blamed me completely – naturally. He was going into adulthood, and he was telling me that he wanted to go to school – “Why are you not taking me to school?” I knew how unhappy he was. I knew how well he had been doing in school, and I knew how angry it made him – and he had *not* been an angry child. It was terrible, but there was nothing I could do about it. And there was nowhere, there was nothing else. I regret that I didn't push enough to have that reversed or to have it changed.

What I did do was I went to the government, and I asked for \$7600 for the year so I could hire somebody to come and take Drew out of my domain and give him an opportunity to have a different kind of life. I didn't mind what it was except I wanted it to be pleasant for him. A social worker came out and talked to me, but they refused completely. I regret not *fighting* tooth and nail for that because it was just unfair. It wasn't right, but that's what they were doing in those days. You know, people were just not fighting for their rights to have support.

I was connected to the local [North Vancouver] association at that time and I had been in the chair. So I had gotten to know some people in the government by then, particularly the deputy minister. He was a lovely man, but hamstrung because the system wasn't built in a way that he could do things. But he did finally offer me money to support Drew when Drew was so agitated. He asked me, “What do you want to do Jo?” and I said, “I want Drew to have a home of his own” – not his mum and dad's home, because I knew we couldn't deal with him – “his own home with people coming in that are trained to help him. And some other people that have a disability to live with him. I want him to live in the community and see if we can't find something for him to do.”

And so he said, “Well okay, I'll give you the money.” They offered me the opportunity but – just to show you how, you know, you do lose your sense of your own worth sometimes – I thought “Can I do this? I need help to do this.” I didn't know where I would get staff, I had no experience. Today I'd

know what to do, but then, I didn't. I didn't have the belief that we could do it as a family. So I went to the [North Vancouver] association to see if they would help me, but they didn't want any part of it because the school had already labeled Drew as "a behaviour problem" and "dangerous." So, there was no point taking the money if there was nowhere to spend it.

That was a lesson because I realized, "Well, I've got to learn to do this myself." But I lost confidence in myself that I could do it. It just seemed so overwhelming. And it hadn't been done anywhere else that I knew of – that way of supporting someone. I was way out on a limb. So Drew stayed home with me. It was a big mistake on my part. I should have taken the money and I should have done it, but there was nobody to help me. I was so alone, you know?

One thing that did happen though, was that it introduced me to the deputy minister, and that was very good because he was the one who arranged later on to have six families meet with the minister out at Woodlands.

At this juncture of her story, Jo describes a loss of confidence and sense of isolation that are remarkable, given her relatively privileged social position, her experience on the board of a parent association and her leverage with provincial bureaucrats, including a strategically located deputy minister. Her experience of isolation speaks volumes about the challenges other mothers without these social advantages might have faced in trying to secure, or even imagine, an alternative to institutional care.

Despite these obstacles, Jo emphasizes her refusal to abandon efforts to seek support for Drew – enabled, in part, by her organizational connections, but also by an ability to imagine what she believed would enable Drew to have a good life: a home with one or two roommates/friends and ongoing care providers who would come in (not live in) and support his autonomy, growth and ability to participate in the community. As a model it incorporated Jo's perception of Drew as a self-determining person and as an adolescent "going into adulthood" and her recognition that neither she, as his mother, nor the family, could adequately address his needs. Though such a small-scale residential model may seem far from innovative from a contemporary perspective, in the 1960s it

was generally unavailable and even beyond the scope of a public imagination that still saw large segregated institutions as the most appropriate, even “progressive,” place for children like Drew. The home Jo imagined for Drew suggested a third option between large institutions on the one hand and the private caregiving responsibility of mothers on the other. Despite these setbacks, she referred to this period as a “beginning” – a key moment in germinating the concept of a “shared home” that she would later develop into more concrete form.

As Jackson (2002) argues, storytelling

is a vital human strategy for sustaining a sense of agency in the face of disempowering circumstances. To reconstitute events in a story is no longer to live those events in passivity, but to actively rework them, both in dialogue with others and within one’s own imagination” (p. 14).

In recalling experiences that one might construe as defeat, Jo finds ways to emphasize her own agency and highlight the empowering aspects of the story. She is able to defend and validate Drew’s point of view. Through expressions of regret – about not “pushing enough” to reverse the school decision, not “fighting tooth and nail” with social services, and deciding to keep Drew at home when the local association denied her request for help – she holds others accountable. Finally, she notes a positive outcome in the personal contact made with a deputy minister who would later prove useful. As my research progressed, I would discover that Jo never underestimated the importance of personal connections in achieving her advocacy goals. Her search for allies crossed all traditional political boundaries.

Drew taken to hospital

Unable to find external supports, Jo continued to care for Drew at home, while Drew's frustration about being isolated from friends mounted.

Drew was aggressive towards me, but I didn't mind, I was managing it quite well. But one day he was really upset and I was afraid he was going to hurt me and then be blamed for it. I could have defended myself, although he was pretty strong, but that wasn't the point – the point was I didn't want him to be blamed. I wanted to take him over to Lions Gate Hospital but I knew I couldn't do it by myself, so I called an ambulance. It was just when they opened up the mental health wing at Lions Gate, so you would suppose that there would be people there who knew how to deal with a person who was going through an aggressive time. Well they didn't.

And I guess when the ambulance came to get him, they put a report in to the police about what was happening. I followed the ambulance over to the hospital and then a police car came. They whisked Drew up to the psych ward, and then I never saw him again, they wouldn't let me see him. Drew was calling down the hall, and they wouldn't let me go to him. Nightmares I had about that. And then near the evening, the two Rods got there – my husband and son.

In a nutshell, the whole absolutely unforgivable situation, as far as I was concerned and for my own family, was when they came down to talk to us – and they still hadn't let us see Drew. We were sitting there, the three of us, and we had stayed up all night in this waiting room. And they said to us, "Well, you've got two choices." And we said "Well, okay, tell us." And they said, "Well, one choice is he'll have to go to Essondale." [Essondale psychiatric hospital in Coquitlam.] And we said, "We don't want him to go there." And they said, "Well then the only other choice is jail." So we sat in Lions Gate Hospital and told them, "Well then you'll have to put us all in jail with him, because we're not going to let him go to jail by himself."

So that kind of stopped it right there. That scared them, because they knew they'd have the media there and everything. I don't regret that at all. I would have regretted if I hadn't said it, or if we hadn't said it – because it was all three of us. In the end, the thing that got him into Essondale as opposed to jail, was that Rod, Sr., was friendly with a politician who was high up in the hierarchy of the government at the time. And he phoned this man, and I guess the politician made a couple of phone calls, so Drew went to Essondale instead of jail. When I think about this now, I think well, at least we've come a few leagues from there.

So anyway, at three o'clock in the morning Drew was hiked away to Essondale. We didn't even see him. And there was nothing we could do about it. Nothing we could do. Or so we thought. And I guess there wasn't, except that now, when I look back, I wonder what would have

happened if we had, you know, gone to court about it. I don't know. I would today. I would today.

Jo recounts here how, having exhausted the possibility of support through educational or social service systems, she appealed to the health care system for what she thought would be temporary assistance. A new mental health wing had kindled her hope that psychiatric expertise could address Drew's behaviour without "blame," but, as she puts it, the result was "absolutely unforgivable." The family was presented with two "choices" – criminal or medical incarceration of Drew. Though the family expressed their wish for neither, when pushed, they strongly resisted criminalization in favour of involuntary committal to a mental hospital. Even to secure this so-called option, however, the family had to resort not only to threatening a dramatic physical act of resistance (accompanying Drew to jail) but also to an appeal for assistance from someone with higher political authority than the medical personnel involved.

In this story Jo conveys how a proactive attempt on her part to prevent her son from being held responsible for a situation he had not created, resulted in the very outcome she dreaded – his incarceration. The perversion of her intentions highlights the gap between her holistic view of Drew and of her role as his advocate and the medico-legal system's conflation of his behaviour (aggressiveness) with disability and "social threat" and its response of stripping him of rights, as well as Jo and Rod, Sr., of parental rights. The family's encounter with the mental health system also highlights the longstanding contestation of boundaries between medical and criminal frameworks,

particularly with respect to people with intellectual or mental health disabilities.³ The involuntary committal provisions of mental health legislation entrench a process that straddles this often blurred boundary by invoking medical diagnosis as the legal rationale for incarceration.

While an outcome of these events in Jo's eyes was that "blame" ultimately fell upon Drew, in retelling the story she is nevertheless able to shift moral culpability onto medical and legal authorities – performing resistance even while recounting defeat. As Jackson (2002) argues, stories can work to deconstruct divisions and redress imbalances, "enabling the powerless to recover a sense of their own will, their own agency, their own consciousness, and their own being" (p. 28). By expressing regret about not having "gone to court about it," Jo invokes a contemporary framework of justice and human rights and invites her listeners/audience to consider the moral and human rights implications of her story. Further, she is able to assert her agency retrospectively, emphasizing the strategic thinking behind her decision to call an ambulance, her outrage at the hospital response, the family's unanimous stand regarding Drew being sent to jail, and the use of political clout in the form of an ally in government. The account represents her as someone who had developed an acute sensitivity to the political dimensions of "disability" and had learned to act proactively and strategically, if not always successfully, to address the needs of her son.

Jackson (2002) argues that not only do stories enable the storyteller to regain a sense of agency, they may "confound or call into question our ordinarily taken for

³ Though beyond the scope of this thesis, a well developed body of academic research addresses debates and negotiations, since the mid-19th century, between prison and asylum authorities regarding the appropriate conceptual, physical and administrative boundaries demarcating criminality and mental disorder (see, for example, Moran 2000).

granted notions of identity and difference” (p. 25) and suggest how boundaries may be crossed. A notable aspect of Jo’s account of resistance to systemic authority was the family’s threat to accompany Drew to jail, a physical gesture of solidarity that would have called into question the categories and boundaries invoked to legitimize his incarceration. As “non-criminal” family members accompanying “the criminal” Drew to jail, their alignment with him would confound the efforts of medico-legal authorities to reclassify Drew as social threat and as “other.” Jo was to return to this embodied form of resistance in subsequent dealings with Woodlands whose rigid boundaries set its inmates apart from the external world, including from their families.

Drew at Essondale

Jo continues her story of Drew’s institutionalization:

But anyway, he was taken to Essondale and I went out to see him the next morning. They wouldn’t let me see him. And I couldn’t see him for three months. When they did finally let me see him, he’d gained about 40 pounds from the medication they were giving him. He had his hair shaved. And his front teeth had been taken out. Why? Apparently he was biting people, or threatening to bite somebody, and that’s what they did about it. If I look at regrets, one is that I should have laid charges against them for that.

After that, I went out there every day to see him, but I was not welcomed at all. And he was there for a couple of years. Or maybe a year, I’m not exactly sure. He got so that he could go out every day on the grounds, and I thought we were progressing. But one time it didn’t turn out well because he wanted me to take him home. You know, it was like a jail. You couldn’t do anything there. But there was no alternative. He became very angry. He never touched me or anybody else in our family, but they were having a tough time with him because *he* was having a tough time. But psychiatrists didn’t know what to do with somebody like Drew. They still don’t know what to do – it’s not part of their learning. I had taken him to a psychiatrist before, when he was at home, because I thought they could help, you know, and calm him down a little bit. But Drew just wanted to be with Walter and his friends and everybody, and he was giving me a message. I knew what the message was, but there was nothing I could do about it.

Jo's brief and matter-of-fact account of the institutional assault on Drew's physical integrity and the unwelcoming attitude towards her visits marks the low point of her story – a point at which no exercise of her agency could alter her son's treatment or circumstances. Yet despite the grimness of the picture, Jo's account of it can hardly help but engender outrage in her audience and restore some agency to her position. In the telling, she once again invokes the law to highlight the injustice of Drew's treatment: "I should have laid charges against them for that." She itemizes features of "psychiatric" care that made it indistinguishable from – if not worse than – imprisonment, voicing the disillusionment of parents who rapidly learned of the negligible difference between these two systems of control: Drew's teeth being pulled, hair shaved, nothing to do, "it was like a jail," and psychiatrists having no idea what to do for Drew apart from medicating him. Further, she represents and defends Drew's perspective, offering an interpretation of his behaviour as an entirely reasonable response to his situation and the original decision that deprived him of school and his friends. At the same time Jo indicates that, once she was allowed to visit, she went to Essondale every day to see her son – resisting the unwelcoming attitude of staff in order to affirm her role as his mother and do what she could to mitigate the impact of institutional life.

In reflecting upon these circumstances, she is well aware of the ontological and epistemological struggle she engaged in with social systems that sought to produce her son as a "disabled object" on their terms:

I never let the system take any part of Drew at all before, but then I got to this stage where the law came in. I got caught – the system took over. I would never have made that call to the ambulance to help me take him over to the hospital if I had known the outcome. I would never have done that.

Drew at Woodlands

Jo told me on several occasions about how Drew was transferred from Essondale to Woodlands, but gave what appeared to be contradictory accounts of her immediate actions. When we reviewed transcript material, she offered this as her memory of the sequence of events:

One day I got a phone call from Essondale and they said, "We just want to let you know that your son is in Woodlands." I said, "What do you mean he's in Woodlands?"

"He's in Woodlands because we took him there in an ambulance last night." They didn't warn me. They didn't tell me he was there until the next day. They didn't say why.

So of course I got in my car and went out there. I got in touch with the head psychiatrist who was the Superintendent of Woodlands [Dr. Pauline Hughes]. I went straight into her office and I said, "I understand you have my son here." She said, "Yes, your son is here."

I said, "Well if it's the last thing I do in my life, I'll get him out of here." And I meant it. So right away, you know, I blew it. But I didn't blow it – I mean, I had to say it right out. But I didn't see my son that day.

I was with the provincial organization [BC Association for the Mentally Retarded] by then, and I knew somebody out at Woodlands, so I called around and found out what ward Drew was on. I went back out there. When you visited, you were supposed to check in to the front desk, and they'd bring your family member out. You'd sit in the waiting room for however long they wanted to be bothered with you, and then they'd come and get your family member and take them back. That was your visit.

But when I walked in, the woman at the desk was on the phone, and I thought, "Good, that's great!" So I just walked right past her and up to the ward and hammered on the door. This man came to the door, and I literally put my leg in the doorway. And he said, "You can't come in."

I said, "I'm coming in. I'm going to see my son." And he said, "Well you can't do that."

I said, "I'm coming." So he got all flustered and of course he was just a staff person, he didn't know what to do. If he left me, I would come in. If he didn't leave me, we would be standing there still, me with my leg in that doggone door. And he knew it!

So anyway, he did leave me finally, and somebody else came and I said "I've come to see Drew." They didn't know what to do. They couldn't

bodily remove me because, you know, it was against the law to do something like that, so finally they said, “Come on in.” Well of course when he saw me, he came rushing over and grabbed me and, “Take me out of here” idea. He didn’t say it but that’s what he was saying: “Oh gosh, I can go home.” But he didn’t get home. He didn’t get home.

So that’s when I knew the only way to get Drew out of there was to actually be part of closing the place. Simple as that, you know. That’s when I decided personally that I would fight with people to close it.

In what she presents here as a significant turning point, Jo mobilizes her body as an instrument of resistance to cross and challenge boundaries. Having earlier taken a physical stand with her family to resist Drew being sent to jail, she describes using her body here to disrupt the coherence of institutional authority as it was configured in physical space. First, she transgresses all professional protocols to walk into the Superintendent’s office and verbally throw down the gauntlet. Second, she breaches the rigid boundary between staff and visitors to proceed past the front desk directly to Drew’s ward, where she lodges herself in the doorway – confronting authorities with a physical act of transgressing their boundaries. These actions are all the more remarkable when we remember Jo’s less than five-foot frame. Interestingly, Jo invokes the law as a higher authority that would protect her as a “visitor” from being bodily removed. Not only does this highlight the stark contrast between her legal status and Drew’s, but it points to a fissure in the institution’s authority structure – offering just enough of an opening for Jo to wedge herself – literally – into its ideologically ambiguous space.

In reconsidering the stories she recounted about this period, Jo commented:

You know, it’s interesting – and this maybe isn’t interesting to your professors – but it’s the thing that motivates us, these horrible things that happen to families. People don’t know about this kind of treatment and the reason that Woodlands is gone. It was the last place on earth I wanted my son. It was hell on earth as far as I’m concerned.

As Jo articulates so poignantly here, her stories are intended to convey an understanding of what motivated parents like herself to become activists. But more importantly, in these stories of events that seemed to overpower her and deprive her of the ability to care for her son, she finds numerous ways to reclaim her power, foreground her agency and hold others to account. She accomplishes this at one level by describing acts of resistance – imagining alternatives, calling on higher authorities, using personal contacts or physically taking a stand. But she uses strategies of storytelling to accomplish resistance at a narrative level – using regret to call the actions of others into question, reconsidering decisions in retrospect, invoking the law and inviting her audience to take a moral stand as witnesses. French & Swain (2006) suggest that telling stories of lived experience that address disability history and activism contributes to a “politics of hope” in which the experience and perspective of people with disabilities takes a priority position. Jo extends this idea to the experience and perspective of parents who have acted as disability allies. By offering her narrative of resistance to “these horrible things that happen to families,” she insists upon optimism and contributes to hopeful activism by affirming the power of imagination and action to create new possibilities.

CHAPTER 4: ORGANIZED ACTIVISM

This chapter presents some of Jo’s stories about her advocacy activities at an organized level, focusing on her efforts with other parents to close Woodlands and other large institutions and on her activities to support the rights and political engagement of people with intellectual disabilities. I juxtapose these with Jo’s accounts of what she was learning about Drew’s treatment inside the institution, in order to highlight two of her narrative objectives: conveying an understanding of the systems of discrimination and abuse that fuelled her activism and affirming the potential of activist mothers (and families) to exercise agency and intervene in social processes. Maddox (1997) refers to resistance as a response to “transgressions of boundaries of the body, the home, or the community by a dominant power” (p. 279), and here Jo vividly demonstrates resistance to intrusions upon the body of her son, the integrity of her family, and the agency of families who sought to improve the opportunities and circumstances of their children with intellectual disabilities (p. 279). At the same time, Jo’s accounts of her activism attempt to question, blur and transgress imposed boundaries (Jackson 2002, p. 25) between disability and normality. And finally, she demonstrates her willingness not only to resist dominant authorities but to push the boundaries within parent organizations.

Supporting “self advocacy”

As indicated in previous chapters, Jo’s organized advocacy activities began long before Drew was institutionalized. When Drew entered kindergarten she joined the

parents' association in the North Vancouver community and soon took up a leadership role. A major focus of early parent organizations was securing educational opportunities for children with intellectual disabilities. However, Jo recounts that while serving as chair between 1965 and 1968, she persuaded the organization to support adults with intellectual disabilities to serve on its board of directors, creating "the first association board that had a person with a disability on it in Canada – probably on the North American continent." She went on to become involved in the provincial advocacy organization, then called the BC Association for the Mentally Retarded (BCAMR), where she served as the president from 1974 to 1976. In that role she also supported people with intellectual disabilities to hold their own meetings and speak out on issues that concerned them:

We [BCAMR] had a conference in Victoria, so we asked some agencies to bring a person with a disability and we'd pay for it. Some did and some didn't, you know. But there were quite a few there in Victoria at this conference.

And I'll never forget it, because I asked the hotel – and I keep saying "I," but you really had to go against the tide because everybody hadn't kind of gotten into that frame. There were just a few that really believed in the advancement in that direction. So anyway, there was a nice theatre there, and I said to the hotel, "I don't want anybody else using this theatre because it's going to be for the people with a disability to have a meeting." So we had a big sign "For people with disabilities only, thank you." (*laughs*) I got in trouble for that [from others in the organization]. And they had a lovely time! And everybody else wanted to be in there to see. We said, "No, not allowed, this is their meeting."

Jo recounts that she continued to pursue this direction provincially by assisting people with disabilities to organize the first Canadian meetings of People First, an organization run by people with intellectual disabilities to voice their concerns. She also brought this issue to the Canadian Association for the Mentally Retarded (CAMR), persuading them to involve people with disabilities on their board and to support a

national People First organization. But as she notes in the story above, it was viewed as radical, even among the supportive community of parents and advocates, to foster the activism of people with intellectual disabilities, and Jo was not initially supported. As Gabel & Peters (2004) have argued, resistance is important within disability discourse as well as in relation to dominant social structures and processes (p. 596), and Jo demonstrates here that even within activist organizations, she was prepared to challenge limited conceptions of the capabilities and rights of people with intellectual disabilities.

Organizing parents

During her participation on the board of BCAMR, Jo attempted to persuade the provincial organization to lobby for small community-based facilities and to oppose institutions or large community facilities, but was not able to garner enough support to go forward with the idea (Panitch 2008, p. 65). However, an opportunity to go beyond BCAMR to organize parents arose in 1976, when noted American advocate for the rights of people with intellectual disabilities Gunnar Dybwad took up a visiting professorship at the University of British Columbia. Formerly the executive director of the Parents and Friends of Mentally Retarded Children in the U.S. (later called the National Association for Retarded Citizens), Dybwad visited Woodlands and made its deplorable conditions the subject of a public lecture, which garnered front page coverage in *The Vancouver Sun* (ibid.).⁴ Jo recalls that the 1976 headline called for Woodlands to be closed down:

Gunnar went out to see Woodlands and when he came back he said the place should be set on fire – “Take the people out and set the place on fire!” He had some choice words – he was like that! It was really quite

⁴ According to former employee V. Adolph, Dybwad’s views contrasted with those of Swedish “normalization” proponent Bent Nirje, who apparently endorsed Woodlands programs after a 1971 visit there (Adolph 1996, p. 104).

something. He was somebody who kind of told us that we were on the right track, encouraged us – a sweetheart of a man.

The news coverage also prompted at least three parents to contact BCAMR with concerns about their children in Woodlands. Jo recalls a conversation with Alan Favreau, executive director of BCAMR at the time, in which they both recognized, “This could be it – this could be our chance!”

The following is Jo’s account of how parents came together:

Al Favreau put a meeting together. He’d heard of another family that were upset, who are still with us today and their child is still in the alternate system. We had tried before to get families together, but we couldn’t find a way to get to the families of people at Woodlands because they wouldn’t give you any names out there and they wouldn’t introduce you to anybody.

So we got together a few meetings, with only a very few families at any of the meetings – you know, probably four to six. But this small group of families, we decided we wanted something better and we wanted Woodlands closed. We said, “Let’s see if we can close it and get an alternative.” So if there was a breakthrough, that was it – people realizing that this was not good enough. Some of these families ... I’m not going to say who they were, but I can remember this one mother crying and saying “Well you can’t close the place!” And this mother has been extremely active in the whole process ever since, but at the time, people just couldn’t imagine that. They were afraid.

So I guess that’s something I’m grateful for, that I could imagine it. I’d had that kind of awareness awakened. I had been through training and worked in hospitals long enough, and saw abuses. So I knew it wasn’t the place I wanted my son. And if it wasn’t good enough for my son, why would anybody else want it?

So that was kind of the start of the whole thing. From then on, it just rolled because we had this small group of families.

Jo acknowledges the influence of the external validation by Gunnar Dybwad in affirming her ideas and helping to crystallize the goal of closing down the institution – the “breakthrough.” The opportunity to contest the institutional system in B.C. also arose in a context of increasing challenges to institutional systems across the continent, including

prisons, mental hospitals and institutions for people with intellectual disabilities. Sociologists in the 1960s (notably Goffman 1961, and Blatt & Kaplan 1966) critiqued and exposed the dehumanizing conditions of total institutions. Goffman contributed to the development of “labeling theory,” arguing that social labels actually produced “deviant” or “normal” behaviour by eliciting performances based on “scripted” expectations associated with different social roles (Goffman 1961). Wolfensberger (1992) applied this approach specifically to people with intellectual disabilities, arguing that supporting them to live in non-institutional situations that were as “normal” as possible would enable them to integrate to a greater degree in mainstream life (Rothman & Rothman 2004, p. 449-50). During the 1970s, Wolfensberger spent a year in Canada as a visiting scholar at the invitation of Canada’s National Institute on Mental Retardation (NIMR) and widely disseminated his ideas about “social role valorization” (earlier referred to as “normalization”) in lectures and workshops across the country. The NIMR was supported by the Canadian Association for the Mentally Retarded, where Jo had already become active as a B.C. delegate by 1976, and would later serve as national chair.⁵

By 1976, Jo had already linked her personal agenda (“I’ll get my son out of here if it’s the last thing I do”) to a collective one (“If it wasn’t good enough for my son, why would anybody else want it?”) and had gained experience and leverage as an activist parent. Her account of these early family meetings suggests that she played a key role in conquering parents’ fears and persuading them to support the closure of Woodlands. In her story of refusing to be daunted by the lack of formal support from BCAMR and

⁵ In 1984, Jo was also appointed chair of the NIMR board.

seizing an ideal opportunity to organize families beyond the organization, she affirms her agency and determination, and demonstrates her capacity to recognize potential allies wherever they appeared.

Approaching government

Jo recalls that the group of families requested a meeting with the Minister of Human Resources to discuss their concerns about Woodlands. The deputy minister with whom Jo was acquainted arranged the meeting, suggesting that the families meet the minister on the Woodlands site in New Westminster.

So we said okay. So six families went out there, fathers and mothers – no brothers and sisters at that time because they were in school. I look back and wish we had brought them in, but anyway, we had this meeting out there at Woodlands. The minister, Bill Vander Zalm, was there. There was a crowd of people outside, and we asked what was going on. He said, “Well I’ve got the press outside, and did we mind?”

And we said, “What have you got the press out there for?”

“Oh, I’ve got a big announcement to make.”

And we said, “Oh, what’s the announcement?”

And he said, “Well, we’ve got two million dollars and we’re going to make this the best and most beautiful institution in the world.”

Clearly, the provincial government had intended to preempt the families’ agenda by emerging from the meeting with a press announcement that would appear to respond to their concerns. As Jo tells it, the family delegation refused to be swayed:

Well, two million dollars is a lot of money. But you know what we said to him? “Take the money back to Victoria, we are *not* interested.” Well, he was absolutely spellbound. He could not believe we had said this to him. We started to leave. But he said “No, no, sit down and tell me what you want to do.”

So we said “We want to close it down. We want to take the people out and have them live in the community.”

And he said, “Well, who are you going to take out?”

And we said “Everybody.”

And he said, “You can’t do that! You can’t do that!” He was just horrified! He lost all the colour in his face!

We said, “Yes, we think we can.” We told him, “We want to take them one at a time, and we want to start in the back wards.”⁶

He said, “Well why?”

And we said, “Because if we can do it with those people, then anybody can come out.”

Now, the guts of 12 people – six families! So he went out and told the press to go, that he didn’t have an announcement. So that was the start of it.

In reflections upon this exchange, Jo remarks on the strategic bravado of the families in that meeting:

We didn’t know, we didn’t trust ourselves. I mean we *said* it, but then we went home and sweated blood because (*laughs*) how do we *do* this, you know? When I think of it now I think, holy smoke, we must have been nuts! But anyway, you know, we just made up our minds. That’s what it was all about.

Nonetheless, underlying the group’s improvised stand was a firm conviction of moving in a direction that would build on the values of inclusion and respect:

It was having faith in our children and in the community itself, thinking yes, we can bring them out and they will be fine. They’ll be fine. To me that was the biggest breakthrough – to convince people that this community is *their* community [residents of Woodlands] as well as yours and mine and everybody else’s. We’re doing them a great disfavoured by putting them out of the community and leaving them there for a lifetime.

From this meeting on, as Jo describes it, “the families were in control.” However, with Woodlands and Tranquille operating at maximum capacity, the provincial government was also receptive to moving residents into the community to relieve

⁶ Woodlands operated several residential buildings, each with numbered wards. Residents were assigned to wards based on the severity of their disabilities. The “back wards” provided custodial care for the most severely disabled.

overcrowding and waiting lists. Further, by this time, governments were entering a period of neoliberal transformation of the welfare state and attempting to reduce public responsibility for spending on marginalized groups (Chunn, Boyd & Lessard 2007, pp. 11, 23). Government ideological and budgetary goals and a community agenda for greater citizenship rights for people with intellectual disabilities coincided to create an opening for activist parents to create new possibilities (Metzel 2004, pp. 432-35). In B.C., Woodlands had begun to implement programs to prepare some residents for release into the community, although these were designed and controlled by Woodlands staff (Adolph 1996).

The core group of parents called themselves the Woodlands Parents Group. As time went on, Jo recalls that it was the mothers who carried the work forward, as most fathers had full-time paid employment in the labour force. The Woodlands Parents Group “started campaigning with the families” to gain wider support, but had to tread carefully around Woodlands staff whose disdain for parents like Jo was palpable (“Oh, they hated me out there!”):

We had tried to get to families, you see, but of course we couldn't get any names out of Woodlands. So we decided we had to do this a little bit sneakily. They had this newsletter at Woodlands that they sent out to families. So we asked them if they'd put a flyer in there from us – the Woodlands Parents Group. Oh it took us a long time to put that notice together, I'll tell you, so that we didn't blow the whistle. We asked if anybody was interested in getting, you know, a “better way” for their family member that's in the institution. So what they thought was that we were getting support for Woodlands to get more money, you see. So they put it in, with a little tear-off section to send us. We got about 350 responses. So then we had these addresses and phone numbers and we bombarded them with information about what we wanted to do. So that became our basis, the basis of it.

Moving residents out of Woodlands

With support from the minister, an active ally in the deputy minister, and a growing family contact base, the group set up the Community Living Society (CLS) and submitted a proposal to the provincial government with a plan for how they would begin to bring individuals out of Woodlands. For Jo and others who had little administrative experience, every step of the process was a challenge. A small seed grant from BCAMR allowed Jo to find someone to help write a proposal. By the middle of 1977, the project was underway, and the provincial government announced its long-term intention to relocate many institutional residents to the community (Panitch 2008). As Jo put it, “He [the minister] took that money and he put it through the CLS.” However, with a government agenda driven by economic and political concerns rather than human rights, government agents did not initially embrace the view that everyone could leave. The province hired a special consultant to work with the group, but as Jo describes it, the consultant was hamstrung by budget constraints and didn’t understand the goals of the family group. He focused initially on taking the most capable people out of the institution, whereas the families had wanted to start “in the back wards” to prove that the principle of community living could apply to all.

Within a year, the consultant had left in frustration, and a consensus between the deputy minister and the families resulted in Jo being placed in charge of CLS. She describes the moment this was first proposed to her: “I was standing there and – I’m only a mother, for gosh sakes, you know? Never run a business in my life! I was speechless. Absolutely speechless. And I’m not sure whether they knew I could do it” or whether “they just got tired of listening to me!” Jo’s modesty seems misplaced, given her already

significant accomplishments as the former chair of the association in North Vancouver and her recent post as chair of the provincial BCAMR. Yet her concern about inexperience as an administrator was genuine. Nevertheless, the new role offered her an opportunity to refocus the group's efforts on bringing out people that government and Woodlands staff viewed as unable to succeed in the community:

Then we started back where we wanted to be, which was taking people out of the back wards, to prove that there was nobody that had to be left. And that worked magic. I think we were being looked after by some force (*laughs*).

Jo also credits the talents of a small team of trusted “brokers” she assembled to work with each resident and their family, develop community living plans and individualized budgets to meet their needs, and present the plans for government approval. “They [the government] gave us individualized funding, but we had to prove first the money that we needed, and secondly the money that we used.” For Jo, the key to their success was the people involved:

The whole process depended on so many people – there was no hero in it at all – and we were so fortunate to get so many wonderful young people. And they didn't want to go *against* the system, they wanted to improve the system – but they didn't even know that's what they wanted to do.

All of those young people, you know, they didn't have training or anything. It's just a sense in the soul about fairness and autonomy. It's called the spirit, you know what I mean? I guess if we were looking for a quality in a person, that would kind of explain what it was. And when someone didn't have it, it was pretty obvious. I can't tell you *how* it was obvious, it just was.

As an administrator then, Jo was guided by her intuitive “gut” feeling about people (in much the same way as Drew), and asserted her right to set aside traditional hiring practices.

At a time when, as Jo tells it, Woodlands staff “figured we would fail” and “were just laughing at us,” she recalls how she and Gerry, a Woodlands staff member, came to know each other. Gerry later joined the CLS staff:

I don't know I guess people were talking or something as I was going down the hall [at Woodlands]. Gerry tells me this now. He apparently said to this other staff person, “Who is that woman?” And this guy said to him, “Oh that's Jo Dickey. She thinks she's going to close this place down. You don't need to bother with her.” And then the guy hooted. Of course, Gerry, being Gerry, made a beeline for me.

She describes later observing the skills Gerry had with people:

I spotted Gerry at Woodlands by the way he managed my son in a crisis. We were at a Christmas party out there with Drew and we were leaving. Drew got very angry because he was trying to get us to take him home, he was upset and he got aggressive. All these people came running with needles and straight jackets, but Gerry came along and took him in his arms and held him. And he said to all the people, “No, stay back, he's ok, he's ok.” They both ended up on the floor because Drew was so strong by then. But Gerry was caring. That was the day I knew we had to have this young man [at CLS].

Despite unorthodox hiring practices, Jo saw the importance of values training and involved everyone in discussing and clarifying values and principles at CLS:

We all chipped in. If you don't have the person in the centre of this whole thing, then you lose out, the person loses out. And that's where the rights are kept and respected. Next in the circle is families and other people who are close. And then it just goes out like this. The other important thing was keeping the idea that this is *Drew's* home, not the service agency's home, and staff come in to help Drew in *his* home. We just pressured and pressured that. And we took people out [of Woodlands] three at a time, with no more than three in a home.

While Jo does not reference the work of Wolfensberger here, she had already been exposed to his ideas through the National Institute on Mental Retardation (later called the Roehrer Institute), and much of the value base developed at CLS aligned with his principles of “social role valorization” and supporting people to live in more home-like settings.

Treatment inside Woodlands

By the time the small group of families met with Minister Vander Zalm in 1976, Drew had been institutionalized for eight years. During those years, Jo recalls experiencing not only direct hostility from Woodlands staff, but also haunting concerns about the safety of her son. She knew he had been beaten on more than one occasion and later found photographic evidence to confirm it in his patient files. “I don’t know if it was because of me and my big mouth, but I tell you, he was beaten up.” She could not confirm whether it was by staff or other residents.

She recounts an incident involving the much-dreaded “side rooms” at Woodlands. These were locked cells where patients were confined in isolation for aggressive or noncompliant behaviour:

Did I tell you about the day I was put in the side room? I’m not kidding you. I went to see my son, and my son was in the side room, and they said, “If you want to see your son, he’s in the side room.” So I said, “Of course I want to see him.” So I went in. Here’s my little guy, and the room is about five feet by five feet and – you’ve seen those rooms. And so I went in and the attendant left, locked the door, and I was in there for about three hours.

She commented only briefly on this experience, which seemed designed to extend discipline and intimidation to her as much as to her son. Yet Jo’s response was to physically cross into a spatial domain not intended for visitors, entering the cell to comfort her son, physically and symbolically joining him in his confinement (recalling her earlier threat at the hospital to go to jail with him). Her account of this event demonstrates how stories themselves can call into question established categories and boundaries.

Jo also described one of Drew's weekend visits home, when she discovered a physical condition (a prolapsed rectum) that led her to strongly suspect sexual abuse:

I phoned our family doctor – the one who had brought him up since he was little, because I trusted him and he was really good to me – and I told him what I had found. There was dead silence. And I said to him, “I think it's sexual abuse.” And there was just a dead, dead, dead silence. And do you know what he finally said? “I never thought of that.” All of a sudden the light bulb went on. Because he had kept saying to me that the place was okay – he had recommended sending Drew there. Obviously he had never thought of abuses out there.

Jo returns here to the failings of the medical profession, using this story to challenge and hold to account both those inside Woodlands who failed to care for Drew and those outside who failed to inform themselves of institutional conditions and to explore other options for families.

Though fearing that Drew's abuse may have been a consequence of her increasingly visible advocacy activities, Jo held on to the long-term goal of getting him and others out:

You know, I'd feel caught. I knew what I was doing so I just thought, Drew you're going to have to help me. I apologized to Drew in my prayers, you know what I mean, all the time, but at least he had all those years to live in the community, and I don't regret that at all.

Jo offers these stories as a way to account for her persistence in her advocacy, while at the same time indicating that it had a cost. As she put it: “Oh it just about killed me. It did kill a lot in me. But it also nurtured something in me, for sure – you'll never get him out of there unless you close the place.”

Drew moves into a home in the community

Despite Jo's concerns about Drew's safety, he was not one of the first to come out of Woodlands. Jo recalls that “before he came out, Gerry used to take him home on

weekends. Drew just loved him. And I just loved Gerry for looking after my boy.” Jo recounts that when a home was finally prepared for Drew – to be shared with his long-time friend Walter and another Woodlands resident, Peter – she “sort of kidnapped him” from the institution:

I went out [to Woodlands] and got him for supper. [Through CLS] we had a house ready for him in North Vancouver. So I went out to Woodlands and thanked them for getting him ready to go out. And I never took him back. I expected the police at my door at any minute – but they never came.

I brought him to my house first. Doug was there. Gerry and I had set up Doug to look after Drew. We needed someone who could manage Drew. I trusted Doug. He had been with L’Arche⁷ – so that was a bonus. Then we all went down to the new house. I slept there the first few nights. Doug took a bit of a beating! Drew was strong and he fought at first – he didn’t want to go back, but he didn’t know whether to trust this man. He had been so abused, he flew at everybody, he didn’t trust anybody. Later Walter moved in – he was so pleased. They were like brothers. They lived together for the rest of Drew’s life.

In describing the careful work of bringing people out of the institution, Jo referred to several strategies that contributed to success: involving the individual as much as possible in planning; gradually familiarizing them with the communities they would move to; reaching out to families to participate in planning; choosing workers based on their human qualifications, rather than paper credentials; trying to ensure that friends came out together; and limiting the number of residents in shared community homes to three so that the home remained *theirs*. She also referred to the considerable efforts required to build trust in communities where “NIMBYism” (not in my back yard) reigned:

We went out to the communities to talk to them. We took cookies over to the neighbours to introduce ourselves. But I’ve never been so abused as I

⁷ L’Arche is an international movement of communities, founded by Canadian Jean Vanier, “where people who have developmental disabilities and the friends who assist them create homes and share life together” (L’Arche website: www.larche.ca/en/jean_vanier/. Downloaded July 18, 2008).

was in some of those community meetings. I think some of them would have lynched me if they could have.

In 1978 the provincial government made a public announcement of its intention to close all large institutions for people with intellectual disabilities, though it would take another 18 years before this was fully accomplished. Though the government's reasons for adopting the strategy likely had more to do with a neoliberal agenda of downsizing government services, for the families who initiated it and community organizations that came to support it, the strategy represented a step toward integrating people with intellectual disabilities into society and supporting their human rights.

Becoming a national and international activist

Jo continued directing CLS for about ten years. The society's work gained worldwide attention, and with Drew safely established in a home in the community, she traveled widely to speak to families about how CLS had moved people out of institutions and into communities. She recalled speaking in Holland, Italy, Austria, England, Scotland, Ireland, Australia, the United States, Brazil, and Puerto Rico. She was also elected to the chair of the Canadian Association for the Mentally Retarded (CAMR) in 1979, a position she filled for three years. During her tenure, she took the campaign to close large institutions onto the national stage. In addition, the association played a key role in lobbying for the inclusion of people with physical and mental disabilities in the Canadian Charter of Rights and Freedoms. For Jo this was a major accomplishment:

It was interesting because some people had never heard of such a thing. It never entered their head that Drew Dickey could be a voting member of our community – that was one thing. But the second thing was the idea that they had rights. You had to distinguish that the Charter covered what they call people with an intellectual disability, because people didn't take it for granted that the Drew Dickey's of the world would fit in there. You

know, they're human beings, and just because it takes a little more support for my son to have those rights recognized for him... Aren't we citizens that want to help everyone be as covered with those kinds of safeguards as we are? Personally I am very glad it's in there today. I think it really was a milestone.

As an officer of CAMR, Jo also participated in the international organization. As she describes it:

If I may say so, it wasn't really up to snuff, you know? Canada was way ahead... They were called the International whatever-they-called-it for the Retarded (*sic* - International League of Societies for the Mentally Handicapped), and it was only after Canada really pushed them to change their name and leave the label behind that they changed it to Inclusion International. That was Canada that did that. I've got a reputation over that. I think that was why I didn't get asked back – they wondered what was coming next!

Jo returns here to one of her favourite personal strategies, which was to use humour both to deflect resistance to her ideas and as an indirect expression of pride in her achievements.

“My motivator, my audience, my life”

Jo's son Drew died in 2004 at the age of 49. Despite his ongoing frail health, Jo experienced it as a shock, though it has not deterred her from continuing her activist work:

Drew had been so close to the edge so many times and made it through, I just didn't believe it would happen. The thing that should prepare you is, in the end, the thing that doesn't. But he had beaten the odds so many times.

Even in his final days, Jo had to call upon her advocacy skills to negotiate with Drew's doctor:

The worst part was that the doctor wanted to pull the plug on him. He was in hospital for about 10 days. The doctor said we should end it. This wasn't his regular doctor – he wouldn't have done that. The doctor asked me, “Can't you see he has no quality of life?” I said to him, “You can't

compare him to you. He is loved, he has a home, he has friends and family. How can you say he has no quality of life?" It was because he had a disability.

Finally, in describing the loss of her son, Jo affirms his humanity, her relational connection to him and the motivation he brought to her lifetime advocacy work:

I don't know why I have taken it so hard – I just can't believe I have. I just miss Drew so much. It just hit me like a ton of bricks. He was my motivator, my audience, he was my life.

The stories in this and previous chapters recount a shift in Jo's political location – a gradual emergence from a place of marginalized disempowerment in relation to her son's care to a position of considerable leverage, with support from families, to negotiate with authorities. While she does not foreground this progression in her narrative, the gradual accumulation of experience and political leverage (through organizing with other parents, taking on leadership responsibilities and making connections with organizations and key allies) appears to have been a strategy Jo adopted deliberately to achieve her advocacy goals. She applied her growing repertoire of personal and collective skills both to the task of resisting oppressive structures and to the challenges of creating new alternatives. Her skills in identifying supporters and connecting allies helped to organize families, gain access to government and bring people together in the CLS project who understood its vision. Her persuasive powers and improvised bravado convinced others even when she doubted herself – whether she was encouraging families to speak out, a board to adopt a policy, a minister to redirect \$2 million or a prime minister to amend the Charter. And an adherence to core values about the rights of people with disabilities

enabled her to build group cohesion, avoid diversions and navigate government political agendas.

Further, Jo draws upon a repertoire of narrative strategies to assert her agency and intervene in dominant discourses about disability. She speaks of Drew's experiences at Woodlands to hold authorities to account for numerous abuses that have never officially been redressed. She describes the use of her body to disrupt rigid institutional boundaries and categories by voluntarily entering the "side room." She continues her efforts to give Drew and others voice, by speaking to the importance of the Charter and emphasizing the value of supporting people with intellectual disabilities to engage in activism. Even her account of changing the name of Inclusion International attests to her understanding of the importance of contesting discourses through language. Jo also draws attention to the hostility, derision and intimidation she had to withstand as an activist, but demonstrates narratively how humour can deflect it and even turn it on its head as a source of pride. Finally, throughout these stories, she affirms the power of imagining an alternative and believing in families and communities to achieve it – contributing to ongoing resistance and a politics of hope.

CHAPTER 5: DISCUSSION AND CONCLUSION

The stories of Jo Dickey’s disability activism address an area of lived experience that has, until recently, fallen “under the radar” of academic research and occupied the margins of disability studies. While there are many ways to interpret such stories, I have focused on the idea of resistance as a way to frame them in relation to the research questions posed at the beginning of this thesis. The questions sought to find out how an activist mother would describe raising her son with disabilities and negotiating his care, and how she would represent her advocacy for the social inclusion and rights of people with intellectual disabilities. The research also sought to explore how stories emerge in a particular intersubjective context and how their performance can operate as a form of social action that destabilizes categories, confronts ideology and reinterprets history (Cruikshank 1997). I begin this chapter with a discussion of some findings and questions related to narrative methodology. I then summarize how Jo’s stories bring her lived experience to bear on theoretical debates in disability discourse and activism. At the close of the chapter, I address the limitations of this study and some areas it opens for further research.

Narrative methodology

In their discussion of oral history research, French & Swain (2006) suggest that narrators do not simply recount pre-existing stories but engage in a “creative process of reformulation and reflection” in relation to their listeners (p. 395). The authors also

defend the work of researchers who occupy an “insider” position, arguing that every researcher is subject to social and historical locations that shape their data and interpretations. These assertions echo theories of narrative ethnography (Chase 2005, Jackson 2002, Denzin 2001, Cruikshank 1997) that reject the notion of stories as articulations of “objective truth” or mirrors of reality, in favour of understanding stories as retrospective interpretations of memory that transform and reconstitute both the narrator and the world. Furthermore, narrative theorists argue that stories emerge through an intersubjective process between narrator and researcher. In my research with Jo Dickey, I experienced the applicability of these theories to the practice of narrative ethnography.

In Chapter 1, I discussed my position as that of a “halfie” – part “insider” and part “outsider” in relation to the politics of disability. This affected both the perspective I brought to the research process and Jo’s perception of me as an informed listener. As a result, interviews often evolved into dialogues, and from these specific dialogues the stories emerged, inflected by Jo’s recall and interpretation of memories, by her interventions in discourse and by my informed listening and questioning. As a listener “in the company of the storyteller” (Benjamin 1968, p. 100), I experienced the performance of Jo’s stories in the moment – stories embodied in her voice and physical gestures, in facial expressions, in dramatic modulations of volume and tone of voice, in pauses, repetitions, silences and laughter. Jo performed the stories improvisationally, moving from one to another and back again, following threads in different directions, and circling and eddying around the many themes that concerned either her or me. She often repeated stories or story fragments, elaborating on certain aspects in response to a question, or

changing details or slant, depending on the point she wished to emphasize or the context in which she was telling it. Through this process, I experienced her stories as recursive, fluid and changing.

As the research progressed, I became acutely aware of the interpretive process I imposed on the stories as they moved further away from the interactive sensory experience of their performance – from embodied storytelling to digitally recorded voice, from recorded voice to transcribed words, from transcribed words to selected excerpts, from excerpts to edited stories, and from edited stories to interpretive thesis. They continued to evolve and change through this process and will no doubt continue to do so in the future. The stories recorded in this thesis, therefore, represent a distillation that emerged through a collaborative process between Jo and me, at a particular time and place, in which both her interpretations and mine play a part. As Lorrie Moore (1998) reminds us: “The trip and the story of the trip are always two different things” (p 237). This thesis offers one interpretive story of “the trip,” while attempting to remain faithful to a collaborative ethical approach. Though the entire process required mutual cooperation and collaboration, there were also stages where I formally incorporated collaboration into the process by revisiting the consent agreement and reviewing transcript excerpts and edits with Jo.

At the beginning of this thesis I noted that I drew upon Castenada’s (2006) metaphor of ethnographic fieldwork as invisible theatre. As a researcher, I designed interview questions and fieldwork activities with the intention of exploring the research questions and engaging Jo in a process that would be valuable for her as well as for me. In this respect the research exceeded my expectations. Jo’s enthusiastic participation in

interviews indicated the value to her of revisiting her activist experiences and discussing the issues they raised with an interested listener. A trip to Drew's former home proved particularly important both for Jo and for the research. As she had not visited there since Drew's death, she was grateful to have someone to accompany her to see his former roommates. The visit demonstrated the power of place to evoke memories and stories, and prompted Jo to raise important issues about Drew's life and last days that she had not previously touched on.

A challenge in doing overtly collaborative ethnography is finding the balance between researcher goals and participant goals. While traditional ethnographers have often claimed to have full control of the research agenda, Castenada (2006) suggests that fieldwork is an improvisational process that can only be partially "scripted" by the researcher. Further, fieldwork must recognize and account for the subjective agency and motivations of research participants, and cannot fully control or predict outcomes (p. 84). In discussing research goals and potential outcomes with Jo, I became aware early on of her keen desire to see the development of an independent organization that would enable families to have a political voice. While my research could help serve her purpose by sharing her stories with families and empowering them to act, I saw her larger goal as beyond the scope of the research. Nevertheless, I felt that Jo perceived me as an ally and as a potential recruit in working toward this objective. She asserted that families need someone "who believes in them" to help with this endeavour, adding:

You understand their situation, and that's what families need is somebody to understand them. And you don't only understand *my* situation, but you understand Drew's even better, and for me that's a quality that's more important than you understanding me, because he's got more need and he's a sinless person, and I'm not.

As she persistently, but ever so gently, raised this issue on different occasions, I experienced the power of Jo's combination of focused passion and soft-spoken persuasiveness. I limited myself for the moment to the hope that creating a narrative "ethnography of the particular" (Abu-Lughod 2006, p. 160) based on Jo's experience would be one way to contribute to a polyphonic "family voice." Jo and I continue to explore other ways to disseminate this research to a wider audience.

In his essay, "The Storyteller," Walter Benjamin asserts:

People imagine the storyteller as someone who has come from afar. But they enjoy no less listening to the man who has stayed at home, making an honest living, and who knows the local tales and traditions" (Benjamin 1968, p. 84).

Benjamin argues that the best storytelling combines "the lore of faraway places, such as a much-traveled man brings home, with the lore of the past, as it best reveals itself to natives of a place" (ibid.). In considering Jo Dickey's stories, I came to view them in this light – as incorporating intimate knowledge of this place, British Columbia, and its past, while representing an experience that for many of us is unfamiliar and seems to "come from afar" – an experience of disability oppression and family disempowerment coupled with a long-term commitment to resistance and activism that helped bring about change.

Benjamin adds that "an orientation toward practical interests is characteristic of many born storytellers" and the storyteller is a person "who has counsel for his readers," counsel that, in the best of circumstances, will be "woven into the fabric of real life" as wisdom (p. 86). Jo's stories arise from very practical concerns about the opportunities, rights and support services available to her son and others with intellectual disabilities,

yet they also offer interpretations of experience that intervene in dominant discourses and contribute both “counsel” and knowledge to contemporary social sciences.

Stories and resistance

I have analyzed Jo’s narrative through the frame of resistance, for this stands out as the essence of the wisdom she has to offer. French & Swain (2006) argue that storytelling by individuals who have experienced disabling social processes contributes to an understanding of the complex relationship between individuals and society. It illuminates the diversity of disability experience while addressing broader social processes that “marginalize, limit and shape people’s lives” (p. 383). As Gabel & Peters (2004) have suggested, resistance is an important concept to hold in view in the development of disability discourse. They argue resistance enables people to “push against dominance” while also pulling others into disabled people’s way of seeing (p. 595). This can apply particularly to narrative accounts that bring forward situated knowledge to challenge hegemonic tendencies both within mainstream society and within critical academic studies. Jo’s stories foreground the perspective of an activist mother who, though she may not adopt a particular “party line,” is committed to emancipatory goals for people with disabilities (Gabel & Peters 2004, p. 596).

French & Swain (2006) also suggest that stories representing “voices from an excluded past” contribute to a “politics of hope” by reclaiming history, providing a foundation of knowledge on which to generate and support change, and fostering collective empowerment and resistance (p. 395). As a mother speaking from the excluded past of activist parents, Jo contributes to all these dimensions of hope. She specifically enumerates strategies that proved useful in resisting disabling social processes. These

vary from improvising interventions with neighbours or shoppers, resisting or rejecting medical or professional advice, and reaching out to other parents, to seizing opportunities opened up by public events or contradictions in public policy, taking a physical stand to disrupt imposed boundaries, organizing parents and people with disabilities, and meeting government officials to advocate for changes in services and laws. The objects of her resistance range from individuals who express disabling ideology, to parents or even disability organizations who feared making radical change, to professional authorities (medical, educational, health care, social service) and institutional staff who engaged in disabling practices, to government agencies and elected officials who held authority over public policy and legal protections.

As her stories attest, Jo's activism (and that of many other parents who acted with her) arose from the emotional bond with her child rather than from a theoretical analysis of the social construction of disability. Nevertheless, her stories also articulate an experiential understanding of disabling social processes. Her activism emerged in the contradictions and spaces between a mother's perceptions of her son and her experience of the processes that sought to define and limit his options and deny his rights.

Resisting the medical model and eugenics

As the discussion of narrative ethnography outlined in Chapter 1, the performance of stories allows storytellers to connect "large issues to local contexts" and to disrupt and intervene in hegemonic ideology (Cruikshank 1997, p. 55). One of Jo's narrative strategies is her insistence upon constructing Drew as a person with citizenship rights. From the outset she chooses not to describe Drew in terms of impairment, but rather to emphasize his personality, his sense of humour, his expressions of agency and his

relationships with others. She focuses on her maternal connection to him and his position as an integral member of the family. This strategy resists medical models that emphasize and pathologize impairments, and it conveys an understanding of Drew's disability as socially constructed by processes that sought to "produce" him as an object that could be controlled by medical or other state authorities and policies. Further, it represents resistance to professionals who seek alliances with parents in their efforts to bring children under the control of authorities. Most importantly, it poses a significant challenge to eugenics discourse that sought to define people with intellectual disabilities as non-members of families, as social or family threats and as *personae non gratae* existing outside the parameters of humanity.

Challenging liberal constructions of personhood

Jo's narrative strategy also challenges liberal ideology that establishes rationality and independence as the qualifying criteria for personhood. As the discussion of citizenship in Chapter 1 argued, the liberal construction of personhood has for the most part excluded people with intellectual disabilities from discourse about justice and rights. Kittay (2001) observes that people with intellectual disabilities are "not recognized as authors or agents in their own right" (p. 559), and have "rarely been seen as subjects, as citizens, as persons with equal entitlement to fulfillment" (p. 558). In her persistent effort to describe Drew in terms of his agency, his subjectivity, his membership in the family and his entitlement to rights, Jo speaks to this invisibility. Through her storytelling, she displaces and contests representations of people with intellectual disabilities as less than fully human. In her defence of his point of view and her support of a political voice for "self advocates," she looks beyond liberalism, as Kittay suggests, for a model of

citizenship that extends justice to those who cannot achieve “cognitive parity,” while “still respecting the values of autonomy and liberty propounded by liberal theory” (ibid, p. 560).

Contesting disability discourse

In approaching narrative in this way, Jo also speaks to the limitations of disability activism and discourse that have sought to integrate disabled people by insisting that independence and productivity are “no less attainable for the disabled than for the nondisabled” (Kittay 2001, p. 558). This approach emerged from the social model of disability that saw the experience of disability as primarily constructed by social, environmental and economic barriers to full participation in society. As Kittay argues, however, “the impairment of mental retardation is not easily addressed by physical changes in the environment” (ibid., p. 558). She argues that disability discourse has failed to apply a social constructionist critique to the liberal concept of personhood and has, as a result, failed to take up issues that would ensure the citizenship of people with intellectual disabilities. She points out that what is often required to enable citizenship for people with intellectual impairments is ongoing supportive or caregiving relationships. Thus, a substantive redefinition of citizenship that does not exclude people on the grounds of dependency or cognitive impairments needs to incorporate the concept of collective responsibility for quality caregiving.

Jo invokes this substantive approach to rights when she foregrounds Drew’s subjectivity and agency while at the same time articulating his need for support and his entitlement to state-funded care in a community setting. While her activism is grounded in liberal notions of autonomy and liberty, it focuses on extending citizenship to include

people like Drew who are dependent on others but are equally entitled, in her view, to dignity, respect and human rights. This perspective is manifested most clearly in Jo's account of activism regarding the Charter of Rights and Freedoms and her insistence that mental disabilities should not exclude a person from its protections. Her discussion of efforts to establish community living situations that respect both the self-determination and the needs of the disabled person also reflects this point of view.

Resisting interpretations of caregiving and mothering

Kittay's discussion of the complexities of caregiving illuminates some of the limitations of both disability and feminist discourse that have an impact on perceptions of activist mothers. She suggests that because good quality caregiving (as opposed to low-cost custodial care) is characterized by an attitude of "other-directedness," it does not easily align with the liberal idea of a rationally self-interested actor. Dependence on care also falls outside of the liberal notion of a self-sufficient rational citizen. Therefore, the caring relationship between a dependent person with intellectual disabilities and an other-directed caregiver,⁸ falls outside "conventional understandings of relationships between equals within liberalism" (p. 562). Feminists have productively critiqued the extent to which such caregiving roles are socially constructed as the work of women (or other disempowered classes), but in studies of families raising children with disabilities discussed earlier in this thesis (Traustadottir 1995, O'Connor 1995), an underlying assumption of caregiving as inherently a burden can also limit interpretations of the role of mothers. Kittay points out that, particularly when caregivers are parents, they adopt the

⁸ Kittay (2001) acknowledges that caregivers – whether paid or unpaid – are usually mothers, women, and/or members of other classes with limited social power. She argues that when caregiving relationships are not valued and well supported the potential is high both for exploitation of caregivers and for abuse of vulnerable people receiving care (p. 571).

role of advocate. And as this thesis has argued, the advocacy and activist role of mothers has been undervalued or overlooked in both disability and feminist studies. Jo challenges this omission by insisting, throughout her narrative, upon the validity and importance of her role as Drew's mother and advocate – indeed, she describes it as a central driving force in her life – without characterizing it as a burden. Further, she values caregiving that fosters self-determination not just in her own family, but in the community support services she helped develop. In her account of working with the Community Living Society, she addresses this issue both by noting the value she placed on the caring skills of workers (over their paper credentials) and on developing practice principles that focused on placing the person with disabilities at the centre.

Contesting interpretations of parent activism

Castles (2004) and Jones (2004) offer an analysis of mid-century parent activism in the U.S. that suggests a conservative agenda on the part of parents who sought normality in a social environment that idealized a “perfect” middle-class white nuclear family and stigmatized parents who were raising a child with intellectual disabilities. Jo's stories contest and complicate this interpretation by emphasizing the degree of resistance required for her to keep her son out of institutions and by focusing on her efforts to achieve appropriate supports for him and secure his rights. While her middle-class social location may have brought with it an expectation of traditional family “normality,” nowhere does she emphasize a need to be viewed as “normal.” Though she acknowledges her husband's initial difficulty with not having a “normal” child and her own experience of stigma in public with Drew, her advocacy appears to have been driven primarily by a concern for Drew's social inclusion rather than for her own acceptance. Further, in

determining the progressive or conservative basis of efforts to “normalize” family life with a child with intellectual impairments, it is important to consider the ideological challenge that such a strategy would have posed to the preceding half century of eugenics rhetoric and policy that defined disabled children as an evolutionary regression, vilified them as a social menace, segregated them from society and severed their family relationships. Finally, Jo acknowledges the social costs of her advocacy – being seen as a problem by the school principal, being “hated” by staff at Woodlands, being seen as too radical in parent organizations, being abused and rejected by communities who did not want homes for the disabled in their area or being viewed as an aggravation by government officials. Though she gained respect and status as a leader in the activist parent community, these negative perceptions suggest that blending in with traditional middle-class domestic “normality” was not a significant goal or even an available option.

Subverting the family tragedy paradigm

Rapp & Ginsburg argue that circulating stories of families that redefine themselves and broaden their kinship network to include and support children with disabilities disrupts the cultural script equating disability with family tragedy. They also see such stories as critical to counter the neo-eugenic discourse of genetic perfectibility that permeates contemporary biotechnology and reproductive discourse. Jo’s narrative attests to the fact that families have been re-imagining themselves and contesting “tragic” constructions of people with intellectual disabilities since the mid-20th century. Like the accounts recently offered in the work of Panitch (2008) and Schwartzberg (2005), Jo’s stories speak to the social challenges faced by parents of children with disabilities, but they also address the richness gained from parenting a child with intellectual disabilities,

the expansion of social networks parents experience, and the value of embracing the range of cognitive abilities found among people.

Holding authorities accountable

Jackson (2002) argues that stories enable the storyteller to “make and unmake” her world, to make links between private and public realms and to actively rework events so that they are no longer experienced passively (pp. 12-15). Jo demonstrates this most vividly in her narrative strategy of expressing regret about moments when she failed to challenge decisions made by authorities in “the system.” She often frames these regrets in terms of justice – invoking the concept of fairness, or the potential for legal recourse – to highlight what she views as wrongs perpetrated upon Drew and the family. While the entire process of storytelling can be viewed as performative, these moments had a particularly dramatic effect in her narrative – often marked by a repeated phrase, or lowered voice, or significant pause. They were moments that invited the listener (myself as researcher, and the audiences who would read Jo’s stories) to participate as a witness and engage in retrospective judgment. In this way Jo injects moral content into her story and holds authorities accountable for events over which she had little control at the time they occurred.

Limitations and opportunities

A limitation of this research identified in Chapter 1 was its focus on the experience of a sole participant. Though this enabled an in-depth study of Jo’s story, the findings were necessarily limited to issues that emerged from her account of parenting and activism. In addition, a focus on one person who proved to be somewhat exceptional

as an advocate also ran the risk of producing a heroic biography rather than an emancipatory narrative focused on resistance to disabling paradigms. Narrative research involving more than one mother would have avoided these risks but was beyond the scope of this thesis. However, there are many parents who have participated in activism to expand the rights of people with intellectual disabilities in B.C. and Canada, and their stories warrant further investigation. In addition, a research methodology that engaged several members of each family (in addition to mothers) would provide valuable insight into family experiences of disability. And further exploring the relationship between family experiences and state policies on institutions and disability services would make an important contribution to disability studies in Canada. A particular focus on Woodlands and other large institutions for people with intellectual disabilities would contribute greatly to an under-researched area of disability studies in British Columbia.

Another limitation of this research was its potential for a narrow analysis based upon the research participant's and my own social locations of privilege. The issues addressed by the research are those that emerged from the stories at hand. These may well be different from issues that would be raised by parents of different social classes, cultural backgrounds or family configurations. Further research among a diversity of families connected to a person with intellectual disabilities – particularly by researchers from a diversity of social locations – would provide much-needed insight into a range of experiences of disabling social processes and opportunities for resistance and activism.

At the same time, Jo's negotiations of mothering, gender politics, finding or creating services, resisting disabling processes and organizing as an activist proved to be complex and nuanced, defying simplistic analysis based solely on class or privileged

status. Nonetheless, this thesis does not touch on poverty or employment issues (though Jo did give some attention to the latter), though these are central issues for many “self advocates” with intellectual disabilities. This omission points to a potential class difference between individuals with intellectual disabilities who have few family support connections and those who are well supported by family or other social networks. The issue of class as it relates to activism on poverty and employment for people with intellectual disabilities warrants further exploration.

My own social location proved beneficial in establishing a rapport with Jo that was characterized by a good deal of trust and intersecting interests. As French & Swain (2006) point out, “telling stories joins lives” (p. 395), and we enjoyed each other’s company as we grew to know each other through the research process. At the same time, the similarities I shared with Jo created the possibility that I did not apply a sufficiently critical lens to issues that might stand out for others.

Finally, this research project suggests the potential to expand narrative methodology further – both to explore constructions of subjectivity, agency and resistance as they evolve through stories and to develop innovative and creative ways to present stories for a broad range of audiences. I view this thesis as a beginning, an effort to open the door to stories of parent activism and families’ experiences of disability to contribute to knowledge in anthropological, feminist, family, and disability studies. I end with the hopefulness expressed by Jackson (2002) that storytelling offers a way to “confound or call into question our ordinarily taken for granted notions of identity and difference, and so push back and pluralise our horizons of knowledge” (p 25).

APPENDICES

Appendix A: Consent form

Form 2- Informed Consent by Participants in a Research Study

The University and those conducting this research study subscribe to the ethical conduct of research and to the protection at all times of the interests, comfort, and safety of participants. This research is being conducted under permission of the Simon Fraser Research Ethics Board. The chief concern of the Board is for the health, safety and psychological well-being of research participants.

Should you wish to obtain information about your rights as a participant in research, or about the responsibilities of researchers, or if you have any questions, concerns or complaints about the manner in which you were treated in this study, please contact the Director, Office of Research Ethics by email at hweinber@sfu.ca or phone at 778-782-6593.

Your signature on this form will signify that you have received a document which describes the procedures, whether there are possible risks, and benefits of this research study, that you have received an adequate opportunity to consider the information in the documents describing the study, and that you voluntarily agree to participate in the study.

Title: Reconfiguring Justice: How a Mother Experienced the Politics of Developmental Disabilities in Vancouver, 1955-2005 [Title later changed & approved, August 11, 2008]

Investigator Name: Patricia Feindel

Investigator Department: Sociology and Anthropology

Having been asked to participate in the research study named above, I certify that I have read the procedures specified in the Study Information Document describing the study. I understand the procedures to be used in this study and the personal risks to me in taking part in the study as described below:

Purpose and goals of this study:

The research will undertake a collaborative narrative ethnography with a mother who raised a son with developmental disabilities. It will produce a life story focused on her

experience of negotiating care for her son within the family and with medical, education, legal and social agencies outside the family, and her experience as an advocate for social justice for people with developmental disabilities. The methodology will incorporate collaborative principles and explore how performative theories apply to the co-creation of a life narrative.

What the participants will be required to do:

The participant will be asked to take part in a series of face-to-face, semi-structured interviews regarding her experiences of raising a son with developmental disabilities and her involvement in social justice advocacy. The researcher will accompany the participant to significant locations and events, and review medical records, photographs, and other family records with the participant.

Risks to the participant, third parties or society:

The research may expose the participant to mild emotional discomfort brought on by recounting difficult experiences related to parenting her child with developmental disabilities in a social context where there was little support. However, the participant is a mature parent and a long-time advocate who has spoken publicly about such experiences before. The participant will not be pressured to disclose information or answer any question that she is not comfortable with, and will be given an opportunity to review transcripts and exclude data from publication. The participant may refer to third parties in interviews and/or disclose records that identify third parties. Where identities or information are not a matter of public record, names and identifying information of third parties will be changed to comply with IRB requirements. Informed consent will be sought from anyone who may be identifiable in photographs to be used for publication, or alternatively, photographs and documents will be altered to remove identifiers.

Benefits of study to the development of new knowledge:

The research will address a knowledge gap regarding the experience of family members, especially women, as caregivers of children with developmental disabilities, as negotiators of services, and as advocates for social justice during the last half of the 20th century.

Statement of confidentiality:

Due to the fact that this research focuses on one participant's unique life story, the participant's identity will not be confidential. Names and identifying information of non-consenting third parties will be changed, unless they are a matter of public record.

Interview of employees about their company or agency:

Not applicable.

Inclusion of names of participants in reports of the study:

The participant's name will be used in reports of this study. Names of non-consenting third parties will be changed, unless they are a matter of public record.

Contact of participants at a future time or use of the data in other studies:

The researcher will be pursuing doctoral studies to continue research on family members of people with disabilities who were institutionalized in BC. Should the researcher wish to use the data from this study in her doctoral research and subsequent related publications, I consent to its use.

I understand that I may withdraw my participation at any time. I also understand that I may register any complaint with the Director of the Office of Research Ethics.

Director, Office of Research Ethics
8888 University Drive
Simon Fraser University
Burnaby, British Columbia
Canada V5A 1S6
+1-778-782-3447
email: dore@sfu.ca

I may obtain copies of the results of this study, upon its completion by contacting:
Dr. Dara Culhane, Dept of Sociology and Anthropology, 604-291-5479

I understand the risks and contributions of my participation in this study and agree to participate:

Participant signature: _____

Date: _____

I agree to contact at a future time and/or use of data in other studies:

Yes No _____

Participant last name (print):

Participant first name (print):

Participant contact information:

Appendix B: Interview dates and schedule

1. Interview dates

14 semi-structured audiotaped interviews were conducted on the following dates:

Feb. 15, 2007

May 23, 2007

June 27, 2007

July 17, 18, 19, 20, 2007 (4 continuous days – 11 interviews)

3 dialogues to review transcripts - November, December, 2007 and May, 2008.

2. Topics and themes raised by interview questions

Collaboration

- informed consent & renewal
- collaborative ethnography - process
- researcher's goals
- participant's goals
- areas of overlap, divergence in goals
- possible outcomes or products of research – thesis, articles, presentations, other forms that are accessible to community

Family description

- family situation - economic & social position, opportunities/plans
- roles of family members – e.g., parenting, earning income, household care, siblings
- participant's career role (working outside home or not)
- understanding of family as a group – e.g. important family activities
- understandings / perceptions of “disability” within family
- concepts of “good mothering” in relation to disability
- involvement of extended family members
- family's support role in relation to her son – benefits, limitations
- different periods – changes over time (1950s-1980s)

Early experience with professionals /outside agencies

- messages from professionals when son born, & her response
- how obtained early support / information (if any)
- choices about schooling, care
- interactions with local community living agency
- interactions with state family and children services, hospital, police, institutional staff
- other parent advocates, contacts, allies

Advocacy experience – organizing parents, closing Woodlands

- how first got involved in broader organizing with parents

- her experience of parent advocacy, strategies used, etc.
- how connected with parents of Woodlands residents
- role in closing Woodlands
- interactions with representatives of government, professionals, other players
- others' perceptions of her as an activist mother
- removing son from Woodlands
- son's life after leaving Woodlands
- recent and current advocacy work (provincial, national)
- how her attitude towards agencies changed over time – personal/social influences

Understandings of disability and justice

- changes over time
- involvement in de-institutionalization advocacy, class action against B.C. government re: Woodlands abuse (discussion may be limited by legal constraints)

Appendix C: Historical timeline

Date	Drew	Jo	General world
1878			Provincial Asylum for the Insane (PAI) opens.
1897			PAI changes name to Public Hospital for the Insane (PHI).
1913			Essondale opens; male patients transferred from PHI to Essondale.
1934			500 residents at PHI.
1943, 1949			Leo Kanner theorizes “refrigerator mothers.”
1950			PHI renamed The Woodlands School.
1953			<i>Angel Unaware</i> – Dale Evans Rogers.
1955	Drew born.		7 Parent Societies form Association for Retarded Children of BC (ARC BC) with focus on education.
1959	Attends kindergarten.	Joins North Vancouver parent association.	
1959			Tranquille TB sanatorium reopened as institution for people with “mental handicaps.” (Woodlands has more severely disabled.) 1,436 residents at Woodlands – peak population 1959-1961.
1960	UBC assessment – age 5.		
1961-1968	Attends school – segregated.		US President JF Kennedy establishes President’s Panel on Mental Retardation (1961).
1962			Olshansky – “chronic sorrow.”
1965-1968		Chair of North Vancouver association 1965 (Panitch 2008).	

1968	Kicked out of school – age 13.	Seeks funding to care for Drew – turned down. Then obtains money, but can't get help from community parent association to set up service.	
Late 1968	Goes to hospital in ambulance; sent to Essondale.		
1969	Not allowed to see family for 3 months; front teeth removed; medicated – gained 40 lbs.		ARC BC changes its name to B.C. Association for the Mentally Retarded (BCAMR).
1970	Transferred to Woodlands ?	On board of BCAMR ? Lobbies board to advocate for community homes. Attends first national meeting of Canadian Association for the Mentally Retarded (CAMR) as BC delegate (Panitch 2008, p. 105).	
1971			Glendale institution opens (Vancouver Island).
1972		Joins CAMR National Task Force on Residences.	
1973			Self advocates speak out at AGM of BCAMR.
1974		Attends CAMR and puts forward resolution to concentrate on community alternatives to institutions; CAMR modifies it to exclude condemnation of institutions.	Woodlands, Tranquille & Glendale transferred from Dept. of Mental Health to Dept. of Human Resources, independent from Essondale/Riverview. The Woodlands School changes name to Woodlands.

1974-1976		Chair of BCAMR. Helps self advocates organize provincially. Gets CAMR to overturn resolution re: institutions & support replacing them with community alternatives.	Adolph (1996) describes BCAMR as more adversarial.
1975-78		1975 – elected national VP of CAMR.	Bill Vander Zalm serves as Minister of Human Resources under Premier Bill Bennett. People First groups start forming around BC ?
1976		6 families meet with MHR Minister Vander Zalm at Woodlands.	Gunnar Dybwad – front page story on Woodlands in <i>The Vancouver Sun</i> . Al Favreau – ED of BCAMR.
1977		Elected chair CAMR 1977-82. Community Living Society (CLS) created.	
1978	Moves out of Woodlands to home in community ? Lives with Walter and Peter.	Became Executive Director of CLS. As Chair of CAMR, sets up Consumer Advisory Cttee with seat on national board; Barb Goode Chair. Brings 100 self advocates to national conference for first time.	
1979		Publishes article in <i>Canadian Family Physician</i> .	
1981		Presents proposal to House of Commons Committee on Disabled and Handicapped to allocate federal funds to provinces to cover costs of de-institutionalization.	UN Year of the Disabled. After BCAMR lobbying, MHR minister Grace McCarthy announces plan to close BC institutions in 10 years. Gunnar Dybwad – President of International League of Societies for the Mentally Handicapped.
1982		Involved in CAMR lobby to include mental disabilities in s. 15 of Charter.	Draft Charter of Rights and Freedoms amended to include people with physical <i>and</i> mental disabilities.

1982 cont'd.		Goes to Montreal to meet families in support of de-institutionalization.	Formation of National Institute on Mental Retardation (NIMR) – later called Roehrer Institute. BC govt allocates \$1.6 million towards community based supports & de-institutionalization efforts. Wolfensberger alleges genocide of the disabled at Toronto conference.
1983			BCAMR becomes BCMHP – British Columbians for Mentally Handicapped People.
1984		Appointed to board of National Institute on Mental Retardation.	CAMR changes name to Canadian Association for Community Living (CACL). Tranquille closes.
1988			BCMHP becomes BCACL (1989?) – BC Association for Community Living. People with intellectual disabilities vote in federal election for the first time.
1989			Ruling re: Employment Standards Act – minimum wage for workers in sheltered workshops. Glendale closes.
1991		Left CLS position to head up Community Brokerage Society.	
1996			Last resident of Woodlands leaves – all B.C. institutions closed. Those in most other provinces remain open.
2004	Drew died - heart failure		

Sources: Val Adolph (1996), newspaper articles, BCACL records, Jo Dickey records.

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