

Empowering Exclusivity

by

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B.A., University of Toronto, 2008

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## **Supervisory Committee**

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## **Abstract**

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The segregation of disabled people is often perceived of as a form of oppression that acts as a means of exclusion from mainstream society. Disability rights activists and theorists have worked to end segregation as a form of oppression using the social model of disability and drawing on feminist theory. Feminist use of disengagement as a tool for empowerment is one component of feminist theory that has been left unexplored as it relates to disability. This work explores the role of segregation within the disability rights movement and within the development of the activist identity for disabled people. Based on the individual and collective experiences of six participants, all of whom are activists who attended segregated summer camps, I use a thematic analysis to reframe segregation as Empowering Exclusivity. This reframing has the potential to shift the strategic goals of the disability rights movement away from binary understandings of integration and segregation and towards a critical analysis of full inclusion and empowerment.

## Table of Contents

Supervisory Committee.....	ii
Abstract.....	iii
Table of Contents.....	iv
List of Tables.....	vi
Acknowledgments.....	vii
Dedication.....	viii
Chapter 1: When I grow up I want to be a protester.....	1
Disability studies and the framing of the disability rights movement.....	2
Research question and scope of research project.....	4
A road map of the thesis.....	5
Notes on terminology.....	7
Chapter 2: Framing segregation and the disability rights movement.....	9
Social movements old and new.....	10
The social model and medical model: the birth of the disability rights movement.....	12
Critical feminist disability theory.....	17
Identity performance and presentation.....	19
Segregation in the era of integration.....	23
Balancing mainstreaming and disengagement.....	24
From theory to practice.....	27
Chapter 3: Creating an accessible research design.....	28
Individual and Collective Narratives as Empowering Tools.....	28
Ethical Considerations.....	30
An anti-oppressive method of data collection.....	31
The Participants.....	34
Julia.....	36
Alessia.....	36
Kirk.....	37
Adam.....	37
Jeff.....	37
Linda.....	38
Collective experience.....	38
Defining voice and drawing out themes.....	39
Chapter 4: Generating a collective narrative.....	42
Places as Context.....	44
Family.....	44
Elementary school.....	45
Summer camp.....	47
High school.....	50
Sports.....	52
Culture of activism.....	53
Navigation.....	56
Transitions.....	56

Community.....	57
Sense of self and identity .....	59
Social acceptance .....	59
Hierarchies .....	60
Self-perception .....	62
Chapter 5: From segregation to exclusivity .....	64
A place of belonging .....	64
Finding balance and defining social position.....	67
The activist identity.....	71
Chapter 6: Concluding observations .....	76
Moving forward .....	82
Bibliography.....	85
Appendix.....	94
Appendix A: Consent Form .....	94
Appendix B: Interview Guide .....	97

## List of Tables

Table 1 - Participant Overview .....	35
Table 2: Themes and sub-themes that emerged from data set .....	40

## **Acknowledgments**

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## **Dedication**

I would like to dedicate this work to the activists that contributed to the research process as well as all the disability rights activists who have inspired me in my academic work and grassroots activities

## **Chapter 1: When I grow up I want to be a protester**

When I was in the fifth grade my teacher asked us to draw pictures of what we wanted to be when we grew up. My best friend drew a teacher and the boy next to me drew a fire-fighter. I drew a stick figure holding up a sign on a stick and wrote across the top of my page, “When I grow-up I want to be a protester.” My teacher asked me why I wanted to be a protester and without a second thought I responded, “so that I can change the world.”

I grew up in an able-bodied world, within an able-bodied family, to be as able-bodied as I could be. I am part of a generation of physically disabled people who had a greater level of choice related to participation in integrated or segregated spaces. But integration never felt like a choice to me. I was the only physically disabled person in my family, and there was only one other physically disabled person at my school until I got into university. My half days of junior kindergarten in a segregated school and my annual two weeks at a segregated summer camp provided me with an emotional and physical sense of relief. These were times in my life that I felt included, at home and in a community that I could claim as my own. By contrast, integration felt isolating and evoked in me a visceral sense of exclusion. The empowerment I experienced as a youth in segregated spaces has been mirrored in my adulthood through engagement with the disability rights movement.

Social movements and the activists who work within them are often thought of as merely “protesters” that stand together in opposition to dominant political authorities (Erickson & Smith 2001). As a disabled woman working within the disability rights

movement, I have come to understand social movements as being both material and discursive spaces that mean different things to different people. Social movements inhabit and change physical spaces through their actions – protests, community centres, ramps and curb-cuts; these movements also generate their own ideas and modify existing public ones – theory, policy, press releases and art. My academic career has focused predominantly on attempting to understand my life as a disabled woman and improving my abilities as an activist.

### **Disability studies and the framing of the disability rights movement**

The theoretical framing of the disability rights movement for the past thirty years or so has been dominated by a social model of disability paradigm, or the social model for short (Campbell & Oliver 1998; Charleston 2000; Barnes, Oliver & Barton 2002; Barnes 2003). The social model conceptually separates disability from impairment and has as one of its central tenets the idea that disability is caused by social barriers rather than the presence of impairment. Furthermore, the social model removes disability from the body and the individual and recasts disablement as physical and attitudinal barriers to active participation in everyday mainstream life. Oppression that is caused by society's disabling barriers creates the common link among people with impairments. The values inherent in the social model have generated a sturdy solidarity amongst a heterogeneous group of disabled people and have enabled an activist practice founded on collective action.

While the social model opens the door for cross-disability activism, it does not explore impairment or acknowledge the importance of the experience of impairment for disabled people (Crow 1996; Humphrey 2000; Morris 2005). By excluding impairment

from the scope of disability activism, the social model embraces the mainstream conception of impairment as negative. To be effective activists under the social model, disabled people must ignore their impairment and present a conception of disability that is separate from their everyday life experiences.

Alongside the social model of disability, discussions related to integration and segregation, inclusion and exclusion, have shaped the dominant narrative within the disability rights movement (Holt 2004; Parr 2008; Barnes 2010). This has created a public rhetoric, a discourse that condemns segregated spaces for disabled people as exclusionary and celebrates integration as a superior means of social inclusion. Yet recently, disabled feminist theorists have argued that in order to achieve a full understanding of disability, the disability rights movement must work to re-incorporate impairment by acknowledging the personal lived experiences of disabled people within the political narrative of the movement (Thomas, 2007; Hall, 2011).

My personal experiences living and working within an activist community have made me re-think the valuation of segregation as a negative experience and integration as a positive one. Many of the activists I worked with while living in Toronto I first met during my time at segregated summer camp. Most of the activists within the community had gone to summer camp or attended other segregated spaces together. I and the other activists remembered segregated spaces as places where we felt we belonged. This shared experience sparked my interest in exploring segregated experiences in relation to the drive to become a disability rights activist. I wanted to understand how relationships may or may not be formed in segregated spaces and if segregated space itself was required for political mobilization to be effective. The idea that segregation could be beneficial for

activism has not been significantly explored by disability rights activists or theorists because of the historical use of segregation to exclude disabled people. Yet the social and political relationships I have developed lead me to believe that segregation can contribute to a positive identity for disabled activists.

### **Research question and scope of research project**

The research interest upon which this thesis is based lies in how segregated settings contribute to a process of empowerment and positive identity formation. With regard to identity, disability rights activists have traditionally worked within a social oppression paradigm that tends to homogenize the experience of disability and demonize segregated settings as inherently oppressive in order to achieve critical political goals (Charlton 2000). However, it was within segregated institutions that confined and controlled the lives of disabled people, that they, and their allies, came together to fight for de-institutionalization (Charlton 2000; Campbell & Oliver 1998). Throughout this process of closing separate institutions for disabled people, a distinct binary was developed which places segregation and exclusion on one side and integration and inclusion on the other. The need for social change and political cohesion left little room within this binary construction to explore the emergence of identities that did not arise in opposition to oppression. This study begins this process by exploring how attending segregated summer camps affected the lives of physically disabled activists. To accomplish my goal, I work with disability rights activists to collect personal narratives related to their time at segregated summer camps and examine how being there might be connected to work they have undertaken to empower disabled people. I explore how

their lives as physically disabled people contributed to political action within the context of the disability rights movement.

Empowering Exclusivity is the term through which I re-conceptualize certain forms of segregation as contributing to positive identity formation for disabled people. The disability rights movement often employs a narrative that articulates social justice for disabled people as a journey; from exclusion to inclusion, from charity to rights, from segregation to integration. My work explores the process of empowerment that contributes to the journey of becoming an activist for disabled people working within the movement. Throughout this study, I illustrate how Empowering Exclusivity results from the need for a sense of belonging and also how it acts as a space and a process for community development and for effective political practice.

While my activist practice has not concentrated exclusively on physical or mobility disability, I have decided to focus the scope of my research by selecting participants who have attended a segregated summer camp and who have lived with and continue to live with physical disabilities that affect their mobility. By centring my research in this way, I personally possess the same set of attributes defining inclusion into the disability communities within which we are active. I can also create a research environment in which I can actively engage in reflexivity throughout the process.

### **A road map of the thesis**

In the next chapter, I present my theoretical approach: a critical feminist disability perspective. I begin by reviewing perspectives within disability studies concerning integration, segregation, inclusion and exclusion. By combining the social model with a feminist emphasis on lived experience as pivotal to the political, I construct a theoretical

framework that supports the idea that the disability rights movement contributes to positive identity formation for disabled people. Disability studies, studies of feminist organizing practices, and the social movement literature inform my methodology and analysis. This chapter outlines how these three bodies of knowledge inform my theoretical, political, and personal positions.

I present my methods and describe my data in Chapter 3. The first part of the chapter shows how my methodological choices are theoretically grounded. Through in-depth interviews and a focus group, I collected the personal stories of five disability rights activists. I also engaged in a self-interview, and participated in the focus group alongside my peers. In the context of disability research, it is important to acknowledge the historical objectification of disabled people. I frame my research and position myself within it by utilizing autobiography as a method to illustrate my journey and illuminate their stories. In the second part of the chapter, I introduce the participants, describe my method of data analysis, and present the themes that emerged through the process of analysis.

Chapter 4 uses the voices and narratives of the participants to exemplify the key themes that emerged during the analysis of the data. The chapter articulates three overarching themes and eleven sub-themes. The overarching theme ‘Places as Context’ encompasses experiences and reflections related to the spaces that informed participants’ activist identities. I include some physical spaces: summer camp, school, and segregated sports. However, ‘Places as Context’ also includes cultural spaces such as family and the activist community. Summer camp and the activist community are explored using Goffman’s conceptualizations of total institutions and performance of stigma. The second

overarching theme is ‘navigation’. Many participants perceive two worlds: the disability community and the mainstream. This section focuses on how participants transition and move between these two worlds. The final overarching theme is ‘sense of self and identity’: participants provide insight into the roles that social acceptance, self-perception, and hierarchies play in the process of moving towards their activist identities.

Throughout the thesis, I position my stories and the stories of participants within the context of the theoretical framework I outline in Chapter 2. I conceptualize the disability rights movement as a new social movement emphasizing the need for cultural development within the community and the fostering of a sense of belonging. I draw connections between navigational skills and the feminist organizing practices of mainstreaming and disengagement. I connect the development of an activist identity to what participants articulate as a process of self-acceptance with Anspach’s (1979) four disability identities: the normalizer, the retreator, the disassociator, and the activist.

In the final chapter I revisit my own journey towards an activist identity within the context of my research. I review my understanding of the contribution *Empowering Exclusivity* makes to the literature, as well as methodological contributions I make through the use of critical autobiography. I explore what future lines of inquiry will position *Empowering Exclusivity* within the policies and practices of the disability rights movement.

### **Notes on terminology**

While many Canadian disability scholars and activists embrace person-first terminology when exploring disability, there are others, including myself, that assert that disability cannot be separated from our identity and to do so creates a context in which

disability is constructed as a de-humanizing feature (Titchkosky 2007). Person-first terms are used by many of the participants in this study and I have included their words as theirs. Indeed, some activists in the disability community use person-first as a means of reclaiming and transforming their disability identities. Still, like Titchkosky, I have decided to use ‘disabled people’ throughout this thesis rather than ‘people with disabilities.’

My decision to use the phrase ‘disabled people’ rather than ‘people with disabilities,’ a term preferred by governments in Canada, represents my political position. Disability cannot and should not be separated from our identities (Titchkosky 2003). Despite the term ‘disabled people’ being historically used as a means of oppression (Anspach 1979), I have decided to use it as a means of empowerment through the reclaiming of language.

## **Chapter 2: Framing segregation and the disability rights movement**

I begin this chapter by exploring social movement literature to present the disability rights movement as a new social movement that places an emphasis on community and cultural development. The next part of this chapter explains how the social model emerged as resistance to the medical model that framed institutionalization and the use of segregated space. The social model acts as a foundation that guides most disability rights activists and academics. The literature overwhelmingly condemns segregation as a form of oppression and ‘othering’.

The third part of this chapter explores the exclusion of disabled women from organizing and theorizing within the social model as it depersonalizes and disembodies the experience of disability. In order to address the disembodiment of disability, I employ critical feminist disability theory (CFDT). Feminists acknowledge the role of the body in the development of social and political identities. In CFDT, there is discursive space for the personal narratives of disabled people thus providing the opportunity to safely question the social model and feminist philosophy while drawing on the best of both.

The fourth part of this chapter provides a conceptual framework for identity formation by contrasting Butler’s analysis of identity and performance with Goffman’s. This lays the groundwork for the next section, which looks at how the integrated and segregated spaces we engage affect how disabled people’s identities are formed and performed. In the last part of the chapter, having destabilized segregation / integration and inclusion / exclusion as symmetric binaries, I connect inclusion with exclusive space. I draw on the feminist organizing practice of disengagement and mainstreaming to

reconceptualise segregated spaces as exclusive spaces. I reintroduce Empowering Exclusivity as a tool for political resistance and community building.

### **Social movements old and new**

Social movement literature often defines ‘new’ social movements (NSM) by contrasting them with ‘old’ social movements. Traditionally this has been achieved by defining ‘old’ social movements through their utilization of a resource mobilization theory (RMT) that focuses on resource distribution and allocation within communities and amongst social movement organizations (SMO) (Adam 1993). Carroll (1997) articulates a historical progression in which ‘old’ social movements have laid the foundation and provided the opportunity for ‘new’ social movements to envision a “culture and politics of praxis” (16) that not only address issues of political economy but also social activity and cultural development based on collective identity. I understand the disability rights movement as a NSM that embraces Carroll’s (1997) conceptualization of NSM as growing out of, rather than distinct from, ‘old’ social movements.

Prince (2009: 15) draws on Charlton (1998) to understand modern disability politics as consisting of “ideas such as citizenship [as] linking actions, processes, and structures across micro, meso, and macro levels of human society exemplified by the disability movement's watchword, 'nothing about us without us'.” The development of the disability rights movement internationally has been based upon strong SMO that “endeavour to assist disadvantaged individuals to express their own voices in order to create new forms of public interaction as peers.” (Prince 2009:120) This model for community organizing draws on RMT by using SMO as a mechanism for enacting social

change, while also maintaining a focus on cultural and community development (Carroll 1997; Prince 2009). Within social movement literature, the role of SMO is emphasized in both RMT and NSM theory. This is clear in Mellucci's focus on SMO within his conceptualization of NSM:

Movements are rooted in micro-organizations at work, in political clubs, in churches, in sport, in support and counselling centres, in spontaneous action groups, and in cultural projects – these are the signs of ‘networks composed of a multiplicity of groups that are dispersed, fragmented and submerged in everyday life’; of ‘short-term and reversible commitment, multiple leadership, temporary and ad hoc organizational structures’ (Mellucci 1989: 60).

Like other NSM, the disability rights movement has moved beyond the realm of resource mobilization to achieve goals of social justice and empowerment by critiquing “able bodied normality” (Prince 2009). One of the issues with developing cultural conceptions of the disability community and engaging in identity politics is that the construction of a disability identity often denies differences between disabled people (Barnes and Mercer 2003: 127-8). However, according to Young (1990), “... contemporary emancipatory social movements have found group autonomy an important vehicle for empowerment and the development of a group-specific voice and perspective”. (168) Young refers to this practice as an ideal of assimilation and critiques it by arguing that “a positive self-definition of group difference is in fact more liberatory” (Young 1990:157). Young (1990) envisions social movements that create empowering exclusive spaces as the first step in the development of a democratic plurality that grants presently silenced collective voices into the current political system.

Adam (1993) argues that NSM have worked to reveal a “set of apparently dominant domination systems” (324), such as structural racism, ableism, and patriarchy.

He further argues that “the feminist insight that the ‘personal is political’ challenges social theory to take account of domination and inferiorization in a wide spectrum of life-world and subordinate subjectivities” (Adam 1993: 324). Within Adam’s framing, the incorporation of feminist principles allow NSM to challenge and resist governmental authority and focus on contextualizing politics in everyday life.

The theoretical framing for understanding disability within the disability rights movement is found in the social model. The next section describes the development of the social model and how this model has created the foundation, guiding the disability rights movement into a NSM. I then explore the limitations of the social model in order to pave the way for the incorporation of feminist principles. Young’s (1990) critiques social movements’ use of ‘ideals of assimilation’ to create collective identity: in the disability rights movement, the social model homogenizes disability in order to build a social movement. The incorporation of feminist principles is allowing the disability rights movement to develop a politics of difference in order to strengthen disabled peoples’ political voice.

### **The social model and medical model: the birth of the disability rights movement**

The first incarnation of the social model of disability emerged in the UK in 1976, and was promoted by the Union of the Physically Impaired Against Segregation (UPIAS) (Thomas 1999a). This organization played a crucial role in developing the intellectual and political ideologies that initiated and have sustained the disability rights movement internationally (Thomas 1999a; Driedger 1993). Many of the founding social model theorists, including the founder of UPIAS, Paul Hunt, lived at Le Court Cheshire Home, a

residential institution for the physically disabled in the UK. These theorists developed the social model as a form of resistance to the dominance of the medical model of disability.

The medical model places the root cause of disability on individuals' impairments (Crow 1996). This model confines disabled people within a framework whereby inaccessibility, medical incarceration, and barriers to social participation are caused solely by the individuals' biological impairment. The social model presented by UPIAS marked a radical shift in thinking about disability by creating a clear distinction between impairment and disability. UPIAS defined disability as: "the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activity" (UPIAS 1976). By framing disability in this way, they created and promoted a theoretical perspective that serves to support activists' claims that oppression and discrimination based on disability is an issue of social and political importance.

The social model operates within a framework that recognizes overarching binary systems such as the individual vs. society, and the worthy vs. unworthy citizen (Thomas 1999). By identifying these systems, social model thinkers have been able to politicize disability. Unfortunately, this has resulted in the depersonalization and disembodiment of oppression related to disability (Thomas 1999). Once the social model had established the dichotomy between disability and impairment, the body and personal accounts of impairment were often disregarded. (Thomas 2001). While many social model theorists explore how disabled identities are produced through social forces in order to clearly position disability oppression as socially constructed, they usually do so using public narratives associated with culturally and institutionally formed stories that are larger than

the individual and do not acknowledge shared oppression on a personal or private level (Thomas 1999). Mainstream narratives of disability still relate to personal tragedy, abnormality, and rehabilitation, sustaining the dominance of the medical model, while simultaneously providing the social model with a position to resist (Campbell & Oliver 1998).

The SMO that first embraced the social model in Canada was the Coalition of Provincial Organizations of the Handicapped (COPOH). COPOH embraces the social model while also drawing on the principles of the independent living movement that began in Berkley, CA around the mid 1970's. The independent living movement promotes consumer control and self-determination for disabled people as a means to full social inclusion (Wharf & McKenzie 2004; Morris 2005).

Some theorists place the social model within the historical materialist or Marxist school. The social model explains the oppression of disabled people as a consequence of the material activities of society; it argues that "attitudes, discourses and symbolic representations are ... themselves the products of social practices which society undertakes in order to meet its basic material needs" (Gleeson 1997: 194). Adam's (1993) conceptualization of NSM as historical progressions from 'old' social movements is exemplified in the social model's focus on material need and the redistribution of resources. The progression of disability theory beyond the social model reaffirms the disability rights movement position as a new social movement.

The historical progression of disability theory, as understood by Hughes (2002), situates the social model as the second historical movement within disability theory, succeeding the medical model. The social model, according to Hughes (2002), is a

political tool used to combat the incarceration of disabled people in institutions as well as policies transferred from institutions into community settings. Community institutionalization, like home-care, day programs, or summer camps, draws from these historical practices, which Hughes explains,

[are] structured by pity and fear, and such negative emotional responses tend to have an ‘elective affinity’ with social responses that are characterized by a policy mix of alms and segregation or, to put it in another way, charitable paternalism and exclusion (Hughes 2002: 62).

Hughes demonstrates the imposition of institutional practices within a community setting by acknowledging that the community itself has been developed by able-bodied people for able-bodied people. The architecture of these barriers within society is an essential component of the social model in its original form. Segregation via institutional space was the medical model’s resolution to accommodating disabled people without having to address systemic inaccessibility. The residual effect of this method resulted in the isolation of disabled people and their removal from public view.

Goffman (1968) defines these segregated spaces as ‘total institutions’. There are four aspects of a total institution:

First, all aspects of life are conducted in the same place and under the same single authority. Second, each phase of members’ daily activity is carried out in the immediate company of a large batch of others, all of whom are treated alike and required to do the same thing together. Third, the day’s activities are tightly scheduled; with one activity leading at a prearranged time into the next, the whole sequence of activities being imposed from above by a system of explicit formal rulings and a body of officials. Finally, the various enforced activities are brought together in a single rational plan purportedly designed to fulfil the official aims of the institution. (Goffman 1968: 6)

The founding social model theorists experienced institutionalization that epitomized all of Goffman’s aspects of total institutions within spaces like Le Court Cheshire Home. Using

the social model, disability rights activists have been successful in promoting integration as a preferred alternative to institutional settings. The process of de-institutionalization was initiated by presenting segregated spaces as exclusionary and oppressive. As integration started to become a reality, it became increasingly apparent that the removal of institutional spaces did not result in the removal of institutional policies and practices in society. In response, disability rights activists began to shift their focus onto other social barriers while maintaining the political message that all forms of segregation are exclusionary.

This approach has revealed a serious empirical and conceptual shortcoming within the social model. In understanding segregated spaces as social practices that produce disability oppression, the social model operates almost exclusively on the level of public narrative. There is little if any regard in the literature for personal accounts of experiences within summer camps or other segregated spaces that reveal their potential to empower disabled people. This is only one example of the ways in which the social model framework has continued to focus on the politically and socially constructed nature of disability. In response, feminist disability theorists have begun the project of developing new discursive space that builds upon the social model while incorporating feminist principles that privilege and honour the embodied experiences of disabled people.

My theoretical framing for activist work began with the social model. In the first year of my undergraduate degree I was browsing through the first floor of the Toronto Women's Bookstore waiting for my political theory textbooks to be brought downstairs for me. I came across a book by Tanya Titchkosky entitled *Disability Self and Society*. It

was in this book that I read about the social model of disability for the first time. It was a life-changing moment to think of disability as a social construction; not due to my cerebral palsy, but caused by stairs that stopped me from getting my own textbooks (Titchkosky 2003). My experiences in the activist community and my later exposure to feminist disability theory led me to value the reincorporation of the embodied experience into disability theory and into the practices of the disability rights movement.

The disability rights movement, when operating solely under the social model, falls prey to Adam's (1993) assessment that social movements tend to disregard diversity among group members. The experience of disability is often presented as homogenous within the disability rights movement due to its focus on collective experiences of oppression rather than on an understanding of oppression as being embodied through disability in unique, diverse and specific ways. The reintroduction of the body into the discourse of the disability rights movement, as well as feminist understandings of the personal realm as inherently political, has sparked debate among disability rights activists (Morris 1991). These debates as well as many others have also shaped my perception of the social movement as a space that is conducive to the development of Young's (1990) concept of collective identity as a "positive self-definition of group difference" (157), rather than a homogenized representation.

### **Critical feminist disability theory**

Feminist disability theory grew out of a sense of isolation on the part of disabled women within the activist community. Disabled women were and are excluded from the disability rights movement because of issues related to gender and the social model's exclusive focus on the public sphere. Disabled women have also been excluded from the

women's movement because of a lack of acknowledgment related to the specificity of the disabled experience. In response to this simultaneous exclusion disabled feminists have developed their own theoretical framework that critically analyzes the limitations of the social model and feminist philosophy while drawing on the best of both (Morris 1995). The resulting body of work relates specifically to the theorization of personal accounts and the embodied experience of disability. It is this theoretical framework that guides my research to value personal narratives as a means to transform the disability rights movement. Some of the thinkers who have shaped this perspective include Morris (1991), Thomas (1999a) and Wendell (2006). Their works share the common theme that the dominant social model discourse benefits from the incorporation of feminist principles that recognize the importance of politicizing personal experience. I argue that incorporation of the personal within a social model framework can strengthen the disability rights movement as a NSM. The movement's capacity for community building and cultural development is enhanced when diversity is acknowledged through the incorporation of impairment and the corporeal experience. Attempts to examine the embodied experience of having impairment and the role it plays in the development of a disabled identity have been resisted by social model theorists (Moss and Dyck 2003). This resistance is caused by fear that if impairment is acknowledged as an experience that is connected to disability, the medical model will have the opportunity to take back much of the political ground won since the development of the social model (Shakespeare 2006). Despite resistance, critical feminist disability theorists that focus on the body remain successful in revealing how the privileging of the particular personal and embodied experience can contribute to a stronger social movement.

Body theorists critique the social model's insistence on disengaging with the body as a means of resistance against the dominance of the medical model of disability (Moss & Dyck 2003). Feminist body theorists problematize dichotomous understandings of sexuality and gender as well as other binaries, including disability and impairment, to support the development of an identity politics to make visible groups that are marginalized (Kopelson 2002). The questioning of these binary systems within body theory and feminist theory stems from post-structural thought that calls for reconsiderations within the social model of disability and the incorporation of feminist body theory into the social model framework (Samuels 2002). Moving away from a purely materialist perspective of the social model towards recognizing the role of impairment and lived experience in the creation of disability identities, or subjectivities, marks a shift in political strategy related to disability. Reengagement of the body and impairment is instigating a new political strategy for disability rights activists that privileges the particular and leads to a stronger sense of community and contributes to identity formation for disabled people.

### **Identity performance and presentation**

Identity politics are used by NSM in order to develop a sense of collective identity. The idea that people can be defined based on one, or even multiple, components of their identity requires the acceptance of some form of fixed identity. Despite the plethora of debates related to the effectiveness of identity politics as a means of solidifying the political voice of a social movement (Young 1990; Adam 1993; Carroll 1997; Poletta & Jasper 2001; Shragge 2003), it is a practice that has been taken up by activists within the disability rights movement through the social model. Disability as an

indicator of identity does not guarantee a political consciousness that would transform a disabled individual into an activist. Anspach (1979) provides a framework for understanding different ways that a fixed disabled identity could be performed or presented.

Anspach (1979) catalogues four disability identities when attempting to define the role the disability right movement plays as a social movement that develops collective identity and a stronger sense of self. The four identities are: normalizer, dis-associator, retreator and political activist. The normalizer can be understood as an individual who values social acceptance by mainstream society, and values mainstream cultural understandings of the world and what has been constructed as 'normal'. While on the surface this creates a positive self-identity, many interactions act as a reminder that the normalizer may never be fully accepted by the society that they idolize. This can also result in a rejection of other disabled people based on self-hatred caused by rejection from a society they strive to be included in. Dis-associators are unable to accept the fact of their disqualification and unwilling to aspire to be accepted by normals; they often hold a dis-associative identity that is tainted and tarnished which leads them to avoid contact with normals. The self-image of retreators is profoundly negative; they neither accept societal values nor aspire to attain them. The political activist, like the normalizer, seeks to attain a favourable self-conception, but unlike the normalizer does this through a claim of superiority over normals. An activist identity is at home in a collective, because in the collective "redefinition, reconstitution, and value-transcendence" is easier to obtain (Anspach 1979: 770). Because activists often hold a separatist stance they are plagued by less internal turmoil than people who engage in a normalizing identity.

Anspach's identities operate within the premise that there is a universal disabled subject that can be performed in four different ways, which can be rather limiting in conceptualizing the array of subject positions possible in everyday life. Using Butler's theory of performativity provides insight into how a universal disabled subject comes into being based on the negative perceptions of impairment contained within both medical and social model frameworks. Butler (1988) deconstructs gender by arguing that genders are not an expression of biology, but are formed by descriptions of entrenched or repeated performances based on societal expectations. Even these expectations, she goes on to say, do not determine what gender is: as a performance, society punishes acts transgressing normal expectations, but gender itself remains open to subversive actors.

Gender is not passively scripted on the body, and neither is it determined by nature, language, the symbolic, or the overwhelming history of patriarchy. Gender is what is put on, invariable, under constraint, daily and incessantly, with anxiety and pleasure, but if this continuous act is mistaken for a natural or linguistic given, power is relinquished to expand the cultural field bodily through subversive performances of various kinds. (Butler 1988: 531)

Performativity is a useful way to begin a process of critical analysis related to the political and social effects of constructing a universal disabled identity which barely acknowledges impairment as a prerequisite for entry into that political group (Samuels 2002; Shakespeare 2006).

Within a medical model, the disabled identity or performance is often enacted as sick, heroic or tragic because disabled or impaired people are relegated to the categories of abnormality and disadvantage based on biological, physical, or mental conditions (Shakespeare 2006; cf. Anspach 1979). In reaction to these categorizations, disabled people enact behaviours that fall in line with either medical or social model public

narratives that construct the disabled subject (Reeves 2002). The universal disabled subject in the medical model is performed as a tragic hero that strives for normalcy and full social integration by the removal or compensation for their impaired body via medical intervention. The social model performance works toward integration by fighting to break down socially constructed barriers and is perceived as angry, bitter and self-entitled because of their focus on external, rather than internal change (Reeves 2002). According to Butler's theory, these kinds of performances are often unconscious, and that is part of the reason that sex, gender, disability and impairment are wrongly perceived as "natural" or biological identities rather than performed actions or "reproduced historical situations". Butler contends that knowledge related to how and why subjectivities or identities are performed provides people with agency and opportunity for empowered resistance (Butler 1988; Kopelson 2002).

Goffman (1959) explores a different framing of performance and presentation of identity, and I use his theories of performance in Chapter 5 to explore the participants' experiences at summer camp. Goffman uses performance as a means to analyze actions in relation to possibly varied social situations. This means of analysis allows me to draw out common themes of identity formation and presentation across a spectrum of places. Goffman's framing of performance, similar to that of identity politics, requires the acceptance of some form of fixed identity that varies in its performance based on context. By provisionally accepting fixed identity, I honour the narratives presented by participants throughout my research. While Goffman's analysis needs to be supplemented with Butler's critical reflections on the ontology of performance, it is useful in exploring how community expectations inform identity formation.

## **Segregation in the era of integration**

Societal expectations of how we perform our identity shift depending on the spaces that we inhabit (Holt 2004). Whether identity is understood as fluid according to Butler, or fixed, as presented by Goffman, the presentation of self varies, depending on socio-spatial location. Social model and critical feminist disability theorists argue that segregated spaces exclude disabled people from full participation in society and negatively reinforce difference (Morris 1991; Thomas 1997; Gleeson 1999). The public narrative that defines segregation as an exclusionary and hence, oppressive practice, often comes from a generation of disability rights activists that experienced segregation within the fixed boundaries of spaces defined as total institutions (Cook 2001). The generation of activists that I engage in my research have experienced segregation within an era of transition. This transition is discussed by Hughes (2002) as the transfer of institutional policies and practices into the community setting. The experience of segregation within a period that I define as the 'era of integration' raises new questions about the role of segregation in the lives of disabled people. While founding disability studies theorists experience segregation as a means of oppressive exclusion, today themes related to belonging and community are often raised throughout the literature related to the experience of segregation within a policy climate of mainstreaming as a means of inclusion (Holt 2004; Parr 2008; Cook 2001; Hall 2010; Oliver & Barnes 2010).

My research involves activists that attended Easter Seals' segregated summer camps. These camps exemplify a segregated space for physically disabled people within an era of integration. While they have all of Goffman's aspects that define total institutions, they are frequented by physically disabled youth who may or may not have had other segregated experiences. Goffman says that total institutions can be

establishments “designed as a retreat from the world” (Goffman 1962: 5). The idea that a sense of community and belonging can be developed through disengagement is explored by feminist theorists through the practice of balancing mainstreaming and disengagement.

### **Balancing mainstreaming and disengagement**

In literature that explores disabled peoples’ experiences within segregated settings, their experiences have been presented using the language of empowerment versus disempowerment. Alongside memories of abuse and oppression, there are also recollections of social benefits that create a sense of community and belonging (Holt 2004; Parr 2008; Cook 2001; Hall 2010). The women’s movement has generated models for understanding the need to balance mainstreaming and disengagement (Shragge 2003). These models understand exclusive spaces, such as women's only centres, as an essential power source for social movement mobilization that are often constructed as ‘safe havens’ for activists and community members (Shragge, 2003; Briskin, 1991). These types of spaces are as difficult to create and sustain within the disability rights movement as they have been within the women's movement (Leathwood 2004; Adamson, Briskin, & McPhail 1988). The instability of a disabled identity as well as heterogeneous political, social and cultural perspectives within the disability movement lead to a multiplicity of opinions related to effective strategies for community organizing (Leathwood 2004; Shakespeare 2006).

The organizing practices within the women’s movement act as a means of maintaining strong ideology while ensuring that social change remains achievable within the mainstream political climate (Adamson, Briskin, & McPhail 1988). Adamson,

Briskin, and McPhail (1988) depicts mainstreaming and disengagement as “the two politics of feminist practice” (p. 176). Mainstreaming focuses on working within current social and political systems to create social change. As a political practice, mainstreaming has been utilized by the disability rights movement in many projects fighting for inclusion and the rights of full and active citizenship for disabled people (Campbell & Oliver 1998; Oliver & Barnes 1998). Disengagement as a political practice is often disregarded by disabled activists (Oliver & Barnes 1998; Simons & Masschelein 2005), perhaps because it moves away from the goals of inclusion and risks further marginalization and segregation (Briskin 1991). However, Adamson et al. (1988) argue that by organizing outside of mainstream structures, disengagement can work to empower activists and community members by encouraging social and political interactions that operate outside of oppressive structures.

Feminist organizers have grappled with many of the same issues that disability activists have. Their common strategic concern is often related to whether to stress sameness or difference in relation to the patriarchy. While many disability rights activists have strategically decided that full integration into the able bodied society and equal power with the able bodied is the ultimate goal of the movement, feminist organizers have attempted to balance that goal with efforts to preserve some degree of separate culture, knowledge and values (Wendell 1997:261).

Wendell acknowledges that many disabled people are tired of having disability or their impairment act as a primary indicator of their identity and that most disabled people would rather go unnoticed and be assimilated into mainstream society. However, assimilation is often not an achievable goal for physically disabled people. In response,

many feminist leaders in the disability community have taken up the project of resisting assimilation (Wendell 1997:261).

Feminist organizers and theorists that embrace separatism argue that:

Separatism promoted the empowerment of women through self-organization, the creation of separate and safe spaces where women could share and analyze their experiences, voice their anger, play with and create bonds with one another, and develop new and better institutions and practices. (Young 1990:161)

Negative perceptions of disengagement within the disability rights movement stem from the imposition of segregation upon the disabled community. While segregation has not become a self-imposed practice for most disabled people, the stories disabled people tell about community and a sense of belonging within otherwise oppressive segregated spaces reveal social and political benefits similar to those found by the women's movement self-imposed segregation. Efforts to create political solidarity and to challenge concepts of 'normalcy' have focused on integration; however, the need for full citizenship and inclusion has remained the ultimate goal (Wendell 1997). As the disability rights movement begins to recognize the need for discourse related to a disability culture and the common struggles of disabled people, the need for practices of disengagement that work to empower and engage disabled people will become more important (Wendell 1997).

Disengagement has the potential to create further isolation and make it more difficult to create change within the current political system. The practice of mainstreaming works to counteract isolation and marginalization by addressing specific and immediate needs such as equal access to employment (Briskin 1991). Then again, mainstreaming carries its' own risks: by shifting focus away from systemic critique

toward immediate need, mainstreaming can focus social movements' attention and resources on incremental change, which limits the amount of strategic change that can be achieved.

### **From theory to practice**

There is a tension between the social model's view of the role of segregated spaces and the experiences that disabled people have had in them. This contradiction creates a discursive space in which to explore disengagement as a means of enhancing political mobilization for disabled people; this space creates room to define Empowering Exclusivity. In this thesis, I reconceptualise political practice within the disability rights movement as (re)balancing mainstreaming and disengagement by drawing on my understanding of social movements, the social model, and CFDT, outlined in this chapter. In the next chapter, I will use this framework in order to read the experiences of participants. I contend that through a process of reclaiming segregation and transforming it into a practice of empowered disengagement or exclusivity, activists can create a balanced and more effective organizing practice.

### **Chapter 3: Creating an accessible research design**

My research explored ways in which exclusivity can contribute to a process of empowerment; my methodological approach and methods of data collection created local exclusive spaces that were empowering. Like the other participants, I am a disability rights activist who attended a segregated summer camp. This insider status allowed me to collect personal narratives and facilitate a focus group within a collaborative and empowering environment.

This chapter begins by laying out how my theoretical framework has led me to my methodological approach. I discuss how the critical framework I've outlined in Chapter 2 required a non-exploitative, non-oppressive, research environment that valued personal and collective narratives. This environment honoured the expertise of the participants, and provided space for collaboration and reflection. I explain how this methodological approach was put into practice while collecting data, through a series of in-depth interviews and a focus group. I also discuss how components of autobiography, through self-interview, contribute to achieving these goals. I conclude my discussion of methods by describing the analytical approach I used to synthesise the data. I close the chapter by introducing the participants and providing an overview of the themes and sub-themes that emerged out of the data.

#### **Individual and Collective Narratives as Empowering Tools**

At its core, my research privileges the voices of disabled people. Acknowledging their expertise is crucial when conducting research within the disability community, given the historical oppression of disabled people. The collective oppression of disabled

people is based upon a history of surveillance, incarceration, and the misguided understanding of disability as the responsibility or fault of an individual (Mitchell 2006). In medical and sociological research, disabled people were historically the subjects of investigation whose input was neither solicited nor valued. These experiences of marginalization require a research paradigm that is cognizant of this oppressive history and promotes social change through connections with emancipating political movements (Oliver 1992).

I concur with Oliver (1990) in conceptualizing disability as a political, social, and cultural identity based within the social oppression paradigm defined in Chapter 2. I maintain that the social model framework is not sufficient, but must incorporate a feminist focus on the embodied experience of disability and impairment. When conducting feminist research, bell hooks (1989) stresses the importance of creating discursive space in order for the voices of the marginalized to be heard.

Cresswell (2008) defines oral history as a qualitative form of biography that emphasizes an interactive process of reflection. This process provides an enriched understanding of the disability rights movement as a social, cultural, and political space, while supporting the activist's role in voicing its history.

My position as an insider in relation to the other participants supported the development of discursive space that honours all of our voices. However, I remain aware that my role as researcher had the potential to shift power relations (Narayan 1993). I addressed this ethical concern by ensuring that all the narratives that I collected were framed as expert knowledge (Oakley 1990). I position our narratives alongside other theorists rather than using theory as expert knowledge to support our narratives. By

taking this approach I was able to maintain my insider status despite my position as researcher, and ensured a non-exploitative and collaborative research environment.

I used autobiography as a way to position myself in relation to my research topic, fellow participants, and findings. Autobiography is a process that positions researchers within a web of power relations that supports critical insights into data gathering through contemporaneous research processes (Moss 2001: 20). Autobiography allows the researcher to explore and voice perspectives ignored and suppressed by dominant discourses (Muncey 2010). I found these qualities of autobiography particularly useful in my effort to create a collaborative working space for the participants and myself. As Moss puts it, “autobiography has proven useful ... to provide, and to promote a continual destabilization in the formation of theory” (2001: 18). I used this approach in the process of making meaning of my experiences in relation to other participants. My stories, and the stories of the participants, are versions of events as we experienced them and are told in a sequence that is significant to us as storytellers.

Critical feminist disability theory is an emancipating research paradigm. As an insider, I was able to draw on feminist and anti-oppressive principles in order to ensure that the methods I used contributed to a process of empowerment for participants and the disability community. These principles led me to collect personal narratives, in the form of in-depth interviews, and facilitated the development of a collective story through a focus group.

### **Ethical Considerations**

As part of the process of acquiring approval from the University of Victoria’s Human Research Ethics Board, I had to address some ethical concerns specific to the

nature of my project. To ensure the physical and emotional safety of all participants, I created a consent form that clearly outlined how any information provided would be used in the research as well as defined an agreement for any future use or publication of personal narratives. This consent form reinforced the idea that participants owned their stories and had the choice to disallow my use of their stories at any time. (A copy of the form is provided in Appendix A.) I provided the opportunity for participants to use pseudonyms, but none elected to do so. To maintain the security of the data collected I kept all records and electronic transcripts in a password protected file, and copies of audio-visual recordings in a locked cabinet. I provided the contact information to the Anne Johnson Health Station, a community centre that provides counselling and psychotherapy specifically for physically disabled people, in case any participant felt distress as the result of traumatic memories resurfacing through the process of storytelling.

### **An anti-oppressive method of data collection**

I decided to focus my work on the collection of individual narratives and a focus group with disability rights activists. Participants had attended segregated summer camp for disabled people and currently live in the Toronto area. My insider status allowed me to easily gain access to potential participants through snowball sampling, by word of mouth, and through community advertising (Browne 2005). My initial goal was to have seven participants; I ultimately interviewed six participants, and engaged in a self-interview. Five of the participants I interviewed took part in the focus group. I chose to analyse only the interviews of those participants who also collaborated in the focus group in order to ensure that all data reflected not only one's personal narrative, but also the

engagement with others in the development of a collective story. I included my self-interview and contributions to the focus group which added to this collective story development. The eventual sample size of six provided enough data to draw out themes from our experiences.

The sample size is too small and specific to make generalizations or universalizing claims that apply to all exclusive spaces, or to the entire disability rights movement (Cresswell 2008). This type of universalizing is not necessarily beneficial in the type of study I have undertaken. The research I have conducted has provided insight into the way activists become activists and effect change. Had I chosen to engage a larger sample of activists, there would have been a greater potential to recreate the dominant discourses of the movement leaving little discursive space for reframing a foundational assumption. I chose a small sample of people who were acquainted with one another in order to create an intimate space for sharing personal stories and honest collaboration.

In the first set of sessions, I interviewed participants using open-ended questions that focused their stories on their memories of summer camp and work as activists. For example, I asked participants, “Can you tell me a story about something you really liked about summer camp?” By posing questions in this way, I encouraged participants to respond by telling stories. (See Appendix B for the interview guide.) I recorded all of the interviews using digital video and had them simultaneously transcribed by a research assistant. While I felt it was important to transcribe interviews in order to more easily analyze the data, it was equally important to acknowledge and uphold the integrity of the audio-visual material as social, cultural, and political artefacts that contribute to a richer understanding of the role that spoken language plays in creating different ways of

knowing (Slim & Thompson 1995). Throughout the process I kept detailed notes related to body language, tone of voice, thoughtful pauses, and any other features that might have contributed to upholding the audio-visual nature of the storytelling process.

Once I completed the interviews, and they were fully transcribed, I did an intense reading of the transcripts looking for repetition. Based on this intense reading I developed a guideline for conducting the focus group organized around the following three repetitive issues:

- **Balancing:** Participants often said that it was important to balance experiences of integration and segregation.
- **Choice:** Segregated experiences were more positive when they were chosen, rather than imposed.
- **Hierarchies:** Most participants told their stories using language that implied the experience of social hierarchies.

I started the focus group by sharing my own story and asked the other participants to share their stories with the group. This reaffirmed my insider status and created a non-hierarchical power dynamic and reinforced the collaborative nature of the project (Kitzinger 1994). During the focus group there was a lot of agreement among the participants; one aspect that was particularly interesting was that despite my efforts to create a space that was conducive to open and honest reflection, participants still seemed to struggle with the incongruity that some of their experiences had with the dominant narrative of the disability rights movement as it relates to segregation. By the end of the focus group, the tension between what participants felt they should say, and what they actually experienced, was overcome through collaborative discussion.

Before beginning my analysis of the data collected, I engaged in a self-interview using the same interview guide that was used with the other participants. By engaging in this process, I underwent the same research experience as the other participants. This

allowed me to participate as a full member of the research group, by making my experiences visible throughout the analytical process, and by using analysis of my story alongside other participants to provide an alternative voice that questions dominant discourse on segregation (Muncey 2010). I will now introduce the participants, drawing on autobiography as a method to frame the contributions of participants in relation to the social network of Toronto's activist community.

### **The Participants**

I feel a strong bond with the participants in my study for a number of reasons. I grew up with many of them, grew into being an activist with some of them, and I feel inspired by all of them. My personal links to the participants have provided me with a unique perspective on how the themes of their interviews connect to our development into disability rights activists. Additionally, their personal relationships between one another enhanced the focus group discussion, allowing for open and honest discussion of issues that related to community organizing, our identities, and how we have come to be leaders in our community. In order to be able to provide a cohesive picture of the activists' stories, I show some of their characteristics in Table 1.

**Table 1 - Participant Overview**

<i>Name</i>	<i>Current age</i>	<i>Age at camp</i>	<i># of summers at camp</i>	<i>Name of camp</i>	<i>Years attending camp</i>	<i>Type of elementary school attended</i>	<i>Type of high school attended</i>	<i>Organizations</i>
Alessia Di Virgillio	Early 30s	10-16 24-25	7 2	Blue Mountain Geneva Park	1990-1996 2004-2005	Integrated	Integrated	SexAbility, Women with Disabilities Action Awareness Group, Canada Wide Accessibility for Post-Secondary Students, Toronto Transit Commission Advisory Committee on Accessible Transportation, Canadian Paralympic Committee
Kirk Ashman	Early 30s	10-13 25-27	4 1	Sunny View Day Camp Geneva Park	1989-1992 2005	Segregated	Integrated	Toronto Power Wheelchair Hockey League
Jeff Peters	Mid 30s	9	1	Wood Eden	1984	Integrated	Integrated	Association of Part Time Undergraduate Students at the University of Toronto, Students for Barrier Free Access, University of Toronto Access Centre, Erin Oaks Treatment Center
Adam Cohoon	Early 30s	7-15	8	Blue Mountain	1987-1992 1994-1995	Integrated	Integrated	Toronto Transit Commission Advisory Committee on Accessible Transportation, Anne Johnston Health Station Barrier Free Advisory Council
Lynda Roy	Late 40s	13-18	6	Lakewood Blue Mountain	1978-1983	Segregated	Integrated	Anne Johnston Health Station, SexAbility, Spring Tide Resources
Julia Munk	Early 30s	9-15	7	Blue Mountain	1990-1996	Integrated	Integrated	Disabled Women's Network Canada, National Educational Association of Disabled Students, Students for Barrier Free Access, University of Toronto Access Centre, Canada Wide Accessibility for Post-Secondary Students

**Julia**

I am a part of a generation of physically disabled people who are often presented as having had a choice whether to be segregated or integrated. However, integration never felt like a choice: segregation did. This is because I was fully integrated from birth as the only physically disabled person in my family and one of only two in my school until I reached university. This integration, I now know, was possible because of the work of disability rights activists that engaged in multiple political struggles to ensure that disabled people in my generation had the right to ‘full social inclusion’. However, my half days of junior kindergarten in a segregated school and my annual two weeks at segregated summer camp felt like a release. I felt included, at home in a community that I could claim as my own. I felt empowered.

**Alessia**

I was twelve years old and on a sunny day in August, I was chasing my brother towards a massive roller coaster at Canada’s Wonderland. As I was running, I heard a loud booming voice, “Hey, I know you!” I swung around and fell to the ground, tripping over my own feet. From the ground I looked up to see the mean girl from summer camp. Alessia was that girl from every high school movie; the one who decided who was socially ‘in’ or ‘out’ at my summer camp. As Alessia allowed me to hold onto her chair to pull myself up off of the ground, I was almost frightened to speak with her. But from that moment onward we were the best of friends. Alessia and I have grown together, from children to adults, girls to women, disabled children to disability rights activists. Alessia currently works at the disability services office at Humber College in Toronto. Her activist work focuses on disability and sexuality, women’s issues and education. Much of her social time is spent with her husband of four years, Kirk, and the electric wheelchair

hockey league members. While I remember Alessia as the mean girl from summer camp, I've come to know Alessia as one of my most dear friends and colleagues, and as a passionate disability rights activist.

**Kirk**

I first heard about Kirk while Alessia and I were shopping at the Eaton Centre; we must have been 18. Alessia gave me her most serious look and said, "I have met someone and my mother will hate him!" According to Alessia, he was just perfect! And once I met him, I could see that Alessia and Kirk were just perfect together. Kirk didn't go to our summer camp, but he did attend Sunny View for elementary school and day camp. Kirk is currently working as an insurance consultant in Toronto, and focuses his advocacy work on the promotion of para-sports, particularly electric wheelchair hockey. He is a coach, mentor, and leader in our community.

**Adam**

Adam went to summer camp with Alessia and me. Adam and I participated in a project called the 'Poster Child Shoots Back', where we made short films related to the experience of disability for presentation at the Human Rights and Arts Film Festival in Toronto. He focuses much of his time on volunteer disability activism, especially with the Toronto Transit Commission's Advisory Council on Accessible Transportation. He also takes a particular interest in cultural development through the arts within the disability community.

**Jeff**

I chased Jeff down Spadina Avenue to convince him to join the University of Toronto's first disabled students' association in my first year of university and we've

been friends ever since. Jeff went to Wood Eden summer camp near London, Ontario.

Jeff is currently the president of the Association of Part Time Undergraduate Students at the University of Toronto. He has been working as a disability rights activist on campus since 2001.

### **Lynda**

While I only met Lynda in person while engaging in my research, I remember reading posts that she put up on a listserv called Disability Issues: GTA, and feeling that I was part of a larger movement of disabled people, with a rich history and culture. Lynda is currently a health promoter at the Anne Johnston Health Station, a non-profit community health centre providing services to seniors, youth, and physically disabled people; she also works at Springtide Resources, a women's shelter in Toronto. She has focused a lot of her work on women's issues and violence prevention.

### **Collective experience**

I share common experiences with all the activists I've worked with throughout my research. We are all physically disabled, we have all worked and lived in the Toronto area, and we have all attended a segregated summer camp. Alessia, Adam, Jeff, and Lynda all went to Easter Seals overnight summer camps. These camps were designed for physically disabled people, and were located throughout Ontario. Alessia, Adam, and Lynda all spent time at Blue Mountain summer camp in Collingwood, Ontario.

Kirk and Lynda attended Sunny View day camp which provided barrier free activities for physically disabled people including para-sports and arts and crafts. It is attached to Sunny View public school, a segregated school for physically disabled people, run through the Toronto District School Board. As adults, Kirk and Alessia

attended Geneva Park, an adult summer camp in Orillia, Ontario. This camp was run through the March of Dimes, a charitable organization that provides programs and services for physically disabled adults. Geneva Park provides barrier free activities for adults and children. All of these camps provided full time attendant care in addition to barrier free and adapted activities.

### **Defining voice and drawing out themes**

Once all the data were collected, I coded every sentence of the transcripts of interviews and focus group using a colour coding system to differentiate topics. These topics ranged from very broad to very specific and included: ‘inclusion’, ‘exclusion’, ‘disability culture’, ‘activist work’, ‘social drama’, ‘hanging out with able-bodied people’, ‘being cool’, and ‘liking people’. I worked with the coding system to see if natural groupings would emerge. Upon completion of this process, I reviewed the data again using the colour codes to assist me in finding common conceptual groupings. Through this process, 29 groupings emerged based on how often a concept or issue arose within the data. I worked to consolidate these groupings into common themes, ultimately categorizing all data into three overarching themes with eleven sub-themes (See Table 2).

The overarching themes, ‘Places as Context’, ‘Navigation’ and ‘Sense of Self and Identity’, that I use to present and analyze the data, emerged through a process of connecting my interpretation of the narratives within the literature. The emergence of the themes can be understood as a narrative in and of itself – they reflect the individual and collective narratives of the participants. My use of the literature to analyze the overarching themes is most apparent in my positioning of ‘the culture of activism’ within ‘Places as Context’. Most sub-themes under this theme are clearly defined physical or

social spaces. While the ‘culture of activism’ within the disability rights movement does not have explicit physical or social boundaries, it shares attributes with the other sub-themes. It provides a distinct social context where disabled people come together for common purposes. Likewise, para-sports represent a selected form of segregation, where disabled people come together for an organized activity. ‘Places as Context’ provide a socio-spatial foundation for understanding our experiences. ‘Navigation’ works to reflect upon how we engage and respond to experiences in relation to ‘Places as Context’. The idea that there is a social or political division of worlds for physically disabled people is a common conceptualization amongst the participants. ‘Navigation’ provides insight into how we experience ‘transitioning’ between worlds and how engagement within mainstream communities drives and supports the development of a stronger disability ‘community’. ‘Sense of Self and Identity’ explores how we perceive our social position and how we perceive ourselves. Within this theme the roles of ‘social acceptance’, ‘self-perception’ and ‘hierarchies’, frame the narrative of forming an activist identity.

The reasoning behind the creation of the three overarching themes is further explored in Chapter 5.

**Table 2: Themes and sub-themes that emerged from data set**

<b>Overarching themes</b>	<b>Places as Context</b>	<b>Navigation</b>	<b>Sense of self and identity</b>
<b>Subthemes</b>	<b>Family</b>	<b>Transitions</b>	<b>Social acceptance</b>
	<b>Summer camp</b>	<b>Community</b>	<b>Self-perception</b>
	<b>Elementary school</b>		<b>Hierarchies</b>
	<b>High school</b>		
	<b>Sports</b>		
	<b>Culture of activism</b>		

These themes and sub-themes created a conceptual framework that provided a better understanding of the experiences of the participants within the theoretical framework and methodological approaches that I embraced. In the next chapter the data are presented utilizing the sub-themes as a means of framing the personal narratives and collective stories of the participants.

## Chapter 4: Generating a collective narrative

Disabled rights activists are not born activists. We embrace this identity through a process of social interactions throughout our lives that contribute to the drive to politically organize. This chapter utilizes the individual and collective narrative of the participants in order to illustrate the development of their activist identities. The three overarching themes introduced in Chapter 3 provide a framework that shows how socio-spatial influences, social interactions, and perception of identity contribute to the development of an activist identity. The overarching themes will be further unpacked using sub-themes that emerged from the data. I will begin the chapter by using my personal narrative to frame the themes and sub-themes, and to position myself within the research.

Nine years ago, I began working as a disability rights activist, advocate and consultant. I organized protests, sit-ins, and petitions and wrote submission papers to government and universities. It was only when I co-organized the first disability pride events in Canada that I truly began to understand the impact that the movement had on people's sense of time and place as well as their sense of belonging.

I sat on stage and looked over the crowd; there were guide dogs of every colour, the sun glared off the cornucopia of wheelchairs, scooters, walkers and canes. I watched and waited for the silent chatter of ASL conversations to cease in the crowd. When I finally built up the nerve to speak, I said,

Rosa Parks is a hero in the civil rights movement; she played a key role in ensuring that today people of all races can ride the bus together. Unfortunately disabled people today are still riding a separate bus [crowd boos]. There is still a long way to go for disabled people and many

barriers to overcome. But today, we come together as people celebrating our lives and identities! By understanding our place in a larger social justice struggle and by understanding our own history as disabled people we can come together to celebrate our diversity and the achievements of this strong disabled community.

A roar of jubilation resonated from the audience; as I left the stage and entered the noise, I was embraced by a collective of people who were changed by my words. Many of them told me that they had finally found the place where they belong; or that nobody had explained disability that way before and that this had changed everything for them. Their words and their responses entered my heart and changed how I understood social movements. From that point forward, I saw social movements as a space for empowerment and political and cultural development, more specifically a community that invokes a feeling of belonging and creates social change by resisting the oppressive effects of isolation. It is this experience, as well as many others, that have driven me to explore and privilege the voices of disabled people, and it is within this context that I work to explore how social movements can thrive in their goal to create social change through a process of empowerment.

My time as an activist reminds me of a feeling that I had at summer camp; or to be more precise, a feeling that I didn't have while I was there. While attending an integrated school, I often felt isolated because I was only one of two physically disabled people at my school. The sense of isolation had a visceral effect, a knot in my stomach that only went away when I had opportunities to interact with other disabled people. The first time that knot went away was when I went to summer camp. Now that knot goes away when I work within the disability rights movement and engage in activities within the disability community. It is that sense of release or belonging that underpins the

connection I find between summer camp and the disability rights movement as places of empowerment.

### **Places as Context**

The places that participants have engaged throughout their lives have affected the development of our identities as activists. This is why I have chosen ‘Places as Context’ as the first overarching theme that I present. The subthemes that fall within ‘Places as Context’ are Family, Elementary School, Summer Camp, High School, Sports, and Culture of Activism. The data within these subthemes depict physical or social places that have informed participants’ understandings of themselves and their roles as activists. I have included ‘Sports’ and the ‘Culture of Activism’ as Places as Context because discussion related to sports and activism amongst participants reflected a socio-spatial understanding of these activities or concepts.

### **Family**

Participants felt that their experiences within their homes and with their families played a crucial role in developing their identities and shaping their responses to other socio-spatial experiences. None of the participants relayed that their parents identified as being disabled. Within their families, participants often represented the family’s first exposure to disability.

Many participants asserted that while their presence shaped their family’s response to disability, their families in turn shaped how the participants understood disability.

I’m wondering if it might be the attitude of your parents that make[s] the difference. When I was a child... My father was very mean. He treated [me] as if I was an animal. I can remember him saying to my mom, he would build a cage and put me in it. My mother would fight with him and

say no to my father. I'll admit now, I associated segregation with animals and cages at that time. Now I know better. Anything segregated at the time was bad! – Jeff

[It was] my mother that said to me, 'This is the hand that you were dealt. You can do things with it. Play those cards or feel sorry for yourself, get out of the game.' I never wanted to get out of the game. I always wanted to be the centre of attention. I wanted to be in the mix, so I just said, 'Okay, so I am disabled, so what! People are going to like me for me.' - Kirk

Some participants felt that cultural background also played a role in their family's response to disability and the choices that their families made on their behalf.

My mother, she wasn't a very proactive mother, because there was like a language barrier there and because she was a single mother. She wasn't very much like "no, my child has to do this", it was like an acceptance because maybe it was cultural issues as well. I was frustrated with a lot of things I couldn't do. – Alessia

My parents come from the Caribbean; it was a little harder for other people from the Caribbean to understand me. [Harder] than it was going to a school with people with disabilities. They [disabled people] accepted me, because the chair made you part of the club. – Kirk

### **Elementary school**

Alessia, Adam, Jeff and I attended mainstream, integrated classes in elementary school, while Kirk and Lynda attended Sunny View public school, a segregated school for physically disabled people. Most participants commented that their elementary school experience affected their perception of summer camp and segregation in general.

Kirk and Lynda discussed the isolation they felt while attending Sunny View public school.

Kirk: Well, when you went to Sunny View, you were in between those walls all the times. Most of the time, you were shut out from society. If you see how Sunny View is, up on a hill, kind of hidden. It was just all I knew...

Lynda: You were usually on the bus for so long on the way home. By the time you got home you had dinner, watched TV and went to bed.

Kirk: Exactly. That's exactly it.

Despite the sense of isolation that Kirk experienced, he also remembered opportunities that Sunny View provided him.

Sunny View also gave [me] an opportunity not to be shy... I remember going to the Toronto Board of Education and singing there. I remember going and singing in front of the Lieutenant Governor... I think that as segregated as Sunny View was they tried to help you as much as possible.  
– Kirk

Alessia never had the opportunity to attend a segregated school, in the focus group she was curious about how integrated or conventional schools were perceived by people that went to segregated school.

Alessia: Did you think about, what it was like? Did you sit there, and think of conventional school? Did you sit there and wondered if you missed something? I never knew there was a place called Sunny View. If I knew, I would have been like dude, “I want to go there!”

Kirk: I didn't, because I was there. Like I said, it was truly segregated there. I knew that able bodies went to school... [...]

Lynda: I still remember the “regular” school always seen as very mysterious to me. And we were always told, either explicitly or implicitly that we would not cut it in a regular school. That there would be no way...

Kirk: Yeah, I remember that.

Lynda: ... because we were academically behind. [...] The thing that I remember about camp was that it was a window for me to see, how kids who were integrated, got through things. It was like in the back of my mind, even though I wasn't really acutely aware that it was there. I remember, making cards with someone who had been integrated, fully integrated, and she went to a Sunny View dance. We could not get over it, we met her at camp and she came to our dances, and she was like, “Oh, man. I really want to go to Sunny View!”, and we were like, “What!”

## Summer camp

All participants had attended segregated summer camps for physically disabled people, and for some participants, this was their only exposure to a segregated setting. Despite differences in other areas of their lives, many participants viewed summer camp as a space to develop socially in a way that contrasted with their everyday experience.

Most participants remembered summer camp positively; it allowed them to gain social skills, independence, and the opportunity to participate in novel activities. These positive reactions often started at the point where participants were presented with the opportunity to go to camp. Many of them were excited about the opportunity to engage in a different social setting and have the opportunity to gain new skills.

I can't really remember much about the way that it was explained to me, the first time I went, but, I probably thought that it was a great experience thing, something new, and something that is just kind of special for me. [...] I remember the first time going to camp, I loved every part of it, and I just wanted to stay. I can't imagine what I would have thought of myself, had I not had it for that short amount of time, in the summer. - Alessia

I went to Sunny View, and a lot of my friends were going to summer camp, and I thought that it was really cool, so I wanted to go, probably wanted to meet boys. - Lynda

I liked going to arts and crafts, activities, swimming and of course sports. - Kirk

For many participants, camp was their first chance to direct their own care. The ability to direct one's own care allowed them to distance themselves from their parents.

[Summer camp] taught most of us: our first taste of directing our own care, our first taste of independence. It was the first time, that I really had a 40 minute debriefing on me, but when they came I was directing what I wanted and I learned tricks that I would take home to my parents and teach them to make certain processes easier for them to do. I think that's another key that we really got our sense of power and self-esteem boost that helped ignite the flame. That helped carry us those two weeks, and pushed us on. – Adam

The distance from family as primary caregivers allowed participants to forge a social identity separate from their families.

It wasn't my everyday world, it was chance that I could go and kind of like analyse with people like me and live another world, and come back and nobody would know what I did. Nobody would know anything about my experiences, and I would just have that thing that would just be about me, that would, I don't know, let me have my own secrets, maybe? When you are always surrounded by your own mother who is taking care of you, you don't have any secrets or any space that allows you to do that. - Alessia

Participants whose only experience with segregation was at summer camp contrasted their social positions at summer camp with their experiences at school.

I think that most if not all of everything that I am today was because of camp. For me, it was the only segregated space that I had. I can't remember anything else that was segregated. I lived in 'burbs. I was the only student until I was in the seventh grade who had a disability... – Alessia

Some of the people that went to Sunny View or some of the disabled schools in Toronto already had some of this stuff, so they already had the self-esteem. But I think my self-esteem would have been different if I didn't know that in the right community [i.e. summer camp] that I could have been an automatic ladder climber. – Adam

When you go to camp, people would be 'so and so is back', 'he is really cute', it was definitely heightened sexual tension. So definitely, there was honest talk, and I do say honest because at the beginning there was more posturing around this at Sunny View, more bravado. Maybe it was a little more stigmatized. But camp was a space that I felt campers would say, 'you know what, I really like this guy in school, and he said to me that he would date me but I am in a wheelchair, so he is not interested'. I felt that those kinds of conversations were taking place at camp but were not taking place at Sunny View and I have no idea why. Those were really important conversations. – Lynda

Summer camp exposed participants to different types of disabled people, and they described this as supporting future activism, by helping them understand issues related to other disabilities.

I guess something about it that probably contributed was that it made me more comfortable with people with disabilities. [...] I think it made me feel comfortable in the community and definitively helped me to understand what other people's concerns were, when I did get into community work. – Alessia

Unlike the other participants, Jeff had negative associations with summer camp.

My father never wanted a disabled son and growing up... They were going to put me into an institution and forget about me. I guess as a ten year old kid, sent to camp, I felt like I was just being put somewhere with some bunch of disabled people. – Jeff

While Jeff associated summer camp with institutionalization, other participants associated summer camp with choice and beneficial social experiences.

I don't think that in any way institutionalization is like camp. I think that the purpose of institutionalization was to bring us apart from the community in a way that was very oppressive and I don't feel that way about camp. Maybe other people did. But I think you are right. It did have to do with choice in that way, and that it was temporary. It was not my everyday world. – Alessia

Technically camp would be segregated but I do believe that for certain social groups and for certain social powers, gentle segregation that is not a forced segregation, does help. Socially, it basically helps to put everybody on as equal a playing field as you can get... – Adam

Participants also spoke about summer camp as a place that provided social support during the transition to and throughout their high school experiences.

I think I started going [to summer camp] when I was 13, there was sort of a lot of posturing. We were scared about not fitting in with high school was just around the corner. I think that there was always that background piece. When I went to camp, I met kids that were fully integrated into schools and it was just an opportunity for me to see how that worked for kids. I had not known it, and at 13, 14, assumed that a kid with a physical disability always went to a place like Sunny View. It was my first exposure to that, and that was important. – Lynda

Nobody would kiss me in school. That was just unheard of. Nobody wanted me, like that and suddenly you go [to camp] and like people want to be with you, or be with you when you are 15, but people think you are

cute, and you can go back and be like, ‘ha ha, I kissed someone, somebody touched my boob.’ – Alessia

The roughest years for me were basically grade 8 through grade 10 and sure, Sunny View or a place like it would probably have been good for my social stamina because those were the years where it was only during the summer that I took the 2 weeks at camp and basically, had my social [life]. That was where I actually met my current girlfriend. Now, her views on camp are totally different. She hated it, but camp wasn't a novelty to her because she went to Sunny View. – Adam

Basically, at camp, I was in with some of the most popular, whereas at high school I might have been in the popular rank of the outcasts. I would be one of the bottom dwellers, but maybe not 'the' bottom dweller in the social ranks. Wherein, at summer camp, I would have been higher up the rank. – Adam

I mean for that little time [at summer camp]; I actually built up that self-confidence to make it through another year. - Alessia

### **High school**

For participants who did not attend segregated elementary school, going to high school did not represent a transition from segregation to integration in the same way that summer camp represented a transition from integration to segregation.

When I went to high school in Port Elgin this was a high school that everybody sort of found a place and believe it or not, there was enough of a disabled contingent and enough of an outcasts contingent that we able to find our little place. Within that group of friends, I was one of the socially popular kids even though, it was, and it was a little league in the big scheme of school. But it was still, at that point, that I was able to find a level where I could excel. – Adam

In high school, I was the only one that was ever integrated even though there were other students with disabilities. Although there were other students with disabilities, I was also in advanced classes. So, I was always the only one [...] So many times I was just frustrated with things. I remember I couldn't go to the grade 8 trip because there was nobody to take me. – Alessia

On the other hand, going to an integrated high school was a major transition for those who went to a segregated elementary school.

When I went to high school, I remember being totally freaked out the first few days that I was there thinking that, 'nobody is going to accept me' and 'nobody is going to understand me'. – Kirk

When I went into high school I felt very stigmatized. I went to a high school that had, a pod, I don't know, I think that it's called a Research Resources Rooms right now. Even though the kids were integrated into the school system, and I went to classes with non-disabled kids, when it came down to it there was always that space where we had this one class, which was a spare. You had to go into this room, and that was very stigmatizing... I went there for a year and really, really advocated with my parents that I wanted to get out of there. I wanted to go to the high school in my neighbourhood. That finally happened and in that process I went from almost having over intervention to almost having no intervention. I really wanted it that way. – Lynda

Kirk's high school also had a resource room for disabled people, which inspired in him a desire to 'branch out' to the mainstream classroom. This created social tension between him and other disabled students at his school.

I socialized with [the other disabled students], but I also chose to go away from the resource room that they had us in. I used to call it the 'pen' cause they liked to herd us in there. I went out and got a locker and started hanging outside of that room a little more. It kind of breeds a lot of contempt with all the people that didn't escape that room. – Kirk

Kirk's time in high school created opportunities to integrate because he found the segregated setting in the resource room, or "pen," negative.

Well for me, it was always about wanting more. I always wanted to branch out. So being in that space in high school, I wanted to get out and experience more. I mean, it kind of pushed me in that way because I felt that being in that space was limiting me from experiencing all these things. So just that drive to get out there and do different things and bring people into my world was one of my big things. I really believed that the resource room, because I hated it so much, set me up for the stuff that I am doing now. I am working and I am the only person with a disability in my entire office. To me that is not strange because I always tried to get out and do different things as much as I could.

...There were a few girls in [the resource room] that liked me. They started seeing me hang out with the able bodied girls and they didn't like that too much. They started spreading crap about me and whatever else,

but it didn't deter me because it was a choice that I made. I wanted to be known in school. I wanted people to know who I was. I wanted them to know that just because I am in this wheelchair doesn't mean that I can't do things with you, because you are an able bodied person. – Kirk

While Kirk felt inspired to integrate, he described high school as the first point in his life that he realized that advocacy was required in order to ensure equal opportunity for disabled people.

Where my real awareness came was when I went to high school and I saw that there were some things that weren't equal there. I took my experiences from what I had at Sunny View and at the camp, and said 'okay, some things need to change around here because it isn't always equal.' – Kirk

### **Sports**

Most participants discussed their participation in para-sports, specifically electric wheelchair hockey and bocce ball. When discussing voluntary exclusive spaces, participants invariably mentioned sports.

I lived a distance from the other people so I didn't get to have some of the same experiences after I stopped going to camp. I still competed on the disability bocce ball tournament for 4 years, so I got to have the same experience of going to events and not having the disability hold me back. - Adam

Kirk started playing electric wheelchair hockey in high school. He remembers that being the first time he took on the role of an advocate. He advocated ensuring that the team was considered just as legitimate as other sports teams at the school.

Being able to be on the wheelchair hockey team, we had one of the people that wanted to make sure that we had a voice in this school as a legitimate athletic team. We fought to get invited to the Athletic Banquet where they used to never recognize us. When I was there we fought for it. We won a championship and they put it on the Wall of Champions. I think, because I had all that stuff in that segregated school and I wanted it into the integrated school, for lack of a better term, that's how I began a fight for that stuff in that school... – Kirk

Kirk continued to fight for the exposure of electric wheelchair hockey as equal to sports for able-bodied people.

We are now are trying to expose people that aren't disabled. We want to bring it out to the masses... We probably would not have been able to do that back in those days. I mean it was a bit sheltered there, you have been to that school, it is on that hill, and it is blocked off. Now, we want to be heard, we want to be seen. It is definitively different from when I was a kid. I mean, it was only a dream to be on television playing that sport and now on the next hockey day in Canada our league is going to be there. – Kirk

Kirk's description of community organizing and activism as occurring as a result of participation in organized para-sport is typical of the participant's discussion of para-sport. Participants also described electric wheelchair hockey as a place of belonging that enhanced the capacity for community organizing, through common experience and mentoring.

When we play hockey we are all people with electric wheelchairs, and that is empowering in a lot ways, because ... getting a flat tire, everybody knows what it feels like, and when you get a flat tire everybody kind of rallies around you, and they know who to call, and they know how to get it fixed. They know how frustrating that is, and they know things about the way you live that are common for them, but uncommon for everybody else who knows you. ... They know what is like to need a Hoyer lift and have to pee, and be holding it for 12 hours until somebody can take you... You don't have to explain to them. That is what I think is empowering and it is empowering to learn about the few resources that are out there, from other people who share your disability. – Alessia

Well, I always told them, when I was coaching them, 'You may not win a championship with me. But I want you to be a better person. I want you to be able to go out there and be a leader, and go out there and show that you are a valuable member of the community despite whatever disability you may have.' I always tried to empower my kids that way, by telling them, 'Be the best hockey player and also be the best person you can be.' – Kirk

### **Culture of activism**

Part of the process of becoming an activist in a community is to stop wanting to be like the people that are kind of ... oppressing you? – Lynda

Participants discussed the experiences of activists in a number of different contexts. The culture of activism, for many participants, was rooted in a strong community and disability culture.

Disability culture means ‘full understanding without having to explain.’ We may all have different disabilities, but you probably can empathize with me. It is getting up in the morning isn’t as easy as jumping out of bed and putting your pants on, and that is a slow struggle. [...] It comes from those experiences and other stupid obstacles that we run into on a daily basis. When we get together, we can have fun, joking, making light of them and that turns out – forms creative ideas – that some of us take up and run with. – Adam

Participants envisioned segregated or exclusive spaces as places to develop disability culture and a culture of activism within the community. When asked about empowering exclusive spaces as a political strategy, participants focused on the unique culture of disability.

Basically there are no hard and soft rules to keep the able bodies out. It is basically where people of like mind and physical disability go to share and be themselves. I considered soft segregation in the gay clubs. In the gay district we don't keep the straights out, it is just that they don't feel as welcomed there. Because it is a different culture and stuff. – Adam

I think that there is definitively a space for both [inclusive and exclusive spaces]. I think that ... when I was growing up ... the goal was, ‘integration integration integration,’ and I certainly fell into that, with that being the ultimate goal for myself. As I get older, I really also do appreciate exclusive space. I do... I think that there is a sense of empowerment that comes from that [exclusive space]. It is common experiences; common experiences of oppression, and also common experiences of – I don't want to sound heroic at all – but resistance. There is resilience in the stories as well. It is empowering to hear those as well. It's a breath of fresh air and it rejuvenates you sometimes, 'cause it really feeds off each other. I also think that if you are too much in one space, it becomes an 'us and them', right? Even marginalized groups can exoticify mainstream. I think that becomes problematic too, for other reasons. I do think that having both spaces for political action, I think that the commonality of the experience is really important too. – Lynda

The commonality of experience was an important component of disability culture for many participants. Participants described this commonality as essential to community organizing.

Right, so because we have all those commonalities its easier for us to a) pick a cause and b) rally around that cause, fully understanding what we all need to meet that goal. So, like now with the Paralympic subcommittee, we know that a getting together might be a little difficult because we have to arrange attendant care schedules, our work schedules, and WheelTrans, so we are comfortable of having teleconferences, or when we do meet, we are really understanding of people and their schedules, and you know, we, we are not very spontaneous in that way, because understand that WheelTrans has to give us 24 hours' notice, so we plan ahead. I think that's helpful in mobilizing, because we know whatever restrictions we have, and we work ... around them. – Alessia

Lynda described how activism for disabled people was segregated, because disabled people were excluded from other activist spaces.

Are we activists in a community that is still segregated? If I wanted to work for sex trade workers, would I be forced to work with sex trade workers with disabilities because that is the only space? There is this community centre downtown and that is the only community centre that is wheelchair accessible. You know what I am saying? So, some of the activism that I am talking about would we be: Is it still something that is segregated for some of us? 'Cause I do know activists that say, "I want to work with women, not necessarily with women with disabilities, but this is where I am stuck, because these are the accommodations." – Lynda

While Lynda focused on the segregated nature of the disability activist community, Alessia's comments illustrated the sense of belonging that resulted from the small social network of disabled people in the city.

When I did become an activist ... people would be like, "Oh, I remember you from camp". [...] As opposed to, I know people have come in that I have never met before, and you are always a little weary about that person coming into your group, even if they are an activist and they share the same thoughts as you. Maybe that's what happens with other people with disabilities other than physical disabilities. I am always a little weary, even though I know we share the same goals and struggles there is just this

awkward moment. I think that helped me, going to camp, has helped me gain credibility later. I can grab a whole bunch of people and say, “come to this protest” or “come to this conference.” I do think that it's about realizing that you have something to offer, and something to teach people.  
– Alessia

## **Navigation**

Building upon their discussions related to the places that informed their identities, the participants engaged in conversations related to how they navigated between integrated and segregated spaces. The idea that there is a social or political division of worlds for physically disabled people was a common conceptualization amongst the participants. The navigation of this division was often articulated as transitioning between two worlds: a mainstream integrated world, and a segregated disability community. Most of the participants focused on the role that experience within the disability community played in developing their navigational skills.

## **Transitions**

Some participants described summer camp as their first transition between integration and segregation, and spoke positively of the retreat it provided.

And for me, it was like my one escape from anything. For always being ‘Alessia, you are like the guinea pig’, you’re starting everything, you are the one that made them build the ramp and for once I wasn't the one that was the guinea pig. – Alessia

Angst in high school is different from the angst in camp. The angst in high school, you are the little guy, whereas at camp for two weeks you get that freedom. – Adam

When describing his transition into summer camp as a segregated space, Adam noted the advantages of having had experiences with integration.

It seemed that some of the people that didn't go to Sunny View that did go to regular school were able to climb up the social ladder. Maybe it was because we also took notes, even though we were shy. We were the quiet kids when it came to the social structures at the regular school. But we

took notes, and we were able, I am going to use a sports analogy: before we were the losers on like a baseball team that was playing in the big league, going to strike out. When we went to Blue Mountain we were playing more teams our level. So, it was like we were able to just keep hitting them out of the park. We knew what we're doing and it gave us so much of a social kick. – Adam

Conversely, Kirk described how having a segregated experience in elementary school helped him transition into an integrated high school.

For the first 13 years of my life, everybody was like, 'Here's Kirk,' and everybody knew who I was, what I did. I think the being segregated did help sort of shape me in the other way, by saying, 'okay you had this before, you need to get this again.' I had to fight to balance it out there. – Kirk

When discussing the benefits of integration and segregation in the focus group, Lynda had emphasized the need for integrated experiences to appreciate segregated ones. Here, she presented to the group a way of rethinking integration as an experience that leads to valuing exclusive spaces for activism.

I think that it is really a process. I've been having a hard time since the interview even to sort of think between segregated and integrated spaces. I think, that's because of my own past experience with segregation. I would be more inclined to really want something more integrated but at the same... It's hard I think because for me, my activism, it was a process in which I had to accept my disability identity. I accepted that because of my experience with segregation and also my experience with integration. The going back and forth, back and forth is for me total empowerment. – Lynda

For us, for some people, that I guess weren't as involved in those groups, who were sort of forced to be friends with able bodied people, it was easier to navigate my way in both worlds. For other people it wasn't as easy. – Alessia

## **Community**

When participants discussed community, they distinguished between a disability community and the mainstream community. They emphasized the importance of a strong disability community.

What's really cool I think about Sexability is that there are older people, who, well maybe a decade older than me, who went to summer camp. Not necessarily at that time that I was there, so there is a lot kind of similarity in their stories, so it is always nice to hear what camp was like 10 years before you were there. – Alessia

I think [camp] lead me to understand that niche groups can be powerful. Of course, everybody wants to be popular in the big pond. But there is great power, and growth, and self-esteem that can be made by being a big fish in a littler pond. – Adam

I remember this one time, because [Geneva Park Camp is] an accessible location there are a lot of parents with disabled children who bring their little kids, and I saw this little girl with the tiny, tiniest, tiniest, little electric chair that I have ever seen in my whole life, and I just remember thinking this the future of our people. And it was so cute! I liked it. I like people. – Alessia

A lot of the conversation related to how integrated and segregated experiences drew them to the disability community. Participants often talked about how balancing integrated and segregated experiences helped them to develop skills for interaction in the mainstream community.

I think that there was this whole period of time where I distanced myself from the community. During that time when I was starting to do that, I was still going to summer camp. I think some of the most positive role models that I had came out of that experience. I think that there was a time in my life when I thought 'I don't want anything to do with the disability community' but I always thought back to that period and to those times at camp. Those experiences were different. It just sort of grounded me in remembering those relationships that I had with those kids and how that was really important to me 'cause a lot of our conversations were around not fitting in and those were not conversations that I was not having with my friends at Sunny View. – Lynda

I remember once having this discussion with a counsellor, who had proposed that he thought that camp should have able-body people there and I remember just being like, 'no, no, I don't want that,' you know, and he was like 'why, it's a great place for people to kind of be together in a setting that has the support for people with disabilities, and so it would kind of level the playing field and help people be more like empathetic of people with disabilities, but I guess I always thought of it like, I don't want camp to be...I don't want to be forced to have to educate people, on not, like being equal, or having equal rights or needing an accessible bathroom,

I want my camp just to be a chance when, when I didn't have to do that, and I could be cool and rude and bitchy, and like any other 16 year old person, without feeling like I had able bodied people like saying 'who is this crippled girl who thinks she is all that, but she is really not, in my world' – Alessia

Alessia described how campers navigated interactions with donors to the summer camp:

We would all kind of joke around and pretend that we were extra disabled, and we have to thank them and I guess that is one of the things that I didn't like, cause I felt like that was more outside world kind of having to be so passive and so grateful and I didn't like that. – Alessia

### **Sense of self and identity**

Participants' descriptions of their experiences navigating integrated and segregated spaces often focused on social acceptance, social dynamics, and self-perception. They discussed struggles related to being accepted within integrated settings, which drove many of the participants to activism. They said that in order to become an effective activist, you had to be open to claiming a disability identity and undergoing a process of redefining that identity.

### **Social acceptance**

Many participants described summer camp as a space where they felt socially accepted. This was especially the case when social relations at summer camp were contrasted with those at school or within other mainstream integrated settings. Alessia's description of her social experience at camp was typical of many participants.

I liked being cool. I liked that there was like a lot of drama. People, liking other people or if you are mean, people making fun of other people. I guess it was a switch from what happened in my regular life. [...] That's just the way that I experienced things and anytime I ever tried to make myself ask out a guy in my home life I was always rejected. For the first time I wasn't rejected. I wasn't the one pushing myself into social events. People were inviting me to social events and it wasn't a big deal to get invited 'cause there wasn't any accommodation. I mean for that little time; I actually built up that self-confidence to make it through another year. – Alessia

When discussing experiences in integrated settings, participants focused on strategies for fitting in.

One thing that I used to do in high school is that I wore these really long flowing skirts. Somehow in my mind, if I was wearing these long flowing skirts, people just wouldn't notice. – Julia

When I was [at Sunny View] I was also part of the choir, so we got to go out and do things that some of the other kids couldn't do. That kind of helped shaped my personality. I wasn't really shy around people, so when I got to high school, I used my gift to talk, to overcompensate for not being able to walk and blind people from me being a person with a disability which helped me to fit into a lot of different circles. – Kirk

### **Hierarchies**

Throughout the data, most participants discussed their experiences in relation to a perceived social hierarchy that in some cases was related to disability. For those who felt that summer camp was an empowering experience, they articulate a feeling of being on the top of a social hierarchy amongst other disabled people.

Alessia: Mostly, it's like the social hierarchy is in connection with the disability hierarchy. It's really rare to find a really cool, amazing disabled person who is like really low on the disabled or like really, really high on the disability needs. [...] If you were less disabled, yeah, the more you fit into the ABs, the less of a nuisance you are to the able-bodied people the cooler you are. But it also has a social component, like I think the more you, you are socially integrated or you have those experiences that link to other people.

Julia: So, it's like the more able bodied people you know, the cooler you are?

Alessia: Yes. Exactly! And it's so true.

Alessia's perception of the social hierarchy would place someone like me (walking, with fewer perceived 'disability needs') at the top, but that is not how the other participants recalled the social hierarchy at summer camp.

At the camp I could do things that most others couldn't, so you were perceived as not really being disabled. If you're able to walk you don't count. – Julia

I would not say that I was on the top [at camp]. I would have to give that crown to Alessia. I am kidding, I was near the top, I was succeeding at stuff like that for sure. You might try in high school, but I knew I was down in the bottom, where the only way that some of the kids could succeed was if I could become the school brainiac. I knew trying to climb the social ladder of my high school was going to be, was going to be, a fruitless battle. – Adam

Adam's comments also demonstrated the disparity in social hierarchies between integrated and segregated settings. Participants commonly expressed this view.

Alessia: Camp was like the one chance to be mean, now that I think about it. Going back to what Lynda said about hierarchy, I was mean. It was like the only chance to be mean. The only chance you got that you felt safe to make fun of other people in that way.

Lynda: Maybe it's important to also have that experience.

Adam: I still think that I have a scar on my arm from you (in reference to Alessia)

Lynda: You were really mean!

Alessia: But I was mean and unsure too and I was so scared I had to be mean. But it was also like, it was my one time.

I am still embarrassed to this day, I am much older, but we called ourselves 'The Tens'. It was a group of 10 of us and we really were thinking high of ourselves. It was actually pretty ableist. It was a group of kids that were, felt they were attractive, felt they were 'normal' and we would make fun of any kid that wasn't quite 'up to par.' There was that dynamic happening there, it wasn't necessarily a space of empowerment per se, might have been for me (laughter) but not for everyone that went there. – Lynda

When reflecting upon social hierarchies at Sunny View, Lynda and Kirk recalled social factors that were unrelated to disability.

If you were athletic you were at the top... If you were in the choir and you got to go out and perform you were also on the top. When you have

those other cognitive disabilities you were kind of pushed down to the bottom. So it wasn't exactly free of it. – Kirk

*Lynda:* Some of the other attributes that I think made it a social hierarchy; we were all white kids, none of us spoke with accents, and it was about opportunities as well.

*Alessia:* Economic Strength

*Lynda:* Yeah, so a lot of us had, a lot of opportunity, there was one person that was from a lower social economic background and she was popular for a couple years, and then we kind of you know, 'cause, it was just sort of, so all that stuff plays out even in a segregated space.

### **Self-perception**

Participants said that their self-perception developed in response to external reactions to disability, including responses to the aesthetic of the disabled body. Some participants associated self-hatred and isolation from other disabled children with disassociation with the disabled identity.

When I was a child I was [an] ablest prick. I didn't want to do anything with kids that were handicapped because I was in complete denial.... I wonder if my childhood would have been better, if I had gone to camp [for a longer period] ... I have a brother who is two years younger, who is able bodied and my mom thought that I would get better if we became the 'boys'. So, everything he did, I went along with. So, all the able bodied people would be riding their bikes up and down the streets and right behind them would be me and my tricycle. I still drive today. – Jeff

I refused to associate with other children with disabilities because of my age, and because of my drooling. I had to have a surgery to stop my drooling. I spent much of my childhood, either alone or the butt of the joke. Because of my own self-hatred, I lost out on a lot. – Jeff

Jeff was the only participant who didn't have positive memories of summer camp; however, he recalled other experiences of segregation as contributing to a shift in his self-perception.

*Jeff:* When I went to camp, I wasn't ready, but when I was 16, at Erin Oaks they started the youth advisory committee; it was the first one in the province. It was at that point that I started to hang around disabled people

and that is when I got to know who I was. Got to accept who I was and love who I am. But when I was 13 my only wish was to be able bodied. By 17, I loved disability and decided there was nothing wrong with who I am.

*Lynda:* I think, you almost need the experience of integration to awaken your self-awareness, unless you are self-aware. That transition that you spoke of, where you have these ableist feelings when you were younger, which lead to this own self-hate that you described. I think you need to develop your self-awareness, and you can't do that unless you occupy integrated spaces because if you are just in a segregated space, I don't know necessarily. If we are talking about summer camp as being the origin of where your political activism lies, I think you can't, be stuck in a space like that and develop it in the same way.

According to participants, self-acceptance in relation to a disabled identity was part of the process of becoming a disability rights activist, and contributed to a sense of belonging.

Say we all agree that it is people without disabilities, who are our barriers, which most of us would agree that that could be the case. Would it be that moment when you stop striving to be like them or to be included? ... I sense in [...] order to say, "yes, I belong here to this group," you need to have self-acceptance and self-awareness of that." – Lynda

## **Chapter 5: From segregation to exclusivity**

In this chapter I recast the disability rights movement as a new type of segregated space; a space of Empowering Exclusivity that supports a strong disability community as we work toward a more inclusive society. Empowering Exclusivity within the disability rights movement evokes some of the same feelings that many of us had at summer camp and within other segregated spaces. I examine the role that segregation plays in community organizing practice. I compare how social hierarchies are understood within the feminist movement and the disability rights movement and how these structures enhance political goals and a sense of belonging. I explore how mainstreaming and disengagement, and the balancing of these two strategies, contribute to strong leadership skills, and how we portray ourselves differently in segregated and mainstream settings. This chapter concludes by looking at how we have developed our activist identities through a process of self-acceptance or empowerment and offers insight into how we develop leaders within the disability community.

### **A place of belonging**

Throughout the interviews and in the focus group, as the six of us described our process of self-acceptance, the development of our leadership skills, and the ultimate creation of our activist identities, we often framed our reflections in terms of physical and social places. We credited interactions in and between our family lives, school communities, summer camp, and sports, with our personal and social development. Electric wheelchair hockey, Easter Seals summer camps, and Sunny View public school all shared a common trait: they were places where disabled people came together. Some, like summer camps and school, were places of imposed segregation. Others, like electric

wheelchair hockey and the disability rights movement, were places of chosen segregation or exclusivity. All provided the opportunity for disabled people to engage in the work of creating a social and political community.

Although there are no physical boundaries that define the disability rights movement, the movement provides a distinct social context where disabled people come together for a common purpose. It is within this framing that I understand the disability rights movement as a 'place' that provides the opportunity for the development of leadership skills and supports the process of self-acceptance. Ultimately the movement provides a place to forge an activist identity.

A variety of models are used to historically contextualize the disability rights movement. As referred to in Chapter 2 (pp.14-15), Hughes (2002) defines political mobilization within a social model framework as a 'second-wave' movement developed to fight medicalized and institutional practices that were perceived as a means of incarcerating and isolating disabled people from the mainstream community. Even after the initial political process of deinstitutionalization, the charitable model was still a dominant construct used to gather support for programs and services for disabled people (Hughes 2002). Easter Seal summer camps also adhere to the charitable model as well as the medical model; they have the characteristics of total institutions that Goffman (1968) defines (see p. 15). They are socially and physically closed spaces that govern the daily activities of campers under a single authority whose aims are to provide 'care' for disabled children and adolescents within a medicalized environment.

Today's disability rights movement shares many features with summer camps. While it is not a total institution and it rejects charitable and medical models, both spaces

provide the opportunity for disabled people to develop a positive sense of identity and to share commonalities and struggles. The positive aspects of segregation within summer camps and the disability rights movement, socially and politically, arose throughout the data. As activists we have all worked with a number of SMO within the community (see Table 1). These organizations are predominantly exclusive to disabled people, creating segregation that is sometimes chosen and often empowering. However, segregation within the disability rights movement can be perceived as imposed when based on the need for physical accommodation (see p. 55). In Chapter 2, I described the disability rights movement as a NSM that provides discursive space for the development of a cultural identity within the disability community. The definition, or even the existence, of disability culture is a highly debated topic within the movement and amongst disability theorists (Finkelstein 1987; Oliver 1990). Discussions that came out of the data positioned disability culture as it relates physically disabled people to shared daily struggles (see p. 53-55). By defining disability culture through shared experiences of impairment, we as participants and as activists engaged in a practice of reincorporating impairment and everyday experience into the disability identity (Wendell 1997).

Adam asserted that there was a social benefit to exclusive or 'gentle' segregated spaces for physically disabled people (see p. 49). Lynda struggled with the idea of segregated or exclusive spaces as beneficial. She attributed this struggle to the focus on de-institutionalization while she was growing up (see p. 54). However, while reflecting on her experiences rather than her ideology she also asserted that there was a sense of empowerment that grew out of exclusivity. Alessia grew up in a different period of political organizing for disabled people than Lynda, and for that reason she developed a

different ideological perspective about the role of segregation or exclusivity in community organizing. While she remembered her experience of segregation as empowering, she also acknowledged the historical use of segregation as a means of disempowering disabled people:

I think it's kind of interesting because a lot of time segregation is used to disempower people. You know, like making disability hospitals in the middle of nowhere. When Toronto was small, West Park was built all the way in the middle of nowhere because they didn't want disabled people around; or Sunny View had to be built on a hill because the people driving by didn't want to see disabled people. In that way, I think segregation is disempowering. – Alessia

Despite her acknowledgement of the historical use of segregation as disempowering, Alessia drew a connection between segregated spaces and the mobilizing capacity of the disability community (see p. 58). Alessia's perception of the little girl in the wheelchair as "the future of our people" revealed a way in which segregation has created a sense of belonging within the disability community. Whether imposed in the style of total institutions or self-selected by activists themselves, segregated spaces have played an important role within the disability community and have supported mobilizing capacity within the disability rights movement.

### **Finding balance and defining social position**

During my youth and adolescence, I found it difficult to find a space of belonging. I felt more comfortable engaging with other disabled people in segregated spaces than I did dealing with able-bodied people in integrated settings. Throughout the interviews and focus group a number of discussions related to the importance of balancing the world of integration and the world of segregation. The sense of empowerment that many of us experienced at summer camp can only be understood in relation to experiences that we

had with integration. Alessia felt that summer camp provided a contrast to her usual experiences of integration and without having gone to summer camp it would have been more difficult to succeed. Alessia described this need for balancing integrated and segregated settings using a hierarchy of “haves” and “have nots”. The “haves” are on the top of the hierarchy because they have integrated more and socialized more with able bodied people; “have nots” socialize predominantly with other disabled people, and do not feel comfortable in highly integrated settings. According to Alessia, “haves” find segregated settings more empowering than “have nots” because these settings offer a departure from their everyday lives. During discussions related to integrated and segregated spaces, we established that segregation is only perceived as empowering and contributing to a process of self-acceptance when balanced with integration (see p. 63).

Many of us used concepts drawn from feminist organizing practices to frame experiences within integrated and segregated spaces as pivotal in developing strong leadership and a vital social movement. Alessia compared her time at summer camp to women’s only hours in gyms and women’s bookstores. When discussing the disability rights movement, Linda drew comparisons with the women’s movement of the 1970’s. Segregation within the disability rights movement is perceived as oppressive, isolating and lacking empowering components. Reasoning that frames segregation as oppressive has driven activists to work diligently against all forms of segregation. By contrast, within feminist organizing theory, the process of disengagement or segregating is thought to have empowering qualities (see pp. 24-27). We all discussed our lives, in both integrated and segregated spaces, utilizing a variety of societal hierarchies that sometimes connected to a disability hierarchy. Within feminist and social movement theory,

hierarchies are often used as a means of understanding social oppression and power dynamics. Critical feminist theorists argue that “hierarchy involves patterned ways of interacting and behaving. In a hierarchy, people (or at least the roles they fill) are ranked, and interactions among them occur through this ranking” (Addelson 1991:161). Within liberal traditions, hierarchies are viewed as a necessary component of social life and when social oppression occurs, it is an indicator that there is a problem with the process of sorting people into hierarchies, and not within the hierarchical structure itself. The socialist perspective argues that in order to enact social change, activists must work against the hierarchical structure itself. Radical feminists reject the need for hierarchy in society altogether and argue that only when hierarchies are eliminated will the process of social change begin (Addelson 1991:161-163). Most Canadian disability rights activists approach hierarchies and activism from a social liberal standpoint (Prince 2009), and consequently tend not to critique hierarchical structures. Although we did not spend time discussing our political understandings of hierarchy during this study, we did spend a great deal of time articulating our shifting positions on hierarchies as we moved between integrated and segregated settings.

From the data I found that the hierarchy of disability had less to do with the severity of physical impairment and more to do with one’s ability to communicate. For example, within a medical model framework Alessia, with muscular dystrophy, who uses an electric wheel chair to get around, would be considered ‘more disabled’ than Jeff, who walks and has moderate cerebral palsy. However, within the context of this study many of us would place Alessia on the top of the disability hierarchy and Jeff on the bottom: Jeff’s disability affects his ability to communicate, while Alessia’s does not. Levels of

cognition and communicativeness define the hierarchy of physical disability in many segregated settings, instead of mobility and need for personal care which defines the hierarchy in many integrated ones. There are aesthetic indicators that would put someone higher on the hierarchy of disability in segregated settings including posture, being in a wheelchair, facial beauty or expressiveness. All of these indicators are classified by some of us as making one more 'able bodied looking'. The hierarchy of disability, as perceived by some participants, is connected to a social hierarchy within the summer camp setting. This social hierarchy and the 'social drama' surrounding it provide a contrast to integration that many of us found empowering.

Participants' experiences of hierarchies in integrated and segregated settings can be understood using the concept that Goffman defines as 'audience segregation' (Goffman 1959). 'Audience segregation' occurs when "the individual ensures that those before whom he plays one of his parts will not be the same individuals before whom he plays a different part in another setting" (Goffman 1959: 49). Alessia remembered having to alter her behaviour when donors came to visit the summer camp (see p. 59) in order to conform to a charitable understanding of disability. However, her more general experience of summer camp provided her with the opportunity to present a different version of herself (see p.61). Adam had a similar experience in that he felt that he held a higher social ranking at summer camp than he did during his time at integrated high school (see p.50). Adam attributed his higher social status at summer camp to the segregated nature of the setting. Alessia and Adam's sense of social hierarchy at summer camp, and their response to it, reflected their perception of segregation as a novelty. The empowerment that stemmed from being at the top of the social hierarchy reflected the

contrast to their everyday lives. Kirk and Lynda both sat at the top of social hierarchies at summer camp and elementary school which were both segregated settings. While they didn't remember finding those settings beneficial at the time, upon reflection, after they entered more integrated settings, they did see empowering attributes to segregation (see p. 57):

Maybe if there had been more inclusion that would have been a different space entirely, I am not sure, I think there might have been a hierarchy then, and I would've been lower in the pecking order. Lynda

The experience of social hierarchies that we had throughout our youth and adolescence supported a process of empowerment by providing us insight into why social change and community development are both important to the success of the disability rights movement. Additionally these experiences supported our personal development of positive identities and leadership skills.

### **The activist identity**

The activist identity for disabled people is defined by Goffman (1963) as the professionalization of their stigma. He sees their roles as activists or advocates as being an opportunity “to break out of the closed circle of their own kind... [and] be a representative... [and] presents the point of view of their category” (p.27). Participants in this study felt that our opportunities to engage in both integrated and segregated settings have enhanced our ability to ‘represent’ our community within mainstream contexts or to those whom Goffman calls ‘normals’. According to Goffman (1963), segregated spaces are used as mechanisms to voice grievances related to disadvantages and stigma in mainstream settings. Nevertheless, he does not envision segregated spaces as places that can enhance the ability for marginalized groups to politically mobilize. Our personal

stories and collective narrative framed summer camp as a segregated space that played a pivotal role in our social development and our activist identities.

The data reflected aspects of Anspach's (1979) four disability identities (see pp. 20-21), and components of these identities are drawn upon in a process of empowerment that culminates in an activist identity. Jeff recalled experiencing self-hatred and a drive to disassociate from other disabled children in an effort to be accepted by his father. When reflecting upon his experiences he felt as though he "lost out on a lot" (see p. 62). His experiences contained elements of Anspach's 'normalizing identity' as they revealed a drive to be accepted and a valuing of mainstream cultural understandings of the world. Alessia experienced summer camp as a retreat and an opportunity to disassociate from able bodied people (see pp. 48, 58). In this way her experiences reflected components of Anspach's 'disassociater and retreatter'. While we all came to our activist identities in different ways and through different experiences, the process of empowerment for each participant included a component of self-acceptance and a sense of belonging within the disability community.

Summer camp provided the opportunity to develop a sense of belonging. The chance to be a part of a clique, the opportunity to perform mainstream social roles, and to be seen as socially desirable or included, were all experiences that we attributed to summer camp and the development of a positive self-image. Alessia and Adam both felt socially accepted at summer camp, while at school they felt isolated and pressured to perform a disabled identity. For them, summer camp was experienced as a release from social pressures that integration imposed. Lynda and Kirk were both apprehensive about making the transition to integrated high schools. Lynda remembered summer camp as

providing support during this transition. The social structures at summer camp mirrored mainstream social structures that many of us felt excluded from or pigeon-holed in. Summer camp allowed us to reshape our identities and social roles. Within integrated settings many of us felt that our self-perception was shaped by the identities we felt compelled to perform. In order for people to feel compelled to perform, they unconsciously or consciously have committed themselves to performing (in Goffman's sense) a specific identity within a specific space. Many of us attributed our leadership skills and roles as activists within the disability community to the balance between integrated and segregated settings in our lives. Goffman (1963) describes an ambiguous relationship between stigmatized individuals, especially those that are visually stigmatized, and 'normals' in mixed social situations. The data consistently revealed that a sense of belonging and the opportunity to 'prepare' or 'recharge' in segregated settings was crucial in order to face integrated ones. Segregated spaces provided the opportunity to feel socially accepted, while it also allowed us to engage in a process of self-acceptance. In integrated settings, many disabled people internalize oppression; according to Wendell,

[d]isabled people can participate in marginalizing ourselves. We can wish for bodies that we don't have, with frustration, shame, self-hatred. We can feel trapped in the negative body; it is our internalized oppression to feel this (1997: 268).

This is because most disabled people embrace mainstream beliefs about identity and normalcy, and while they acknowledge society's perception of them as different, they often hold a self-perception of being a normal person (Goffman 1963; Titchkosky 2003, 2007).

While Wendell argues that disabled people may never be able to overcome the frustration and self-hatred associated with embodied difference, Lynda believed that overcoming self-hatred is an important part of becoming an activist (see p. 63). The need to “stop striving to be like them” and to embrace a positive disability identity enacts Young’s (1990) politics of difference rather than an ideal of assimilation (see p. 11):

If the only alternative to the oppressive exclusion of some groups defined as ‘Other’ by dominant ideologies is the assertion that they are the same as everyone else, they will continue to be excluded because they are not the same (Young 1990: 168).

Given Lynda’s agreement with Young (1990) that a politics of difference was required in order to end oppression and exclusion, the disability community needs to celebrate our differences collectively and create the political solidarity necessary through empowered identity formation in order to enact social change. Wendell describes this as a process of self-acceptance that will ultimately lead to liberation for disabled people.

Encouraging everyone to acknowledge, accommodate and identify with a wide range of physical conditions is ultimately the road to self-acceptance as well as the road to liberating those who are disabled now. (Wendell 1997:263)

From an activist perspective, it is essential to acknowledge difference within the disability community, especially within the context of cross-disability activism. While everyone that has participated in this study shares the commonality of being physically disabled our roles as leaders within the community require that we expand our scope of understanding.

We have developed the drive to politically mobilize through a process of self-acceptance or empowerment. Additionally, the balance of integration and segregation provided us with different experiences of social acceptance and empowerment that have

shaped our activist identities. Within integrated settings we were often exposed to social and systemic barriers to participation. The sense of injustice that stemmed from those barriers contributed to our drive to mobilize politically. When segregation contrasted with our everyday lives, it inspired a sense of belonging, social acceptance, and contributed to a process of empowerment; it also contributed to our drive to develop a sense of community and collective responsibility.

## Chapter 6: Concluding observations

On a sunny day in May 2003, during National Access Awareness Week, I organized my first rally. Two hundred disabled people, and allies, gathered outside the governing council chambers at the University of Toronto to protest a lack of accessible housing for disabled students. As university administrators arrived in suits, by limousine, they had to push their way through a crowd of students in wheelchairs holding signs and helium-filled balloons.

I explained our strategy to key protesters, amidst the megaphone's claxon and our chant, "real people deserve real access!" The university had to hire extra personnel for the day to operate the usually unstaffed one chair lift to the governing council chamber. There was a moment before protestors started going up into the chambers to protest the meeting- that I looked around at everyone chanting with balloons and signs because I had asked them to and told them that it was important- that the protest took on a life of its own.

Students were not angry because I told them to be; they certainly had their own concerns and shared aims with the cause; but I brought them together. That was the moment I realized that I was a protestor. They were waiting, with anticipation, for me to say something into the megaphone. My fifth grade picture had come to life: I was an activist.

The group I had founded, Students for Barrier Free Access, had just organized Toronto's first disability pride parade; the Ontario government had just passed the Ontarians with Disabilities Act. It was an exciting time for disability rights activists in

the city; I was becoming an expert in my field. One of my colleagues was working on an anthology that explored the diversity of experiences of disabled people and asked me to write a chapter. I wrote about growing into a disability rights activist, at that point I thought: “It’s only when I am more accepting of who I am that I can look at how I can advocate for other people. I need to understand myself before I can understand others” (Munk 2005:151).

In 2008, I moved to Victoria to undertake graduate studies, thinking that British Columbia was more accessible and had a strongly established disability rights movement of its own. I left an active and independent disabled activist community, one that provided an empowering and exclusive space for me. While I felt welcomed by the disability community in Victoria, it did not provide the same sense of empowerment for me. In Toronto, I was able to work within the disability community and create a social network that was completely separate from the mainstream. The ability to choose to disengage in that way strengthened my role as an activist and provided me with a sense of belonging.

That sense of belonging and the opportunities that I had to work with activists that I knew since I went to summer camp pushed me to explore how communities developed by undertaking this study. The purpose of this study is to provide insight into the role that segregated spaces play in community and political development for disabled people. The disability rights movement in Toronto creates a space that contributes to my process of empowerment and my interest lies in understanding whether this is a common experience amongst my peers. Upon reflection, I found that a number of my social networks within the disability community began as a youth attending segregated summer

camp. Full inclusion has been the language used to articulate the goals of the disability rights movement since the beginning of the struggle for de-institutionalization. The goal of inclusion normally gets articulated in terms of escaping exclusion; inclusion is framed as the absence of segregation on the basis of a disability identity. So understood, inclusion is achieved when disabled people have equal access to employment, education, transportation, family, and other factors that contribute to full participation in the mainstream. In other words, the goal of full inclusion is achieved when full integration is put into practice.

As activists, all the participants in the study have been working toward full inclusion, through integration. Their reflections on experiences in integrated settings paint a picture of struggle, frustration, and isolation that contradict the goals of much of their work. The participants' recollections consistently evoke a sense of being excluded within integrated settings: not engaging on the same social levels as other students at school; sitting in a different area of the classroom; or in a different classroom for part of the day; having to act as an educator on disability issues; not being invited to parties or asked on dates; being the only disabled person in a given setting. In the integrated settings we grew up in, we often or always felt frustrated, excluded, and isolated.

Segregated summer camp provided us with the opportunity to feel socially included and engage in the activities that we were excluded from while in integrated settings. At these separate camps, there was a different social hierarchy that gave us a chance to feel 'cool', socially desirable, and to occupy and perform different social roles. Instead of enacting our disability identity as educator, pitied, or victim, we could be

popular, cute, and even mean. This created a space where we could build our self-esteems, and retreat from feelings of exclusion by developing a sense of belonging.

My research has revealed that part of the process of becoming an activist is having an opportunity to choose and to create spaces that are exclusively for disabled people. The balance between integrated and exclusive settings increases the capacity of the disability rights movement by strengthening the community. More importantly, experiences in exclusive settings, regardless of whether they are chosen or imposed, can provide feelings of inclusion. How can we critically engage or conceptualize full inclusion without an experience of what it feels like to be included?

This study suggests that a process of empowerment can lead to an activist identity and the strengthening of leaders within the disability community. Summer camp, understood within the context of other integrated and segregated encounters, has provided participants within this study with a unique or distinctive type of social knowledge. When discussing our time at summer camp, we reflected upon shifts in the perception that we had of ourselves based on our ability to hold a different social status within the segregated setting. For many of us, summer camp provided the opportunity to move up a social hierarchy from lower positions in integrated settings. This upward mobility provided the opportunity to move away from self-hating toward a positive disability identity. Social acceptance and shifts towards a positive sense of self contribute to the drive to take on leadership roles and activist identities, while also leading to engagement in segregated or exclusive spaces by choice because they create a sense of empowerment.

The concept of Empowering Exclusivity is one that certainly challenges and might possibly change the mainstream disability rights movements' strategic goals. The

concept also has the potential of strengthening the disability community by shifting internal discussions away from integration and segregation toward empowerment and belonging. Empowering Exclusivity is a term that I used to understand experiences of segregation that have enriched the lives of participants by providing a sense of belonging.

Whether Empowering Exclusivity translates into physical spaces for activists to gather, it has the potential to change the value we place upon segregation within the disability rights movement. The concept will support a re-visioning of how the movement works towards its goals. My work has provided conceptual, analytical, and theoretical room and also political/activists space to question binary understandings of integration and segregation and inclusion and exclusion. The metanarrative of the disability rights movement often conceptualizes segregation as oppressive and exclusionary, and integration and inclusion within the mainstream as the way of fighting this oppression for disabled people. By refocusing on a process of empowerment that leads to positive identity formation, I have started the project of deconstructing this binary. According to my research, the process of empowerment is a process of self-acceptance and the development of self-awareness through a diversity of experiences within integrated and segregated settings.

Methodologically, I have utilized a mixture of critical auto-biography as well as both individual and collective narratives as the means for exploring and understanding the development of our activist identities. By privileging our narratives and creating a collaborative and non-hierarchical environment throughout the research process we created a sense of community and empowerment and transformed the research environment into an *empowering, exclusive space*.

A number of current theoretical framings contribute to a public narrative related to disability that illustrate a journey that begins within the walls of institutions and within medical and charitable model frameworks. There is an expectation within these framings that disabled people should present as either invisible or tragic heroes fighting their own bodies in an effort to be as 'normal' or non-disabled as possible. Within this context, the activist narrative begins to develop through the social model paradigm that conceptually separates impairment and disability. Within this framing, disability becomes the social and physical barriers that exclude disabled people from society. There is an emphasis on integration as the primary means of inclusion for disabled people. The social model's focus on the public political sphere and its disregard of personal experiences of disability and impairment has left many women feeling excluded and unrepresented within the movement. Many disabled women have turned to the women's movement but have also felt excluded and unrepresented because of a lack of critical understanding of physical disability and impairment. In response to a sense of exclusion from both social movements, CFD theorists develop their own narrative that draws on the best of feminist philosophy and social model principles in order to politicize the personal and re-incorporate experiences of impairment into the social movement. My theoretical contributions to this narrative look at an area of feminist theory and practice that has not been explored within the context of disability: the organizing practice of balancing mainstreaming and disengagement. The political work achieved by the disability rights movement has predominately focused on mainstreaming through a push for integration and equal access within society. Feminist organizers have also used this practice to gain political and social rights. However, feminist organizers as well engage in a practice of

disengagement through women's only spaces and women's centres. This practice of disengagement from the mainstream is thought to provide a political power source and create stronger cultural understandings of women's experiences, a sense of empowerment, and a place of belonging. Disability rights activists and theorists have not explored disengagement as a viable organizing tool because of the historical understanding of segregation as exclusionary and oppressive.

By utilizing CFDT as a foundation for exploring the experiences that activists have had in segregated spaces, I have worked to understand the role that disengagement plays in the development of an activist identity. My research has supported me in defining the role that segregation can play in political mobilization and in identity formation for disabled activists. By using the term *Empowering Exclusivity* to reconceptualise certain segregated spaces and experiences, I have developed a clearer understanding of disengagement, as praxis, in the disability rights movement.

### **Moving forward**

My work makes strong methodological, theoretical, and practical contributions to the field of disability studies and the disability rights movement. This study suggests a different starting point for many disabled activists and disability studies scholars. It begins a new, and needed, conversation that provides room to question how we become who we are. For activists within the disability rights movement, the concept of *Empowering Exclusivity* has the potential to change the way that we organize by creating new spaces for community and leadership development. *Empowering Exclusivity* does not singularly replace the goals of the disability rights movement: rather, it acts as a tool

for supporting consciousness raising and the development of strong and positive social and political identities.

The notion that a legitimate goal for disabled people is to create exclusive spaces that can be empowering is ground breaking within disability literature. However, the introduction of Empowering Exclusivity does mirror some of the existing literature about social movements and feminist organizing practices by acknowledging that disengagement can be a tool for social change. My social and political position provided me with a starting point to explore the experiences of physically disabled activists. A future line of inquiry that could support a fuller understanding of the impact of Empowering Exclusivity in the disability rights movement would be to expand this type of study across multiple disabilities or to undertake a research project with a cross disability perspective in its research design. Also, within a framework that values Empowering Exclusivity as a mobilizing tool, further exploration must occur related to how to balance exclusivity within the disability rights movement. Based on this study, segregation is only empowering with a balancing of integration; the sense of empowerment that summer camp provided can only be understood in relation to experiences that we had with integration. Our personal and collective narratives explored summer camp as a segregated space that played a pivotal role in our social development and our activist identities. Thus, if Empowering Exclusivity is used within the social movement there would need to be a set of collective tools in order to ensure that empowerment is not lost. Future study that explores the inclusion of allies within the disability rights movement would also be required. Charlton (1998) put forward a mantra for the disability rights movement “nothing about us without us”. Empowering

Exclusivity suggests that we need to develop a stronger sense of 'us' in order to critically redefine full inclusion understood, based on my analysis and conclusions, as the mutual and respectful recognition of people, as individuals and members of different social groupings.

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## Appendix

### Appendix A: Consent Form

You are invited to participate in a study entitled Redefining Oppressive Segregation: Claiming Empowering Exclusivity that is being conducted by Julia Munk.

Julia Munk is a graduate student in the department of Studies in Policy and Practice at the University of Victoria and you may contact her if you have further questions by email at [REDACTED] or telephone at [REDACTED] (please feel free to call collect).

As a graduate student, I am required to conduct research as part of the requirements for a master's degree in Policy and Practice. It is being conducted under the supervision of Michael J. Prince. You may contact my supervisor at [REDACTED] or by email at [REDACTED]

#### Purpose and Objectives

The purpose of this research project is to explore how the experiences of activists with physical disabilities, within segregated summer camps, affected their decisions to become politically or socially active. A key question that guides my work is: Are segregated spaces a power source in the process of political mobilization for the disability rights movement?

#### Importance of this Research

Research of this type is important because it supports a fuller understanding of why people become active in the disability community, and will therefore help to promote social change for people with disabilities. By providing practical insight to how and why one might choose to mobilize politically or socially.

#### Participants Selection

You are being asked to participate in this study because you are a person with a physical disability who is currently undertaking political, social or cultural work that empowers people with disabilities, or who works toward creating shifts in social consciousness related to disability, and you have attended a segregated summer camp.

#### What is Involved

Participation in this research is voluntary. If you agree to become involved, your participation will include: one individual interview that explores your experiences at summer camp and any relationship those experiences have to the work that you do now, and one focus group involving five other participants in order to explore collective experiences.

With your permission, both sessions will be recorded using a digital video recorder and will also be simultaneously transcribed by a research assistant.

#### Inconvenience

Participation in this study may cause some inconvenience to you, including: the need to travel in order to participate in a focus group and or/the individual interview. In order to lessen the level of inconvenience for you, individual interviews will be conducted in your home. If you require travel assistance to the focus group, or any other accommodation every effort will be put forward to support them in full and active participation.

#### Risks

There are some potential risks to you by participating in this research and they include emotional, psychological and/or physical stress and fatigue. To prevent or to deal with these risks the following steps will be taken: all participants, research assistants and the researcher are asked to refrain from using other participants' names or identifying them with any other characteristics outside of the research setting without explicit written consent of the affected person. Throughout the process, participants will also have the opportunity to take breaks as needed. Additional accommodations in order to ensure full and active participation will be available upon request. Contact information for the Anne Johnson Hall Station, a community organization that provides counselling and psychotherapy specifically for people with physical disabilities, is available for any participants who experience distress as a result of traumatic memories resurfacing through the process of storytelling

#### Benefits

The potential benefits of your participation in this research include: the opportunity to enhance your social and political networks, and the chance to take a leadership role in strengthening the disability rights movement through the contribution of individual and collective stories that may potentially inspire and empower others.

#### **Compensation**

As compensation for any inconvenience related to your participation, you will be given a late lunch before the commencement of the focus group. Additionally, travel assistance, child care, or both may be provided on an as-needed basis. It is unethical to provide undue compensation or inducements to research participants. If you would not participate if the compensation were not offered, then you are asked to decline to participate.

#### **Voluntary Participation**

Your participation in this research must be voluntary. If you do decide to participate, you may withdraw at any time. You need not provide any explanation. If you do withdraw from the study, your individual data will not be used for analysis without your consent. However, if you decide to withdraw from the study after participating in the focus group the information that you provide will be used but only in summary form, and you will not be identified as a participant in the study unless they agree to it. If you withdraw from the study after consenting to release of audiovisual and other materials then it will no longer be released or analyzed by Julia Munk. However, as there is no viable way to control data that has already been released, there is no guarantee that information will not be utilized by other parties.

#### **Researcher's Relationship with Participants and Relationships between Participants**

The researcher and or other participants may have a relationship to potential participants as colleagues, friends or acquaintances. To help prevent these relationships from influencing your decision to participate, the following steps to prevent coercion have been taken; no participants will be recruited that hold a position of power over the researcher or other participants.

#### **On-going Consent**

By signing this document you are consenting to ongoing participation in this study; both an individual interview and a focus group unless and until you withdraw your consent. You will not be asked to sign additional consent forms.

#### **Anonymity**

Due to the nature of this study, anonymity cannot be offered.

#### **Confidentiality**

Your confidentiality, and the confidentiality of the data, will be protected by ensuring that all written and recorded data are secured within password-protected files. Throughout the research process, participants are also asked to refrain from using other participants' names or any other identifying characteristics outside of the research setting unless your explicit written permission is obtained. Unless consent is given, participants' identities will be disguised through the use of pseudonyms. Please be aware that if you decide to consent to release of data to other parties, confidentiality cannot be guaranteed.

#### **Dissemination of Results**

It is anticipated that the results of this study will be shared with others in the following ways; a published thesis and a thesis presentation, and with research participants. Results may also be disseminated in part or in full at scholarly meetings, or in published, scholarly articles. In the event that not all participants agree to the dissemination of audiovisual material, the focus group recordings will not be disseminated in any way.

#### **Disposal of Data**

This study aims to contribute to the development of historical, social and cultural knowledge within the disability community. For this reason, data will be securely stored and not disposed of unless disposal is requested by a research participant that has not consented to release of information. In the event that such a request is received the participants' individual interview recordings and transcripts as well as focus group recordings and transcripts concerning that individual, will be electronically erased.

#### **Future analysis & Release of Data**

All participants will have access to audiovisual and other data related to your individual interview. In the event that all participants consent to release of audiovisual and other data, the focus group relate data will become available for release to participants and/or for future analysis.

Julia Munk or another researcher may perform analysis using the data collected during this study in future and different projects. Only data provided by participants who consent to the future use of audiovisual and other data will have information analyzed or presented in future projects or studies. In the event that any participant does not consent to future use of audiovisual or other data, the focus group data will not be released or analyzed in the future.

### **Contacts**

For information concerning individuals that may be contacted regarding this study, please refer to the information at the beginning of this consent form.

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or [ethics@uvic.ca](mailto:ethics@uvic.ca)).

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researcher.

**Visually Recorded Images/Data** *Participant to provide initials:*

Videos may be taken of me for: Analysis \_\_\_\_\_ Dissemination\* \_\_\_\_\_

\*Even if no names are used, you may be recognizable if visual images are shown in the results.

**Waiving Confidentiality** (Participant to provide initials)

I agree to have my responses attributed to me by name in the results.

Yes \_\_\_\_\_ No \_\_\_\_\_

I agree to have any activity I participate in be included in this study regardless of whether or not I withdraw from the study. Yes \_\_\_\_\_ No \_\_\_\_\_

I agree to allow Julia Munk to use audiovisual and other materials in future projects.

Yes \_\_\_\_\_ No \_\_\_\_\_

I agree to allow Julia Munk to release audiovisual and other materials to follow participants other researcher. I understand that once I consent to release audiovisual materials they may be utilized by other parties.

Yes \_\_\_\_\_ No \_\_\_\_\_

\_\_\_\_\_  
*Name of Participant*

Date:

\_\_\_\_\_  
*Signature*

***A copy of this consent will be left with you, and the original will be retained by the researcher.***

## **Appendix B: Interview Guide**

### **Interview Question:**

1. What did you do at summer camp?
2. Did you want to attend the camp you went to? Why or why not?
3. Did you have a good time?
4. Can you tell me about something you remember that you really liked or did not like?
5. Have you remained in regular contact with anyone you met at summer camp?
6. Is the disability-related work you do today affected by anyone you met at camp, or by experiences you had while attending camp? If so, how?
7. Can you tell me a little bit about your work?
8. Do you consider yourself an activist?
9. Do you work or socialize with anyone you met at summer camp?
10. How do you think your experience might have been different if you went to camp with disabled and nondisabled people, or with only nondisabled people?

### **Focus Group Questions:**

1. Have any of you gone to camp, worked or socialized with others that are here today? (If yes) Can you tell me a bit about that?
2. Here are some key themes that you all brought up while you were talking to me. I thought we could take some time to reflect on these common ideas, experiences and memories. Does anyone have any thoughts about (relay a least three themes, one at a time with intervals for comments)?
3. Overall, how you think your experience at camp affected your life? Positively? Negatively?
4. If you could all change one thing about either your experience at camp or your experience working in the disability community what would it be? Why would you want to make that/those particular change(s)?