

**Left Out of the Picture:
Intersections of Gender & Dis/ability**

by

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Abstract

This study explored the possibility of a relationship between gender and disability through participatory research with persons with intellectual disabilities. It sought to provide individuals often left out of social science research an opportunity to contribute. Five individuals with intellectual disabilities were consulted on themes of home, important people, and work through individual and group photo-elicitation interviews. The photos making up these interviews were participant produced and a result of Photovoice methodology. Photovoice provides research participants cameras allowing them to image different aspects of their lives.

The following thesis establishes an absence of perspectives from persons with intellectual disabilities in the literature, outlines the Photovoice methodology, and presents the findings of the study. The paper argues that there exists a significant intersectional relationship between gender and disability. By engaging with this relationship the author identifies other intersectional influences such as generation and suggests further intersectional research in this area.

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A Narrative: Dis/Able

My first engagement with dis/ability was a personal one. When I was 9, my youngest brother was born with mild Cerebral Palsy (CP) – a concept my two siblings and I at the time didn't fully grasp. Our understanding of it, if I remember correctly, was limited function in his left side – something that he would slowly 'overcome' with rehabilitation and exercise. My strongest memories come from my mom picking my brother Tim or I up from school early on alternating weeks, taking us out for lunch, and then taking us along to Evan's occupational therapist. Similarly, I'll never forget the thrill we got when we were able to stay home to play "the games" that the speech therapist brought with her – clearly more excited than Evan. Our attendance made these sessions more fun for Evan, but it also made us, as children, very aware of our own personal limitations and how we didn't quite measure up to the baseline either.

This hyper-awareness of 'ability' grew as Evan progressed through school. I was not a math whiz – but Evan was. I watched in wonder as Evan tore through his math homework without the tears, door slamming, or fights that I will forever associate with numbers. That said, the CP had affected his penmanship – leading to significant difficulty in English and social sciences. Combine difficulty writing with ongoing speech difficulty, and French classes also proved a challenge. Evan's experience emphasized the importance placed on handwriting and verbal communication in education. It also made clear the limited number of alternative learning methods available for students with different strengths.

Moving away from home for University – my knowledge of Evan's everyday activities came from our sporadic telephone conversations. I knew that he had become a paintball addict and that he knew more about small engines and all-terrain vehicles than I ever will – but that was about it. Until, of course, the day I gathered up the courage to tell my parents I was gay. Supportive as always, the conversation slowly came around to Evan. It seems that the physical symptoms of CP (slurred speech, a limp left side) had led to significant ridicule at school and he was having a rough time. He was not ridiculed for being dis/abled, but for having stereotypical gay mannerisms. Suddenly, the already physical barriers of pencil and paper were amplified by the social torment of teasing.

This brief narrative is meant to show the fluid nature of the term dis/ability. It is meant to convey how I reached a personal awareness of the ambiguity that exists between the prefix 'dis' and 'ability'. It also perhaps captures what disability activists term the 'social model of disability' in a way that the following introduction may not.

Introduction

The questions motivating *Left out of The Picture: Intersections of Gender and Dis/ability* stem from questions raised during my undergraduate and graduate studies. Throughout coursework and independent study dis/ability perspectives were absent and experiences of gender seemed underemphasized.¹ When approaching literature that engaged gender I found myself asking "what about persons with dis/abilities", and when approaching dis/ability literature I found myself wondering, "what role does gender play in these lived experiences?"

This curiosity - and at times frustration - has led to a research project that seeks to understand possible relationships between gender and intellectual dis/ability. I started off with two simple questions. First, how might a researcher seek to do gender-oriented research amongst persons with intellectual dis/abilities? And, secondly, what role does gender play in the everyday lives of persons with intellectual dis/abilities?

The study that has developed from these questions has three main objectives: a) to ensure the realities of persons with intellectual dis/abilities are recognized in academic discussions through empirical work; b) to recognize and provide an academic work that can problematize absences of gender in dis/ability literature and the absence of dis/ability in gender literatures; and c) because of minimal inclusion of persons with intellectual disabilities in both disciplines, the thesis seeks to provide a medium through which persons with intellectual dis/abilities can speak to gender.

¹The spelling 'dis/ability' will be used until I define the term later in this chapter. Doing so will serve to problematize the term and challenge somewhat static notions of ability and dis/ability. For more see Floyd Merrell and Myrdene Anderson (2001) "End Notes: Semiotically Digesting Dis/Ability", in *Semiotics and Disability: Interrogating Categories of Difference*. New York: State University of New York.

Before engaging the study more directly, I first outline how the following thesis is organized on a chapter-by-chapter basis - and then briefly establish what I see as the three main concepts woven throughout the study: intersectionality, gender, and dis/ability.

Following this I briefly review my findings and situate myself as a researcher.

Chapter Outline

Chapter One outlines the absences in gender and dis/ability literature that motivated this study. A review of gender literature, for example, shows an absence of considerations of dis/ability. A review of dis/ability literature, contrarily, focuses primarily on the experiences of disabled women; those discussions of gender that do take place prioritize physical impairments. Relationships between intellectual disability and gender are largely absent.

Chapter Two seeks to address the question of how one might do gender-based research amongst persons with intellectual dis/abilities. In this chapter I outline the methodology that underpins the study. Recognizing gender as a rather abstract concept for the research participants, the methodology seeks to ground discussions in participants' lived experiences. I emphasize participant participation and engage in qualitative knowledge production through the use of participant produced photography (Photovoice) and photo-based interviews (photo-elicitation) at group and individual levels. Participants took and discussed photos around three themes: home, important people, and work.²

² Interestingly, Coles (1995) identifies work, housing, and the family as the three key themes in the transition to adulthood.

Chapter Three communicates the results of the photo-projects and photo-elicitation interviews. It begins with a brief overview of my five research participants and the residential care environment in which they live. The chapter then delves into the results of the projects. It explores participants' constructions of home, relationships, and work. The chapter does not focus specifically on gender, but establishes a multitude of intersectional forces that make up participants' everyday realities. It serves to determine environments where, and relationships within which, gender might be produced.

Whereas Chapter Three looked at each photo project, Chapter Four explores mutual themes amongst all three photo-projects. The first half of the chapter is devoted to these themes, such as the influence of space on participant's relationships, the relationship between an individual's language and behavior, and the existence of a collective political identity shared by participants. The second half of Chapter Four narrows its focus to specifically interrogate a relationship between gender and dis/ability. In short, participants describe a largely closed living environment that is designed around a sexless and genderless individual. This genderless environment changes significantly when one leaves the home and enters the workplace.

Chapter Five engages in a process of generalization. It uses secondary literatures to build on the patterns established in Chapter Four and to move farther away from the specificity of Chapter Three. Chapter Five also incorporates seemingly obscure patterns in the data to provide a larger, more generalized, picture. It explores, for example, how the cultural construction of intellectual dis/ability as perpetual childhood has encouraged ideas of a genderless individual and how a hierarchy of impairment may produce and reproduce established gender norms.

The work concludes with a review of the thesis' key findings and with a summary of participant's reactions to these findings. In keeping with the prioritization of participants' voices throughout the work, the final paragraphs present participants' responses to my conclusions.

Main Concepts

Three main concepts flow throughout this thesis and have shaped the project from creation to conclusion. Speaking to these concepts early in the work will allow the reader a better engagement with the project. The project is grounded in an intersectional framework leading to a particular view of gender and a particular view of dis/ability.

Intersectionality

At the core of this paper is an intersectional perspective. This has informed the research questions, choice of methodology, and how the concepts of gender and dis/ability have been engaged. Intersectionality is a theoretical framework emerging out of Black feminist responses to accumulated disadvantage and additive models of identity (e.g., Mullings 1997; Nakano Glenn 1999). Additive models of identity suggest that as one accumulates more identity statuses (race, class, gender) he or she becomes 'more disadvantaged'.

This model, for example, has been employed in discussions of dis/abled women. Dis/abled women are often portrayed as doubly or triply disadvantaged. 'Doubly disadvantaged' suggests that disabled women are first discriminated against on the basis of gender and secondly on the basis of their dis/ability (see Deegan & Brooks 1985, Driedger 1996). Triply disadvantaged has two meanings. First, it may add ethnicity into the additive model (Pane 1999). Or, secondly, it suggests that double disadvantage leads

to further discrimination within the 'women' identity category. The argument is that disabled women are oppressed because they are women and because they have a dis/ability. The third disadvantage stems from the combination of them being women and having disabilities, therefore women with disabilities are seen as 'less than' abled women (see Shakila and Geetha 2004, Pane 1999). This idea of triple disadvantage is most often found in discussions of employment, education or training, for example or when discussing why disabled women face increased risk of abuse. Scholars often divide women in these settings into two groupings (abled and disabled) instead of approaching differences from a more intersectional viewpoint.

Intersectionality, in contrast to accumulated disadvantage or an additive model, sees identity as a web of "mutually constitutive relations" (Shields 2008:302). Gender and dis/ability, for example, are but two interlocking categories of experience that make up an individual's everyday living (McCall 2005). Intersectionality argues that identity categories do not exist in isolation but occur simultaneously. Multiple, sometimes seemingly unrelated, dimensions of social structure and social identity might influence a category's operation and meaning.

This also means that identity categories might not be hierarchical. One is neither 'woman' before 'dis/abled', nor 'dis/abled' before 'woman'. The experience of multiple categories is diverse; individuals who share categories may not experience them similarly. Mullings and Shulz (2006:5) provide a more concrete example, "the very meaning of manhood may vary when applied to one's own racial group as compared to another group; similarly the meaning of a given racial category may vary for men and

women". There is no single identity category that satisfactorily describes how we respond to our social environment or are responded to by others.

Siltanen and Doucet (2008:187), in *Gender Relations in Canada: Intersectionality and Beyond*, respond to the complexities this point introduces for researchers when discussing how one might do intersectionality research. They identify two strategies researchers may engage, particularly in regard to gender. They draw a distinction between gender-based analysis, "a method which acknowledged differences *within* gender categories" (Siltanen and Doucet 2008:187) and a gender-based approach, which acknowledges intersectional factors outside of gender categories; "some women may be disadvantaged even further because of their race, colour, sexual orientation, socio-economic position, region, ability level or age" (Status of Women Canada 1995: paragraph 23). These categories are not mutually exclusive. Indeed, good intersectionality research should engage in both (Siltanen and Doucet 2008).

This argument for the use of both approaches is also transferable to dis/ability research. 'Dis/ability-based analysis' looks at acknowledged differences within dis/ability categories. However, participants are not solely dis/abled persons, just as they are not solely gendered. When combined with a 'dis/ability-based approach', which would acknowledge factors outside of dis/ability, dis/ability research can explore multiple intersectional identities simultaneously.

This thesis will establish that there are significant intersectional relationships that run through gender and dis/ability. One cannot look solely at gender or solely at dis/ability – or solely at the relationship between gender and dis/ability. These two identities sit within a web of "mutually constitutive relations"(Shields 2008:302). As

Chapter Three will show, identities may be influenced just as much – and sometimes more – by constructions of space, relationships, generation, and labor as they are by gender and disability. Recognizing different constructions of space and different identity categories that intersect relationships of gender and disability serves to establish that gender and disability need not be primary nor dominant identity categories. It also serves to engage intersections of gender and disability that may flow through other categories within the intersectional web.

Gender

The intersectional grounding of this project has led this thesis to approach gender as more than a simple male/female dichotomy. It recognizes that gender intersects with a number of different intersectional categories. Intersectionality suggests that gender is "a complicated and evolving realm of meaning making among people with sexed bodies" (Meekosha 2005: 240). As meaning making, gender is an accomplishment. It is produced consciously or unconsciously. In identifying, or being recognized as, male, female, or trans, one demonstrates that he or she has "achieved" his or her gender. Gender emerges as an "achieved property of situated conduct" (West and Zimmerman 1987: 141).

Connell (2002) takes this understanding a bit further to recognize the role of sex and power. He describes gender as a structure of social relations centering on the reproductive arena, and the sets of practices (governed by this structure) that bring reproductive distinctions between bodies into social processes. Gender is relational in that, for example, my gender is formed in part through reflecting on the relationship I have with reproduction. At the same time, Connell recognizes that gender is not solely

formed in relation to the reproductive arena. Gender is relational in that it emerges from a reflection on one's own identity. It is important to recognize that there are more than two biological sexes and, indeed, more than two ways of "doing gender"(see Siltanen and Doucet 2008).

In addition to gender being relational, it is also produced in interaction. It goes beyond reflection and is also produced through interaction. Thompson and Walker (1989:865) make the simultaneity of relations and interaction quite clear, stating "women and men participate together to construct the meaning of gender and distinguish themselves from each other as women or as men". This move from recognizing gender as relational to one that recognizes gender as also being a product of interaction, is leading scholars to question how significant the relationship between sex and gender truly is (see Umb-Carlson and Sorrunder 2006). A male sex need not necessarily mean a male gender. To understand ideas of gender among persons with intellectual disabilities I sought out both male and female sexed participants as opposed to male and female genders. This allowed my research to engage gender through participants' interaction with each other and allowed a reflection on their differences.

Before moving to a discussion of dis/ability, it is important to note that intersectionality has led to a change in how we understand gender and how we engage in a gender analysis. As Shields (2008) points out, research that approaches 'gender-as-difference' or seeks to illuminate 'difference-as-explanation' is becoming increasingly criticized. As a researcher, one cannot explain differences between male and female participants as solely stemming from a male / female binary. Instead, researchers must recognize the almost endless number of social identities available for individuals, in

addition to the relationships between participants and the larger community that shape their gender identities and how they interpret the genders of others (see McCall 2005).

Dis/ability

This emphasis on intersectionality has not only shaped the concept of gender, but also the understanding of dis/ability. In approaching this thesis, there were three possible models to choose from: a medical model, a social model, and a social relational model. Contrary to most Canadian dis/ability scholarship - and most of the scholarship from the U.S. and U.K - this thesis employs a social-relational model of disability (see Figure 1) that was made popular in the Nordic countries (Denmark, Finland, Norway, Iceland, Sweden).

The Social Relational (SR) Model

Although I will later directly tie this choice of model to my research findings, it is important to lay the model out beforehand. The model is summarized by Tøssebro (2004) and colleagues (see Gustavsson, Tøssebro and Traustadottir 2005). It involves three points:

1. Disability is seen as person–environment mismatch or poor fit. Disability occurs because the individual does not have capacities within the typical range and because the environment is not adapted to the whole range of human existence.
2. Disability is situational or contextual. Whether a specific impairment is disabling or not depends on the situation in which the individual is interacting.
3. Disability is relative. Social construction of disability takes place both in the relationship between the individual and the environment and in relations between individuals (Schneider 2009, 13).

The SR model recognizes that individuals have differing levels of function, with reduced

function resulting in personal and social effects for the individual. However, disability emerges if “restrictions within various macro levels in society ... are imposed *on top of* the social effect that the reduced function implies for that individual”(Reindal 2008:144).

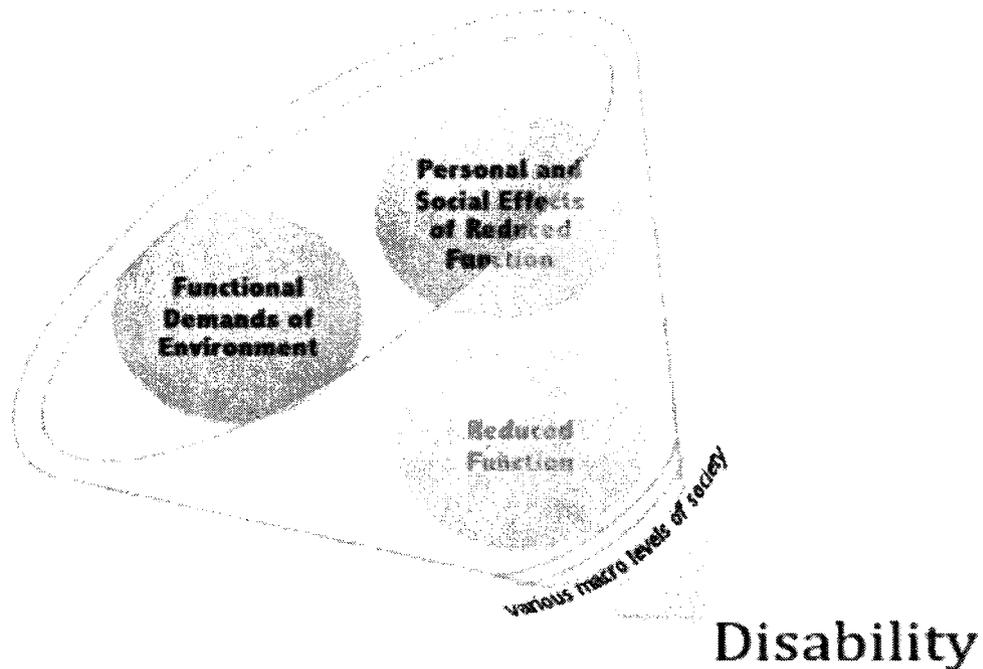


Figure 1 : The Social Relational Model of Disability

The SR model views disability as a mis-match or gap between an individual's capabilities and the functional demands of his or her environment (Tøssebro and Kittelsaa 2004; Tøssebro 2004).

The Medical Model

It is important to note that the SR model differs from the two most common models of dis/ability: the medical model and the social model. The medical model approaches disability as a medical issue. Human variation is seen as deviance, deficit, a possibly pathological condition, and often an individual burden and personal tragedy. An

individual's impairment is presented as the whole of his or her identity - requiring both the condition and the person with the condition to be 'treated'.

As Rapley (2005:11) eloquently notes, "measurement, quantification, [and] classification has not provided illumination but served to obscure and delimit the competence and humanity of those [the medical sciences] claim to serve". Medical sciences, by focusing on the body, have not tackled the social or structural systems that have turned impairments into disablements. It is this critique that led to the emergence of the social model from UK disability activists.

The Social Model

The social model sees disabled people as an oppressed social group and argues for a differentiation between disability and impairment. Disability refers to the socially generated system of discrimination that oppresses disabled people. Impairment is seen as referring to a functional limitation of the individual actor (Meekosha 2005). Within the UK this discrimination is often material; advocacy focuses on physical barriers to participation. The response to disability has been a movement seeking to remove and/or disassemble these barriers (Shakespeare and Watson 2001). In the U.S. the social model has led to a focus on oppression at large (ibid). The focus is directed more towards the societal attitudes that construct and reproduce limited participation and less on physical factors limiting participation. Importantly, this perspective does not seek to deny physical or mental differences between people with and without disabilities. Instead, it argues that the nature and the significance of these differences depend on the way members of society perceive and interpret them (Bogdan and Taylor 1994).

The distinction drawn between disability and impairment has led to critiques of the model. Klotz (2003:21) summarizes, noting "[b]y constituting social constructs and structures as the primary cause of problems associated with being disabled, disability scholars have often denied the real and ontological implications of living with intellectual, physical and/or sensory impairments". The social model prioritizes disability over impairment – it has as its focus a grouping of people as opposed to individual realities. However, 'accessible' cannot necessarily be universal. As the discussion of intersectionality has shown, the individual is a web of complexities. Although the medical model is knocked for being too biologically focused, the social model is knocked for overlooking the realities that impairments cause.

Comparing The Models

The medical model of disability combines disability with impairment – establishing disability as existing 'within' the individual and arguing for medicalized approaches to 'fix' the individual. Both the SR model and the social model are responses to, and seek to replace, this dominant medical model. The difference between the SR model and the social model lies in how the SR model responds to reduced function. The SR model recognizes reduced function as resulting in differing personal and social effects on the individual. The intersectional nature of each individual means different people with the same impairment may experience it differently. Therefore, the SR model advocates that responses to impairment are the individual's to make. This leaves the door open for medical science if an individual wishes to pursue it, but it also establishes the individual as the decision maker. Arguably, the SR model recognizes that an individual

with disabilities is not more or less capable of making decisions than a medical professional, and therefore positions him or her in control of medicalization.

The social-relational model, for this reason, has faced the critique that it maintains disability as a health rather than a political concern (see Barnes 2003). The social model is much more hostile towards medical sciences. It seeks a stronger disconnect from medical language and medical perspectives (ibid). As was mentioned, the social model is often critiqued for failing to recognize the realities of persons with impairments and for perpetuating a homogenous disability identity. At the insistence of project participants that medical professionals play an important - and arguably empowering - role in their lives, I argue that maintaining this space for dialogue is important and need not minimize the political aspects of a disabled identity. The SR model is the model adopted by this thesis and shapes understandings of disability in the following pages.

Terminology

In writing this thesis I have also spent a significant amount of time considering terminology. I have opted to use the term 'disabled people' over 'disabled persons' when referring to a collective grouping because of the ability of 'people' to prioritize political organization. That is, disabled people are a class of people united by their shared experiences. However, building off of earlier discussions of intersectionality, when referring to an individual I have opted to use person with a disability or with disabilities. I do so in an attempt to recognize the multiple belongings of the individual. This is a political decision influenced by my research; the connection between the SR model and my choice of terminology will be seen in my analysis section. In the case of a quotation I have kept the author's original terminology.

Conclusions

This introductory chapter has as its goal an introduction to the organization of the thesis - accomplished through the chapter summaries - and an introduction to the core concepts that flow throughout this text. Before concluding this chapter, I would like to take a few more paragraphs to note the overarching arguments the thesis makes and overarching conclusions the thesis draws. This provides the reader knowledge of where the thesis is going and better allows him or her to engage with the arguments and sub-arguments made in the next few chapters.

In addition to having three objectives, the thesis hopes to make three arguments. First, it establishes that empirical research can and should be done amongst persons with intellectual disabilities. This argument goes two ways: disability should be engaged from a variety of disciplines and disability studies should engage a number of disciplines. It is not enough to simply expand the triad of race, class, and gender to include disability - particularly in theoretical works. Disabled people must be consulted and brought into knowledge production. Second, there are significant intersectional relationships that run through gender and disability. This thesis will show how this relationship influences and is influenced by different spaces. It will also show how understandings of gender and associated gender roles influence how project participants see themselves and see others. Third, this thesis argues for further disability research to take an intersectional approach. A study of gender and disability makes clear the influence of a multitude of intersectional categories (such as class, age, and employment) but does not engage them. The thesis will establish and argue that more intersectional research must be done. Researchers should not be afraid of the complexity such an approach might foster.

I consider it important to situate my own perspective as the researcher and writer of this work. I write from an interdisciplinary perspective, informed by undergraduate degrees in political science and human rights, and recent MA training in sociology. The result is a thesis that is informed by literature from a variety of disciplines - a decision that recognizes the difficulty of any one discipline to represent the multifaceted realities of everyday life. This interdisciplinary background might also be credited for the strong emphasis I have put on intersectionality.

Because I do feel it has impacted the relationship I have had with project participants, I recognize that I am a middle class white male with a relationally privileged upbringing. I also recognize that, in relation to those participating in the study, this position of privilege remains. However, it should be noted that this distinction would appear to be made primarily on an ability/disability binary as opposed to a larger discussion of "quality of life" (see Nada, Ferrari et al. 2008). Participants were largely happy with their current living situation. Four of the five participants were not seeking any large-scale changes. This class-based distinction between the participants and myself is one that I have drawn. It does not appear to be shared by project participants.³

It should also be noted that I have maintained significant work experience in the residential care environment working with persons with intellectual disabilities while completing my MA studies - meaning I have lived the 'caregiver' role and gained an intimate knowledge of a similar residential care organization. This said, discussions with colleagues have suggested that my experience within, and perspective of, this

³ The relationship I formed with project participants is discussed in greater detail in Chapter 4.

organization has been much different than theirs.⁴ I have been much more critical and reflexive of the policies and procedures. This has allowed me to approach the research environment as both an insider and an outsider and has significantly influenced the research methodology laid out in Chapter Two.

⁴ This point has been explored in more detail in Chapter 3, page 55. It is also raised in the second and third narratives, “Work in the Field” and “Gender and Care”.

Chapter One: Location within existing literature

The introduction made clear that this study was largely motivated by absences within the gender and disability literature. This chapter seeks to demonstrate these absences and provide the reader with a sense of where disability studies and gender studies have successfully intersected one another and the conclusions resulting from these intersections.

The chapter is organized around three larger bodies of literature. The first section seeks to establish the strengths of disability studies. Disability studies, at present, are increasingly progressive in terms of the intersectional framework established in the introduction. In contrast, the second section provides a brief critique of disability studies as a whole. This section is important because it establishes the prominence placed upon physical disability and establishes my particular grouping of research participants as individuals left out of the larger disability literature. The third section speaks specifically to the study at hand by interrogating the interaction of disability and gender and of gender and disability. This section is the core of the chapter. It situates the research project, provides context, and also seeks to establish why this project is important. The section concludes by arguing for gender and disability literatures as intersectional literatures.

Disability Studies

A Progressive Direction

I have deliberately opted to explore the progressive nature of disability research before engaging in a critique of its shortcomings and absences. I do so because, despite some flaws, the discipline is important and, as this section will show, has a solid base from which to build.

The progressive nature of disability studies can be seen in its attitude towards three areas. First, the embrace by disability studies scholars of reflexivity. Disability researchers are very open to critique of their arguments and their methods. They often engage in this critique themselves. Secondly, because of its relatively recent founding, disability scholars have varied backgrounds leading to interdisciplinary influence. Furthermore, most disability scholars also identify as disabled people, leading to a personal identification with the literature and with intersectional approaches, and encouraging a diverse multifaceted field of study. I argue that the combination of reflexivity, interdisciplinary backgrounds, and recognition of intersectional identities has led to a strong groundwork from which the discipline might build.

The reflexive nature of disability studies can be seen in the work of one of the discipline's founders - Michael Oliver. Oliver (1997) is well known for going beyond critically engaging with his work - some arguing he has engaged in "harsh scrutin[y]" of his own research (Gibbs, D 1999:6). The conclusion of his efforts was that the main beneficiary of his research was himself - the researcher. This conclusion has led him to argue against research as investigation and in favor of research as production (see Oliver 1997). Knowledge cannot be collected; it must be produced. However, Oliver argues, knowledge production brings with it an added responsibility. The researcher is building knowledge about a group of persons he or she is often unfamiliar with. How he or she (re)presents these individuals grants the researcher significant power. Oliver argues that this power brings researchers a responsibility to go beyond knowledge production. Researchers should also seek to engage with participants in a way that allows them to

change their lives and communities. Participants should be encouraged to (re)present themselves.

This critique goes beyond Oliver's own reflexivity - and can be found in disability research as a whole. A review of scholarship around the social model, for example, establishes this (see Hughes and Patterson 1997). Although central to disability studies and disability activism, critiques of the social model and suggestions for its 'tweaking' from a variety of multidisciplinary scholars dominate disability literature. Disability scholars engage, employ, and critique the social model and - perhaps because of the relative newness of the works - are equally critical of canonical texts.

What Oliver is arguing for is very much in tune with recent commitments to 'post-positivist' research (see Siltanen and Doucet 2008, Flyvbjerg 2002, Denzin and Lincoln 2005, Bryman 2006). Post-positivists argue that all observation is fallible and has error and that all theory is revisable. Flyvbjerg (2002) takes up a similar argument as Oliver arguing that social scientists must rediscover phronesis, with the "principal task of phronetic research [being] to clarify values, interests, and power relations as a basis for praxis" (Flyvbjerg 2007: <http://flyvbjerg.plan.aau.dk/whatisphronetic.php>).

This discussion of post-positivism demonstrates a dialogue between Oliver and a larger academic community. However, it also draws attention to the interdisciplinary backgrounds that make up the discipline. Because of the discipline's relatively late development, scholars in the field hold a variety of non-disability related backgrounds. These backgrounds shape their work and their approaches to disability studies – strengthening the discipline as a whole. Works by disability studies scholars, such as Lennard J. Davis (2001; 2002), Simi Linton (1998), and Rosemarie Garland-Thomson

(1997), for example, argue that the experience and representation of disability has strong connections to experiences of gender or race or sexuality. And, they go farther than recognizing that disability is as socially constructed as other forms of social experience – they recognize it is intersectional with these other forms.

The intersectional nature of disability studies is also a result of the prioritization by disabled researchers of lived experience. Disabled authors know that they are not solely disabled authors. They are complex individuals. These authors come to these conclusions because they are disabled people themselves (see Morris 1991; Butler, R 1994; Barnes and Mercer 1997). For example, Morris (1991), who identifies as a disabled woman feminist, critiques Finch (1984) for emphasizing the family as playing a significant role in women's oppression without recognizing that it has also served for other women as their greatest satisfaction. Morris is not attempting to speak on behalf of all disabled women, but is using her own experience as a woman with disabilities.

A Work in Progress

Reflexivity, intersectionality, and an interdisciplinary background have provided disability studies a progressive bedrock, but the discipline also has shortcomings. It is important to recognize that the discipline is prone to excluding those that do not meet popular, often homogenous, ideas of disability. This weakness is responsible in part for an absence of empirical data, something that has inspired this study and that has perhaps prevented prior instances of intersectional research. Instead, disability studies has relied on self-generated theory resulting in few prominent voices in the discipline. One might contest this, arguing disability studies is unique because it prioritizes disabled researchers as discussed above. The response, in contrast, is that this suggests a monolithic

conception of disability. It suggests that experiences of disability are the same for all disabled people. The prioritization of disability also serves to emphasize researchers of particular social identities as more credible. It also leads to a dominance of theory directed towards physical disability. Persons with physical disabilities are more likely to engage in the discipline than an individual with intellectual disabilities (see Kristiansen and Traustadorrir 2004).

Roulstone (1995), in his paper on sociology and disability studies provides some explanation for how disability studies have - despite the progressive veneer - not followed through on their potential. Roulstone argues that disability research can be broken down along gender lines. Male researchers are often credited with, and found working on, the 'theoretical bedrock' of the discipline (see Fine and Asch, 1988; Linton, 1998). In contrast, empirical research - or theory drawing on empirical research - would appear to be done by female researchers or "researchers with a female consciousness" (see Roulstone 1995:12; Charlton 1998; Fine and Asch 1988; Morris 1993; Stuart 1992; Vernon 1999).

Roulstone (1995:3) goes further in his critique to argue that this results in a 'hierarchy of credibility' that dissuades change. He argues that the discipline - because it is founded on a theoretical base that has been quite successful in accomplishing social change (see Oliver 1996) - encourages and prioritizes further theoretical works. Empirical works require more fieldwork, receive less attention and respect, and are therefore pursued less (see McDonald, Keyes and Balcazar 2007). Indeed, I would argue empirical works also face a lingering stigma from exploitative research practices among disabled people (see Barnes and Mercer 1997). This 'reality' has led disability

researchers to avoid engaging in their own knowledge production - with those who do engage in empirical works relying heavily on works from other researchers and other disciplines (See Gabriel and Gardner 1999; Roulstone 1995; McDonald et al. 2007).

The solution, I argue and Roulstone might agree, lies in recognizing disability studies as a relatively new academic discipline with roots in a social movement - not in academia. A history is perhaps required of disability research prior to the creation of the discipline. Although a majority of these studies may be medical and many exploitative - there are some that are not. For example, Klotz (2003) argues that the earliest studies of disabilities were through anthropology - engaging the same qualitative techniques (narrative analysis and multi-method interviews) disability studies have come to encourage today.

The unintended consequence of this focus on disability theory by disabled people, and lack of engagement with a larger demographic of persons with disabilities, has been to prioritize physical disabilities. Much work over the past few years has slowly reintroduced learning and memory disabilities into the canon. However, as Chappell (1998: 214-216) argues, disability studies and disability activism, shaped largely by the social model, still focuses on physical and/or sensory barriers. It does not take into account intellectual experience. It does not look at the barriers posed for differing types of cognition.

Interestingly, Chappell goes beyond disability studies to argue that intellectually disabled people have been marginalized within the larger disability culture. This is a result, she argues, of the focus placed on a singular analytical category: "disabled" (1998: 214). Chappell's solution: a call for greater focus on intersectionality. We must, like

Siltanen and Doucet's (2008) distinction between gender approaches and gender analysis, look both within the disability category and outside of it. Chappell argues that discussions of disability should be open to, and engage, variables such as age, gender, ethnicity, class and sexuality (see also Block, Balcazar, and Keys 2001; Olkin and Pledger 2003).

Disability and Gender

The first half of this chapter is particularly important to understanding the second half. Both the strengths and shortcomings of the discipline are repeated in and, arguably, connect with absences in discussions about gender and disability. This next section - which seeks to illuminate absences in gender and disability research - draws heavily from research focused upon the relationship between physical disability and gender.

Work on disability and gender in the social sciences has grown significantly over the past ten years, inspired largely by a recognition amongst disability scholars such as Shakespeare (1996:54) that "there is an absence of sociological work on disability and gender". The diversity of this work, however, remains limited; a number of absences still exist. My contention is three-fold. First, explorations most often occur through a focus on policy over people (see Barnes 1991; Hales 1996; Meekosha and Dowse 1997; Swain et al. 1993), with explorations of lived experiences being limited most often to self-narratives (see Wendell 1996). The stories that are told are limited to intersections of gender and physical disabilities - tied to the trends in disability studies established above. Finally, the field remains focused on female experiences of gender - maintaining a meme that men with disabilities have been overrepresented (see Kristiansen and Traustadottir

2004: 38).⁵

Work on policy – development and analysis – is important. Disability studies has become a tool to challenge the “normative framework” underpinning policy-making (Swain et al., 1993; Hales, 1996). Indeed, it has been argued that as a result of this focus, disability has climbed up the social policy agenda and made itself prominent on the political radar.

However, I argue that a strong relationship between policy and praxis must be recognized. These policies undoubtedly affect individuals. Similarly, the enactment and interpretation of policy is the work of individuals. The lived realities of individuals should inform policy. Waxman Fiduccia (2000:173), drawing on her experience of Canadian institutions, perhaps best captures this policy/practice divide:

Mental institutions, nursing homes, intermediate care facilities and the like prohibit in policy/practice any sort of privacy, especially sexual activity by inmates. In fact, most states [sic] do not recognize inmates’ right to privacy and sexual relationships. In

⁵ The idea that men with disabilities are overrepresented is repeated in a significant amount of disability literature, with most authors referencing others who make the claim in contrast to citing empirical research that looks at men with disabilities. A search for literature on men with disabilities, for example, is sparse. Shakespeare (1996) devotes a whole article to combating this myth. It continues, however, to be reproduced and seems unwilling to go away. This cultural reproduction has led me to term the pattern a ‘meme’.

Richard Dawkins coins the term ‘meme’ in his 1976 book, *The Selfish Gene*. Initially defined as "a unit of cultural transmission, or a unit of imitation," the concept has grown to become “a cultural unit (an idea or value or pattern of behavior) that is passed from one person to another by non-genetic means (as by imitation)”. See R. Dawkins (1976), *The Selfish Gene*, Oxford: Oxford University Press.

practice, the right to sexual interaction often depends on the whim of line-level staff or on whether such interaction is seen as a feature of the inmate's treatment plan.

What Fiduccia concludes is that an analysis of policy is limited when not matched with empirical fieldwork. Policy needs to be informed by real people with real experiences.

This is not to say that all work on disability and gender is solely focused on policy. A significant amount of the discipline is made up of the exploration of disabled women's lives and experience (see Wendell 1996; Morris 1991; Butler R 1999). The literature ranges from scholarly books and papers to personal biography, poems, and fictional writings. It covers areas such as friendship, motherhood, sexuality and sexual violence. The problem, as alluded to in the earlier section, is that a reliance on disabled researchers and the allocation of greater credibility to disabled researchers prioritizes physical disability.

Recalling Roulstone and Chappell, the question becomes what does the literature have to say about intellectual disability and gender? The research that does exist appears limited to psychology (see Umb-Carlson and Sorrunder 2006), a field up until now resistant to intersectionality (Shields 2008: 202). Studies within psychology that include people with intellectual disabilities are diverse, covering areas such as health (Rubin et al. 1998; Davies and Duff 2001; Lunskey 2003; Thompson et al. 2003), cognitive differences (Kittler et al. 2004), subjective well-being (Matikka 1996), identity, social positions and roles (Barron 2002) and employment (Levy et al. 1994; Olson et al. 2000; Julius et al. 2003). As Shields (2008) notes, the majority of such research is gender blind. Most studies divide participants into groupings of women and men, and may even play female responses against male responses. They do not go further. Understandings of gender

remain static, largely homogenous and strongly connected to sex (see Umb-Carlson and Sorrunder 2006).

The absence of intellectual disability is not the only absence. Although Shakespeare's assertion that there exists limited literature on gender and disability has been challenged by the increase in works on women and disability, the main thesis of his 1996 piece remains intact – the men are missing (Shakespeare 1996, Kristiansen and Traustadottir 2004: 38). This stems from a number of factors: the idea that gender relations within patriarchal societies advantage men and disadvantage women (see MacKinnon 1996); the reality that the majority of disability activism was led by males (Shakespeare 1996); the prevalence of men in the founding of the disability studies discipline (see Barnes 1990; Morris 1991; Oliver 1996; Campbell and Oliver 1996; Shakespeare 1998); and, the fact that prior to the 1980s the private lives of disabled women were not seen as 'worthy of concern' (Shakespeare 2000). The move to include women, however, has had the unintended consequence of limiting studies on male identities (Kristiansen and Traustadottir 2004: 38). Gender, as a result, remains conceptualized as man/woman (homogenous) as opposed to men/women (heterogenous). Gender is not necessarily presented as something 'done' but instead remains a significantly essentialist category.

Gender and Disability

The discussions of intersectionality so far have made clear that the relationship between disability and gender does not go one way. The question then arises - how is disability recognized or conceived in literature that would, first and foremost, categorize itself as gender studies?

This is a rather difficult question to answer. Feminist works have been increasingly intersectional and are credited with the development of the concept (see McCall 2005, Shields 2008, Siltanen and Doucet 2008). This intersectional nature leads to openness towards and often inclusion of disability. It is becoming more difficult to suggest that disability is underemphasized in gender studies. However, two additional points must be made. First, as mentioned in the paragraphs above and briefly in the introduction - the research seems unable to escape the politics. Concerns arise when one begins to explore how disability is presented, represented and engaged. Secondly, one has to ask why disability is included. Is the intent genuine or has it merely become another tag along for the triad, 'race, class, gender, ethnicity, age, ... and disability?'

The easiest critique to make is that disability is not in the cross hairs of gender studies. Prominent gender scholars, such as Judith Butler for example, have come under critique for proposing an understanding of gender that overlooks disability (see Samuels 2002). Gender studies has responded to these critiques, however, with great vigor. Disability is being recognized in an increasing number of gender-oriented works. Disability scholars, furthermore, would appear quite grateful to gender studies because of the theoretical groundwork that feminists have developed and from which disability scholars can now borrow. The critique is no longer about gender studies not recognizing disability; it has transformed into a claim that gender studies is not recognizing disability enough.

A second response to critiques of Butler (and gender scholars at large) would seem to be a significant engagement with – and to some degree adoption of – her thinking. Instead of engaging solely in critique, disability scholars have engaged in an

attempt at modification. Cho (1997), for example, has adopted but modified Butler's theory based on personal narrative or disability theory. Indeed, from Samuels's (2002) view, modification might be too generous a term; "in his insightful article on 'Compulsory Able-Bodiedness and Queer/Disabled Existence', Robert McRuer (2002) excerpts a paragraph from *Gender Trouble* and inserts the words "able-bodiedness," "able-bodied identity," and "disabled" in brackets where Butler (1990) had originally used "heterosexuality" and "gay/lesbian"" (Samuels 2002:122). Disability experience is sometimes presented as synonymous to that of gender.

Of course, with this increasing recognition of disability, the critique over representation has changed from one of absence to one of how disability is included. The critique has always existed in discussions at the core of both gender and disability communities, but is becoming more widespread because of the slowly increasing recognition of disability as an intersectional category. Feminist works, for example, have been quite progressive in discussions of caring – a conversation of understandable importance to disabled persons (see Baldwin and Glendinnin 1983, Bright and Wright 1986; Traustadottir 1991, 1998). These works, however, have frustrated a number of disability scholars for prioritizing an 'abled' caregiver. Morris (1991, 1993, 1995) has been particularly vocal in targeting these works as focusing primarily on female caregivers and portraying disabled women as dependent. This reinforces gender stereotypes, disability stereotypes, and fails to recognize that disabled women are also care providers.

The latest critique facing gender literature would appear to be around the 'intent' of the inclusion. Are scholars including disability because of genuine interaction with the

concept, or has it become just another identity category one must recognize to get their work published? This critique is particularly strong in the work of Carol Thomas (2006:183):

I would suggest that disabled feminists must be aware of the danger of tokenism here, and of the possibility of a second type of exclusion – what we might call *exclusion by nominal inclusion*. Simply including disability in a list of discursively constructed differences will sell disabled women very short indeed, because much more sustained analyses of the social and gender character of disability and impairment – both culturally and materially – is required.

I see no reason not to extend Thomas' argument to men with disabilities. I argue they face the same danger of 'tokenism'. Indeed, I might even argue that the meme of male overrepresentation has inadvertently encouraged a situation of "exclusion by nominal inclusion"(ibid). An overemphasis on the needs of females with disabilities serves only to encourage assumptions of male advantage, which, arguably, leads men with disabilities to unnecessary difficulty obtaining services or other needs.

Conclusion

To conclude this chapter, gender and disability have become ideas increasingly engaged in academia. The development of each has led to new disciplines: gender studies and disability studies. Both disciplines have their strengths, but also have much to offer the other. There is potential for gender research and disability research to come together prominently. Although a significant amount of theory might be exchanged between the two, the next chapter will demonstrate that great similarities occur in the area of research methods.

A Narrative: Work in the Field

In the summer of 2007 I obtained employment as a personal assistant within a community of adults with intellectual disabilities. The job required me to do everything from personal care to yard work. I entered the workplace prioritizing a social model of disability and found myself up against both medical and religious models.⁶

This experience – and ongoing employment in this organization – has significantly influenced the questions this study asked and how it has gone about asking them. Working with an individual labeled “non-verbal” caused much reflection on communication methods and a personal relationship very much influenced by visual cues and guesswork. I cannot even imagine the patience he must employ everyday – his frustration perhaps increased by the fact that although he is trained in sign language he deals with a staff that is not.

For reasons like this, I argue, a number of residents in the home where I worked were often described as being difficult. The suggested response was an emphasis on routine (in everything from weekly activities to meals) and on clearly defined protocols for ‘problem’ behaviors. A violent outburst, for example, resulting from the frustration of not being ‘listened’ to was responded to primarily with isolation.

These protocols, I found, were context-independent and failed to take into account the “why” behind the behavior. Yes, an individual hit me, but why did he or she do so? Indeed – did I do something to instigate a punch? This, of course, leads to a series of questions, such as: should one face consequences for hitting someone if he or she was experiencing pain due to poor care?

What I took away from this experience, and what has been reinforced throughout this study, was an amazement at the extreme behavioral expectations for disabled people. I remain in awe at the work ethic, the almost unfaltering optimism, and the ability to find ways around a stifling environment. The routine is so embedded, followed so strictly, and surveillance so strong – that deviation from the routine is responded to swiftly.

By the end of the summer I was burnt out, exhausted, and starting an MA. But, I also found my questions surrounding gender and disability to be heightened – and my interests had shifted from gender and physical disability to gender and intellectual disability. Indeed – I began to wonder – what effect did this strict environment of

⁶ This religious model suggests that disability can be seen as necessary affliction to be suffered before some future spiritual reward.

surveillance and routine have on how one expressed him or her self? And what effect did it have on the production and reproduction of one's gendered self?

Chapter Two: Methodology

Research Question

As mentioned previously, this research was motivated by two questions. The first sought to explore how one might include persons with intellectual disabilities in empirical research about gender. The second sought to explore how gender was situated amongst other personal identities and behaviors. Put simply, how does gender influence a participant's thinking in comparison to identity categories such as disability, generation, or class? The following chapter explores how I went about doing research alongside individuals with intellectual disabilities and how grounding this research in everyday lived experiences allowed for discussions of gender as one factor in a larger web of relations.

A Participatory Methodology

As introduced in Chapter One, my research interest stems from an absence in gender and disability literature of disabled voices and perspectives. Put simply, discussions of possible intersections between disability and gender centre on policy analysis and focus less on lived experiences and personal narratives. To explore my research questions more fully, I felt it important to prioritize the narratives of persons with intellectual disabilities. A participatory methodology would allow me to accomplish this goal.

In addition to contributing to academic literature, providing opportunities to participate in, and contribute to, research also serves to empower research participants – and increases the likelihood that research participants will benefit from the research (Olivier Wood and Delange 2007). In this particular instance, the final printed thesis

might offer little benefit to project participants. However, a participatory methodology that encourages participant agency, and views participants as fellow producers of knowledge, allows for the very process of the research to be beneficial (Olivier Wood and Delange 2008:14). This project is as much about a successful participatory methodology as it is about an academically defensible final product.

Participatory methodologies, however, should not be seen as having fixed criteria. The level of participation is directly influenced by the particularities of the researcher, the research participants, and the details of the research project (see Jurkowski 2008). This project, initiated to fulfill the requirements of an M.A. thesis and subject to the approval of the Carleton University Ethics Review Board and Department of Sociology, was designed prior to the selection of research participants. Participants did not participate in the initial design. The design, however, was undertaken in such a way as to best foster the participation of adults with intellectual disabilities. Design decisions were not made in a vacuum, but were made through informal consultations with leaders in the field, literature on disability (see Barnes and Mercer 1997), personal relationships with persons with intellectual disabilities, and employment in the residential care field. Although the research methodology and design was developed without the participation of the research participants, it was developed so as to maximize the possibility that the process be empowering and beneficial to those participating.

It is also important to note that participants were encouraged to question and challenge the research design. Decisions made following the required ethics approval, or those that could be amended, were discussed with the participants - such as the themes of the group discussions and the success or failure of the Photovoice methodology. These

decisions were not made through a formal decision-making process but were discussed at the end of each group interview. Furthermore, participants were encouraged to take ownership of the data they produced and were sought out for their input on the final results. Those issues identified by participants as most important are emphasized in the 'member check' section of the concluding chapter. I sought a methodology that would recognize the multiple means of expression engaged in by persons with intellectual disabilities, and that would provide participants an experience or skill set that could be continued even after the research project had been concluded. I also sought a design that would allow participants to engage with something concrete. I wanted to focus on the lived experiences of participants instead of more conceptual ideas. This, I argue, better allowed participants to engage with the knowledge produced. Reflection on this methodology and its success was discussed throughout the interviews and is considered further at the end of this chapter.

Photovoice

The methodology I chose is popularly known as Photovoice (Wang and Burris 1994, 1997; Wang et al. 1996, 1998; Wang 1999). It emphasizes maximizing participation and communication pathways through visual research methods. It also speaks to the unequal power dynamic between researcher and research participants. Photovoice provides research participants with cameras and asks them to photograph aspects of their everyday lives. This serves to create and promote knowledge about personal and community issues and grants the researcher a unique form of access into participants' lives. The resulting photographs are then discussed in individual or group setting through a photo-elicitation like process. The design of this process varies, often

depending upon the objectives of the researcher and particularities of the research participants (See Jurkowski 2008; Wang and Burris 1996, 1998).

The Photovoice methodology best fits with research that is in keeping with its three main goals. These are:

- to encourage people to reflect on and record aspects of their own identity and experience;
- to enable them to find personal strength and common cause with like others through sharing and group discussion of their photographs;
- to project a vision of their lives that might educate others, especially power brokers and policy makers, to better understand the realities of their condition (Wang et al. 2000: 82).

Often, when working with participants who lead a different life than the researcher, researchers encounter a lack of access to the participant's world. This limits his or her ability to produce knowledge. Photovoice offers access to these previously restricted places, however such access requires more than an analysis of the photos. It also requires a dialogue around the pictures. Indeed, Burris and Wang argue that 'voice' be thought of as an anagram for "voicing our individual and collective experience" (Wang and Burris 1997: 381).

As Collier and Collier (1986:105) note about visual methodologies and photo elicitation, "images invite people to take the lead in inquiry, making full use of their expertise... We were asking questions of the photographs and the informants [sic] became our assistants in discovering the answers to these questions in the realities of the photographs. We were exploring the photographs together". Photovoice goes both ways. It offers researchers the opportunity and "possibility of perceiving the world from the viewpoint of the people who lead lives that are different from those traditionally in

control of the means for imaging the world" (Wang 2005: <http://www.photovoice.com/background/index.html>) but it also offers participants the opportunity to perceive the world from the viewpoint of the researcher. In many cases, the participant becomes a fellow researcher, working alongside the researcher (Graue and Walsh 1998).

The participatory strength of Photovoice, I argue, comes from its flexibility towards research objectives and participant demographics. This flexibility is also the cause of many critiques of the methodology.⁷ A number of these critiques - such as how one might differentiate between documentary photography and visual research methods (see Prosser 1998), the degree to which anonymity can be achieved, and how anonymity affects the research findings (see Clark 2006, Prosser 1998) - have been carried over from visual methodologies as a whole. Other critiques have been more focused on the lack of methodological deliberation over Photovoice practices by Photovoice researchers (Graue and Walsh 1998).

Recognizing these critiques, it is important to understand that Photovoice results from a mixing of methods – and as such draws from a wide range of methodological theory. It is similar to, and sometimes used synonymously with, photo novella (Wang and Burris 1994), photo elicitation (Harper 1987; Collier and Collier 1986; Curry and

⁷ Those wishing a more step-by-step guide to photovoice are encouraged to consult Wang 2000a. My research deviates from Wang's suggested framework because of my research question (I am not engaging a public-health question) and other particularities that are developed in the section. Although it could be argued that a methodology with clear, formalized, steps allows researchers to strengthen the quality of their research – I would argue that a methodology that is too rigid also threatens to alienate certain demographics and prioritizes set forms of knowledge and communication.

Clark 1977), photo interview (Kolb 2008), Photolanguage (Bessell, Deese, and Medina 2000) and visual ethnography (Pink 2001). Where Photovoice does differ from these methods, however, and where it is the most methodologically clear, is its emphasis on participant-generated photography. A Photovoice project emphasizes the voice of the participant. That said, Photovoice is not a single approach. A Photovoice project requires researcher to engage mixed methods such as interviewing. This is most important in the data analysis stage. My study engages Photovoice in combination with individual and group interviews and adopts grounded theory to shape its data analysis strategy.

Methodological Amendments and Research Design

Like Photovoice researchers before me, I have adopted the Photovoice methodology but amended previous research designs to fit the needs of project participants. This also allowed me to strengthen the methodological underpinnings. The Photovoice methodology appears to have only been used twice with persons with intellectual disabilities – although this depends also on how one defines intellectual disabilities (Jurkowski 2008:2). It was used once with persons having 'intellectual disabilities (Jurkowski 2008:3), and once with mothers having learning difficulties (Booth and Booth 2003). Speaking to their choice of the methodology, Jurkowski *et al.* (2007:1) note, "it is still relatively rare to find literature in which specific methods for engaging people with intellectual disabilities in participatory research is described" . Jurkowski (2008) also notes that both studies focus more on the knowledge produced than on building a methodological underpinning aimed at assisting other photo-voice researchers working within this demographic.

Stage One

Put simply, my research design can be thought of as having three stages (See Figure 2). Stage one consisted of an initial recruitment presentation (see Appendix 4), followed by an informal preliminary interview (see Appendix 5A). This preliminary interview consisted of: 1) a discussion of why the participant wanted to participate in the project; 2) a discussion of how the participant came to live in the community and a brief discussion of the participant's life history; and 3) a discussion of camera use. The discussion of camera use was brief – as most participants anticipated the guidelines. It included: a discussion of the photographer's responsibility to his or her photo subjects; the importance of, and how to, obtain permission from possible subjects; and how to operate the camera.

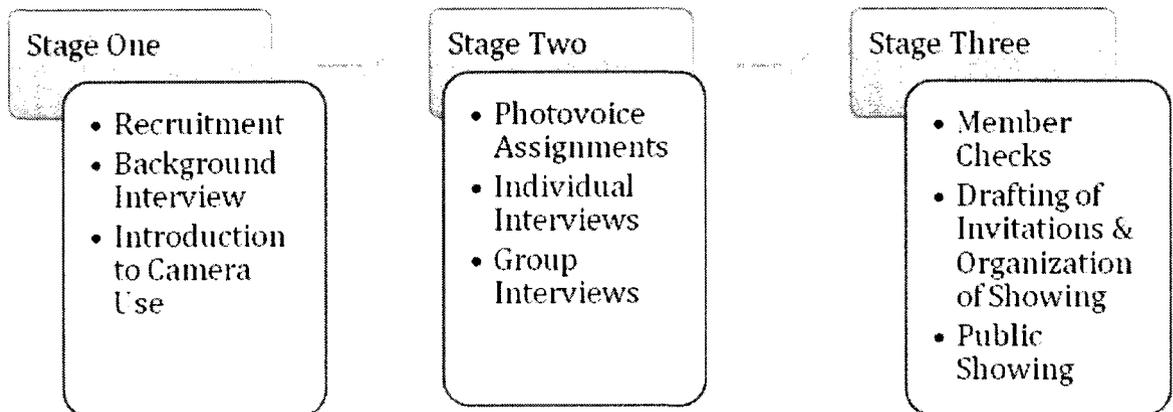


Figure 2: Three-Stage Research Design

Stage Two

The second stage consisted of three Photovoice assignments – one on home, one on important people, and one on work. Three assignments were chosen in anticipation of the need for possible design alterations – the success of the Photovoice methodology was unknown. For each assignment, an unstructured individual interview occurred (usually

four days to one week after photo development). This individual interview (see Appendix 5B), a step unique to this Photovoice study, was important in establishing a sense of achievement in participants (see Jurkowski 2007, 2008). It provided a one-on-one setting in which participants could be congratulated on their photos – an important step when learning a new skill (Ibid). It also gave participants the opportunity to ask technical questions (such as why a picture may or may not have turned out) without the criticism of the larger group. Perhaps most importantly, however, was the opportunity offered to participants through the individual interview to verbalize connections to the photographs prior to presentation in a group setting. In many cases this individual interview seemed to operate as a preparation session.

The individual interview was followed, usually within a one week time period, by an unstructured group interview (see Appendix 5C). Participants were encouraged to bring their three favorite photographs for discussion. To facilitate the logistics of this group meeting, it was held prior to a community gathering and usually consisted of a dinner provided by the researcher – most often pizza and soft drinks. This group interview is common to Photovoice and is seen as an important part of critical consciousness raising (see Wang 1997). Unique to my research is the use of the group interview with persons with intellectual disabilities – Jurkowski (2007, 2008) opted for solely individual interviews. This would also appear the only Photovoice study that has mixed the use of group interviews with individual interviews. It should be noted that I found the group interviews to be most informative – with personal interviews allowing participants time to digest different themes and ideas discussed.

Briefly, it is important to note that the combination of the individual and group interviews also served to provide an interesting moment of reflexivity. By contrasting the conversations held in the individual interview and group interview, I was able to see if any of my questions or comments during the individual interview had somehow transferred into the group interview. For example, did a participant bring up a point or question in the group interview that she or he had dismissed in the individual interview? The combination of interview formats allowed me to reflect on my influence. I was also able to see if changes in position occurred often - a pattern that would affect the quality of my interviews.

Stage Three

In the third stage of my design, I met with research participants to discuss the findings of my research and to obtain secondary consent for the publishing of direct quotations and photographs. This member check was engaged so as to ensure accuracy, credibility, validity, and transferability of the study (Flick 2008). Because of concerns over literacy, participants were presented with a verbal and informal summary of the findings. These sessions were one-on-one and averaged 45 minutes in length. The discussion guide for the final member check can be found in Appendix 7. Participants were also involved in choosing a date and location for a showing of their work, and in drafting invitations for others in the community to participate. This showing was intended to create a sense of closure for participants, to recognize the effort they put into the project, and to convey a sense of ownership over the photos.

The cameras purchased for this study were disposable 'Fujifilm 27 Exposure Quicksnap Flash'. Disposable cameras were chosen for three reasons: ease of

replacement; relatively low price points; and because, as self-contained units, they would prevent the possibility of premature exposure. This particular camera was chosen predominantly for its large viewfinder, durability, and gender-neutral design. Additional benefits were a simplistic and quick loading flash, the ability to connect it to a lanyard, and a transferable design: knowledge of this camera could be carried over to other cameras. An anticipated difficulty posed by the design was the manual winding of the film. One participant, due to deteriorating eyesight, would have benefitted from a larger viewfinder or digital camera. To facilitate return of the photos, the first picture of each roll was the participant's pseudonym. However, this photo and the associated negative were not returned to participants. Participants are unaware of their pseudonym. The participant's name was also taped onto the camera, as was the researcher's telephone number, in case of a problem or in case the camera was misplaced.⁸

Research Participants

All participants resided within a 'community' of adults with intellectual disabilities within the National Capital Region, and as such were familiar with one another. This 'community' designation was built and fostered by the organization in charge of operating the homes. For the purposes of this thesis, I will refer to this organization and community as Elkwood Heights. Before approaching possible project participants, I first sought the permission and input of both the Executive Director and the Board of Directors at Elkwood Heights. Following this process, I contacted a number of homes and asked to make a recruitment presentation. It was my goal to recruit six

⁸ It should be noted that no cameras were misplaced. With this in mind, and given lowering price points, digital cameras may be advantageous in future Photovoice research.

persons, anticipating that two might drop out of the project. Five participants were ultimately recruited. No participants opted to drop out. My two male and three female participants were between the ages of thirty and sixty-five. Particularities of the project's participants can be found at the beginning of Chapter Three.

All five of the project participants have been categorized by Elkwood Heights as having 'developmental disabilities'. It is with great hesitation that I speak more specifically to what developmental or intellectual disability means. Briefly, developmental disability is often the umbrella term for early onset disabilities (those acquired before the age of 22) that interfere with many 'life functions'. The perceived synonymy between developmental disabilities and mental retardation has led many individuals who might qualify under this 'criteria' to refuse the classification. They have opted instead to use the term intellectual disability, which is seen as prioritizing social-political influences over biomedical influences. I also argue that the term intellectual disability is more in keeping with the social-relational approach described in the introduction.

The Association for Persons with Severe Handicaps
argues an intellectual disability is:

a disability that requires extensive ongoing support in more than one major life activity in order to participate in integrated community settings and to enjoy a quality of life that is available to citizens with fewer or no disability. Support may be required for life activities such as mobility, communication, self-care, and learning as necessary for independent living, employment, and self-sufficiency (2008: <http://www.tash.org/faq.html>).

This definition would seem to accurately capture the situation of all five of the project's participants – noting that they themselves often attribute their

limitations to medical and biological reasons. For example, when speaking of life goals the phrase “I wanted to be..” or “I wanted to do..” was often followed by “But I have..[medical condition]”.

Notably, this definition is not perfect. It fails to fully recognize the social barriers that maintain and (re)produce disability as discussed in regard to the social and the SR model. However, pragmatically, I present it as something to grasp on to. I stress that the definition can and should be problematized (see Rapley 2005).

Data Analysis Strategy

Photovoice encourages a data analysis strategy that engages and includes research participants. The process has three stages: “selecting (choosing those photographs that most accurately reflect the [project theme]); contextualizing (telling stories about what the photographs mean); and codifying (identifying those issues, themes, or theories that emerge)” (Wang and Burris 1997: 380). Participants excelled in the first two stages. However, following the first Photovoice project (on home), I found that a group coding process only served to differentiate the researcher from the participants. Participants would get hung up on the speed of my writing or spelling and feel left out because of their limited literacy skills. While photos were discussed and themes suggested, no group coding occurred.

My data analysis strategy would seem more complicated than what Wang has suggested. It sought to strengthen the Photovoice methodology by engaging and incorporating grounded theory (Strauss and Corbin 1998). This analysis technique argues “novel theoretical ideas or hypotheses [arise] from the data as opposed to testing theories specified beforehand. Insofar as these new theories ‘arise’ out of the data and are

supported by the data, they are said to be grounded” (Gibbs 2007: 49-50). Therefore, researchers simultaneously produce and analyze their data.

My data consisted of digital recordings and transcriptions of each interview. I also kept a research diary with brief reflections on each interview - behaviors that the digital recorder could not capture. This was intended to help clarify and validate findings (Miles and Huberman 1994). It also consisted of 139 photographs. It was the content of the photographs that served as the discussion guide for the interviews.

While conducting the interviews, ideas began to develop and themes began to take form. For example, after completing the first interviews it became clear that the participants did not see their environment as gendered. The second interviews provided an opportunity to explore other areas where gender might exist and pursue them more thoroughly. More conceptual discussions could be had, with gender eventually rising; *“Boys are a lot more [in] control. Girls are supposed to be more sissies”* (Aidan). The interviews were transcribed as quickly after the interview as possible, and they were coded to focus the data and create a format that could better be analyzed. Comments were made on the transcripts where repeated concepts and themes arose throughout interviews and across participants. Photographs were often coded prior to the individual interview to help develop the discussion guides. These codes were later amended based upon the content of the transcripts. Slowly, general concepts and themes were related to potential sub-themes and relationships were produced. This process allowed me to begin reassembling the data (Strauss and Corbin 1998).

To avoid potential misinterpretation of the interview data, several criteria were employed. First, conclusions were verified through member checks with research

participants. During individual interviews we would review the prior interview.

Participants were also consulted on the broader findings. This process was difficult because of my chosen demographic and I found it much easier to review the themes from the individual interviews in the group interview. Participants were also consulted for their views on the findings. These views conclude the thesis. Second, so as to connect the themes raised in Chapter Four to a larger picture, I returned to the literature for assistance in generalization. As Chapter Five shows, this was quite important and productive.

Methodological Assessment

Although covered in more detail in the project's conclusion, it is perhaps important to provide a brief assessment of this methods success. Foremost, Karlsson's (2008) advice should be heeded – a Photovoice study for a solitary MA researcher is grueling. Because of the emphasis on cameras, and the necessary training, support, and follow up, the research at times seemed overly administrative. Instead of engaging with participants, I was developing film and scanning photographs. A significant amount of time was also spent following up with participants as to the status of their projects – made difficult by (at times) uncooperative care staff. It was not as simple as leaving a message on an answering machine; multiple phone calls had to be made until the participant was at home. Furthermore, transportation was a significant challenge with participants' schedules erratic and undependable due to a transit strike in the city at the time. That said, grumbling over transit and transportation did serve to develop a significant rapport between researcher and research participants.

Ethics

The project's participants have been identified as belonging to a vulnerable population. In an attempt to lessen the role of the researcher, my research emphasizes participant control and participation. A series of consent statements were obtained (see Appendices 1-3). First, approval of the organization responsible for participants' everyday well-being was obtained through a presentation to the Elkwood Heights Board resulting in a signed letter of support. This was followed by a consent statement by each participant's legal guardian and the participant him or herself.

The involvement of the legal guardian added a difficult power dynamic to the situation. Granting the legal guardian the ability to veto aspects of the final report, or requiring them to approve quotations or photography, would greatly reduce the autonomy and confidentiality of the process. It would also go against the project's stated ambitions of participant participation, participant control of data, and participants being the owners of the knowledge produced. Guardians were asked to grant research participants' final approval over the publication of their words and photos. Guardians would not see the photos or the quotations unless participants opted to show them. This was done without any hesitation.

The use of interviews in this research project and the heavy involvement of care staff in participants' lives meant that I was not able to promise participants full anonymity. The use of cameras also served as an obstacle – as anyone aware of the project and seeing an individual with the camera would be able to identify him or her. Persons within the participant's home and community were very aware of his or her participation in the project. For this reason, the participant's privacy and access to

confidentiality was stressed. In most cases, following individual and group interviews, the participants displayed their photographs to staff. Discussions between the researcher and participant, however, were not repeated.

As for protocol in this thesis, it is worth noting that quotations used in this work are associated with a pseudonym (of my choosing and chosen prior to participant recruitment). All in-text participant quotations are also italicized. If not clear, quotations are followed by the pseudonym of the speaker. I have also, to the best of my ability, used a pseudonym for other names, places, and possibly identifying information; Elkwood Heights is not a real place. Quotations are a direct transcription of participants' statements. Information that has been added is noted in square brackets "[]", while large pauses in the speech are noted by round brackets "()". Participants have also been asked to sign secondary consent statements for quotations and photographs used in the project. Participants are not aware of their pseudonyms.

Conclusion

As mentioned earlier, this project was designed so as to: a) best include persons with intellectual disabilities in empirical knowledge production, b) encourage feelings of empowerment and participation amongst participants, and c) make a significant contribution to the literature. As the conclusion and methodological assessment will make clear, the methodology succeeded in accomplishing these aims. Interactions with participants since the conclusion of the project have been encouraging – each wants to know whether we will be taking any other pictures and how I did on the final thesis. Participants have also asked where they can obtain more cameras and if I will develop them after their use. As the prior sections hopefully demonstrated, this thesis also marks

a starting point for discussions on gender and intellectual disability. It provides, at minimum, proof that such research can be done. It goes farther by having something important to contribute.

Chapter Three:

Home, People, Work: Co-produced Knowledge

Having spoken to the motivations behind the research, let us turn to the outcomes of the research. This chapter has three sections. First, it discusses intersectional invisibility. The discussion is meant to establish the largely invisible status of persons with intellectual disabilities (and project participants) in a variety of intersectional categories – such as gender, class, ethnicity and disability. Section two provides a more detailed description of the participants and a general overview of the group home environment. These two sections lay the groundwork for section three: a summary of the knowledge produced. In section three I review the findings from the Photovoice projects on home, important people, and work.

Intersectional Invisibility

All five participants appear to fit within what Purdie-Vaughns and Eibach (2008) term intersectional invisibility. I begin the chapter with this concept because I feel it increases the importance of what the participants have to say. Intersectional invisibility argues that, "within a social category (e.g., race), those members that have more social power or status within that group tend to be perceived as prototypical for that social category (e.g. Black men are seen as more prototypically Black than Black women; White gay men are seen as more prototypically gay than gay men of color)"(Purdie-Vaughns and Eibach 2008:378). As was established above – the prototypical members of a disability grouping are those with physical disability. Purdie-Vaughns and Eibach go one step further, however, to suggest that "[w]hen individuals are non-prototypical in multiple social groups (e.g., Black women; gay men of color), they are rendered

intersectionally invisible”(ibid). The research participants are not part of the prototypical disability group – nor are they part of a prototypical gender group – nor are they part of a prototypical ethnic group; they are intersectionally invisible.

The results of being intersectionally invisible, Purdie Vaughns and Eibach argue, are "misrepresentation, marginalization, and disempowerment" (Ibid). In none of the categorical groupings is their perspective given the same attention as those of more prototypical group members. This creates an added importance to engaging this group in research. The thesis, for this reason, attempts as best it can to avoid a direct comparison between ‘abled’ and ‘disabled’. Such a comparison might only serve to further obfuscate disabled voices.

Participant Profile

Having established participants as falling under the umbrella of intersectional invisibility, I now turn to a brief summary of each.

Aidan⁹ is a male in his forties who has lived within this organization for close to ten years. His siblings enrolled him following a brief hospitalization and the deteriorating health of his mother. He lives with 4-5 other individuals with developmental disabilities and 4-5 staff members. His work week is split in two, with half devoted to general cleaning in an office environment and the other half working in a hypermasculinized athletic environment; *“I wanted to be.. I thought I.. I wanted to be a broadcaster, but my problem is my speech. I talk really too fast, you know. I couldn't do that. Plus, you need to have a very good education. I had an average education. I'm a*

⁹ It should be noted that Aidan was unable to attend the final group Photovoice session on Work.

pretty good reader but my problem is spelling, you know". On weekends he likes to relax, watch films, and go for beers with friends.

Caleb¹⁰ is a male in his fifties who began living in a group home environment approximately 30 years ago. It is unclear if he has been with the same organization for that entire time. Prior to residence in this environment he had been in an institution; *"I couldn't stand it any longer; I didn't like their attitude; I felt uncomfortable with them. If you wanted help or something like this they would turn around, have the nerve to say to you, or whoever, "No! No deal!" And I thought oyoyoy!"* His week is divided between two day-programs – one involves a surveillance or security like position and the other (which he much prefers) involves recycling. On weekends he likes to go for coffee, attend sports games, and socialize with other members of the community.

Madison also came to reside within this organization following institutionalization; *"I don't like [the institution]! I don't like [the institution]! They're bad!"*. She is in her sixties and retired. Nevertheless, she continues to attend two day-programs throughout the week. One is run by Elkwood Heights and one by an organization outside of this community. Activities range from physical recreation to group activities such as cooking. She also produces a fair amount of crafts that are sold as a fundraiser for a similar organization in the majority world. She is quite proud of this fact. Her favorite television show is *Law and Order*. Of all the participants, Madison took to the project most forcefully.

¹⁰ It should be noted that due to difficulties with the camera – arguably caused by deteriorating eyesight at the time – Caleb's photos for the Important People Photovoice project came from photo albums. His photos for the work session were taken in the workplace however with the assistance of the researcher. Caleb identified tasks/people important to him and I simply made sure the camera captured the photo.

Sarah is in her sixties and has a diverse residential history. Her current residence is her favorite. She attends two day-programs. One involves preparing tables for dinner, and the other, run by the city, involves structured activities. She has recently begun experimenting with the computer; *“There was a person... there was a person who, who brought Beethoven - it's a movie - and, and, another one took it off. So I didn't like it, so I, so I, asked James, if it's alright I come up every Friday, and Susan said yes”*. In her free time she likes to take friends out for coffee or do a specific series of shape puzzles.

Sienna¹¹ is in her thirties and has only recently taken up residence within Elkwood Heights. She was the youngest of the participants and provided an interesting insight into generational influences. She identifies her prior residence by its address and says that it was not with her parents. She appeared to be the closest with her family. This is perhaps because she was one of only two participants whose parents were still alive. Sienna lost her job during the study and returned to a city-operated day program; *“I go to different groups: bowling Monday, play bingo Tuesday, go to all the other groups, computers is tomorrow. This is different because I don't get paid”*. She misses the extra income the part time job provided but likes the day program. It is less stressful. She notes she is unsure of why she lost her previous employment.

Environment

All five of participants live in a variety of residential care environments, or ‘group homes’, operated by Elkwood Heights. In the next few paragraphs I will present a generalized summary of these environments. The differences between the Elkwood

¹¹ It should be noted that Sienna was unable to make the group Photovoice session on Important people – but shared these photos in the session on Work.

Heights' approach, and other residential options for persons with intellectual disabilities, is better verbalized by participants and comes out more clearly in their discussions of 'home'.

Group homes are a community-based approach to residence emphasizing concerns with the rights and autonomy of their members. In this particular case, residents pay rent and are also expected to contribute through everyday tasks. Although one goal of these homes is community integration, the success of this approach is questionable. Difficulties around zoning for these residences are well documented. The next chapter shows that the community-based approach has instead culminated in a sense of community amongst these residences leading to a withdrawal from larger community integration. All participants, for example, despite living in different neighbourhoods, see each other multiple times a week through structured 'community' events organized by Elkwood Heights. Engagement with the general neighborhood or larger community seems limited at best. The exception to this pattern would appear to be Elkwood Heights' volunteer outreach or fundraising that engages and prominently relies on resident narratives.

Although I will engage with Levinson (2003) in more detail in Chapter Five, I note here his description of the group home environment. The group home is both a 'home' and a 'workplace'. This liminal status, he argues, allows "the local order of the group home [to] be understood in terms other than professional domination and social control" (Levinson 2003:901). This point will be exemplified in later discussions of interpersonal relationships between staff and clients. Levinson (ibid) further notes, "[a]s a workplace, the ongoing and knowledgeable participation of residents as well as counselors can be

seen as integral to the accomplishment of group home life”. The group home is perhaps more an atmosphere than it is a physical space.

I bring up Levinson here in anticipation of critiques that may be leveled towards arguments made later in the work. Group homes seem to escape critiques of power by positioning themselves as “an ongoing dilemma of liberal freedom” (Ibid: 899). The group home structure does not allow residents’ full autonomy or freedom, but it does allow them to achieve a taste of such things. Its imperfection is justified by the idea that it is a better solution than previous approaches – such as institutionalization. One wonders, however, whether this method of justification is preventing the development of alternative means of care.

This ‘best available option’ argument has also come up in personal discussions I have had as a care-worker with colleagues about changes to routine and protocol. When I have challenged my current employer for not approaching intellectual disability in a more progressive manner, I have been rebuffed with the reminder that, although not the most progressive, the organization remains one of the more progressive thinkers. Suggestions of change to the environment – or encouragement to ‘think outside the box’ – face resistance. This discussion of Levinson and the environment is meant to put forth the idea that the group home environment is resistant to change; it justifies this resistance by comparing itself to previous models of care experienced by persons with intellectual disabilities.

Summaries of Photovoice Project Results

Three Photovoice projects were engaged in with these five individuals – two of which engaged significantly with the residential care environment. Pictures of home and

of important people, for example, were taken primarily within the Elkwood Heights community. This third section of the chapter looks at all three of the Photovoice projects (home, important people, and work) and summarizes the knowledge produced from them.

Photovoice Project One: “Home”

The three main themes that came out of discussions on home were: a connection to physical spaces; home as a space for safety and security; and comparisons between different residences. In discussing home, conversations centered on how participants arrived at Elkwood Heights, their responsibilities and interpersonal relationships within the home, and more broadly what makes a home feel like home. The photographs that were taken were all taken within the individuals’ main residences and did not include photos of family houses or events. Recognizing that it was a cold Ottawa winter, no pictures were taken outside of the home – in the yard or driveway, for example. However, discussions of home did extend to the vehicle(s) associated with the house;

the other thing that I'm concerned about is that [the van is] getting old. And I know I told.. I said to [a coordinator] here talking to me the other day, when Mary tries to get in, it's very difficult. And I said, I said, the mechanic won't do anything about it - and we're paying big bucks to him. ()

I think what we should do is - if I had my way - is get us a nice big open house going and see what people think. If it gets to that I will. I don't care how we do it - it's important as far as I am concerned for that. 'Cause the last thing you need is someone going through the back or whatever - and then you have to fill out an incident report!(Caleb).¹²

¹² The use of round brackets denotes a significant pause in an individual’s speech. The researcher, to clarify the meaning of the passage, has added words noted in square brackets.

This inclusion of the vehicle is important because transportation for all five participants was a major concern and was associated with the home.

Physical Spaces

The majority of the photos for this assignment were space oriented. Participants captured rooms and objects. When discussing spaces, most often it was an object that connected the space with its title as opposed to a characteristic of the room. This can be seen in Caleb's discussion of what is presented here as photo 1; "*Where the heck is that? oh boy, oh boy, kitchen! Yes, yeah, ok. You know, you know what gave that away, the kettle!*".



Photo 1 – Participant Kitchen

That said, there were also person-oriented pictures including both assistants and persons with intellectual disabilities; "*Ok, I took, that's Caroline [an assistant] and Keith [a resident] in my house, in the kitchen*"(Sienna). This differs from the kitchen picture above in that the participant suggested the individuals were the focus of the photo, as opposed to a space or object.

Safety and Security

All participants noted feeling safe in their homes, and connected their sense of safety with safety procedures; *“and when Sheila [assistant] says fire - then we get out. And then, over there [points to hallway], and then out the front [points to door]”* (Sarah). Furthermore, all participants identified their bedroom as a private space, with all except Caleb taking one or more photographs of the room. Explaining her bedroom, Sarah noted, *“My bedroom! Nobody can get in! It's the law!”* Explaining his absence of a bedroom photo, Caleb noted *“Well, my bedroom isn't the best for pictures, believe me. The, my bedroom is dark, very dark, yeah, that's the thing. But, it's dark. The windows are not the best either. I'm going to have to get my room fixed. Take pictures and they don't turn out”*.

That said, Caleb still chose his bedroom as his favorite room because of the furniture, *“My room was given to me by my family. They got the stuff and they chipped in... They said, 'yeah, we want to do something for him'. My god, the day the truck arrived from Toronto, I looked at the guy, I said 'good morning'. He said 'are you Caleb Martin?'. He said 'please sign'”*. Similarly, other participants described bedrooms as a container for one's possessions. This 'safe space' for possessions also came through in the photographs, as demonstrated in photos 2 and 3.



Photo 2 – Participant Bedroom



Photo 3 – Participant Bedroom

Comparisons of Homes

Our discussions of home also included comparisons between the current environment at Elkwood Heights and prior residences. Caleb and Madison, as was mentioned previously, both grew up in an institutional setting. Aidan, Sarah, and Sienna all grew up with their parents before moving into a residential care environment - with Elkwood Heights being Aidan's first and Sienna's second group home. Sarah seems to have lived at a number of homes before the present one.

When asked what was different about the current environment and their prior homes, a number of responses were provided. The relationship between staff and residents was emphasized most. Staff are seen as support, assistants, friends and colleagues instead of as employed staff. It seems that this difference stems from Elkwood Heights' emphasis on live in caregivers where possible – made possible, one might argue, by the lack of a unionized workforce. It was also noted that these homes were larger;

Christopher: How is this home different from the other homes that you lived in?

Sarah: I lived [at a prior residence] and there was there was only one bathroom.

Christopher: How many bathrooms are here?

Sarah: Four! [sic]

() There's one upstairs - one there - and one downstairs!

Christopher: Is that important to you?

Sarah: Yeah. It's important to me () because.. because.. I clean the bathroom.

One might also argue that Sarah feels more involved in home life. In drawing distinctions, Aidan emphasized and expressed frustration with the structure of the environment,

Part of the difference here is that with my Mom and Dad I had more freedom. Like, you can eat any time with my mom and dad, you know. But here you have to always be here at five-thirty, six o'clock, and I don't always want to eat around four, four-thirty, five. And after that we have prayer and that. And I don't really go for that. I don't really like that. I just like doing, after supper, just go and do whatever I want to do, but I have to wait until everybody's finished and clean it all.

This emphasis on, and response to, collectivity is interesting and will be picked up later.

Interestingly, Caleb expressed strong concerns about changes to the present environment which would move it from a ‘home’ to a more medicalized and formal care environment, *“I remember when they came to, at one point they wanted the idea to put an elevator in. I said ‘No, I’ve been through that where I used to be’. I said, ‘Why don’t I move [rooms]? I can get around. I can talk or whatnot. Give me a room upstairs and Maria [who cannot use stairs] can have my old room’”*.

I reference Caleb’s observation because it seems to speak to a larger theme in the interviews. There is a tendency among all five participants to associate an individual’s perspectives and personality to a physical space. This theme is present also in the next two Photovoice projects on important people and work. Who is or is not a ‘friend’ seems significantly affected by where an individual is encountered. I will expand this point in the next chapter.

Photovoice Project Two: “People that are Important to Me”¹³

The second Photovoice project was originally designed to be family-focused and occur over the Christmas holiday. However, care staff raised concerns about participants’ limited contact and access to family. In consultation with research participants the theme was expanded to ‘People Important to Me’. The photos and conversations resulting from this project can be divided into three groupings: friends,

¹³ Because photographs from the ‘important people’ project centered on individuals close to the participants and individuals that either worked or resided at Elkwood Heights, I have not included a diverse selection of photographs from this project. To do so would challenge the anonymity of the participant who took the photo, fellow participants in the project, and of the Elkwood Heights organization. I have, however, included a photo of ‘friends’ from the ‘Work’ project because I felt this photo allowed me to make a significant point in this section without the risk to anonymity outlined above.

family, and staff. A comparison of these three groupings presents interesting insights into these relationships.

Friends

Most intriguing to me were discussions of friends and friendship. Friends, it seems, were presented as ‘just there’. They were not the product of a long-term relationship but simply ‘provided’. This is perhaps best seen in conversations with Madison and Sarah about whether or not friends visited the home. Madison, particularly

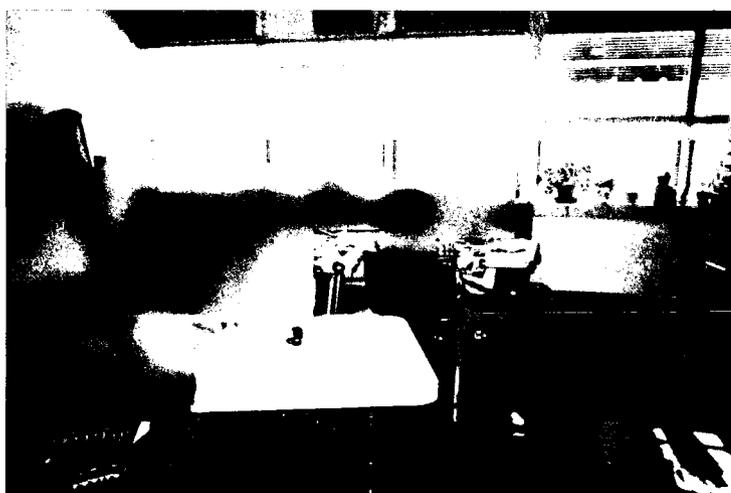


Photo 4

in her pictures of her day program, identified individuals at a senior’s day program as “*just friends*” noting that different people showed up over time and that this made it difficult to remember their names.

The relationship – the ‘friendship’ – did not leave the day program. Sarah reiterated this in discussions of her day program. However, when asked why friends did not visit Sarah presented an interesting answer. Friends did not need to visit the home because friends already resided at home – as care staff and as residents;

Christopher: Do you ever see them outside of work?

Sarah: No.

- Christopher: Why?
- Sarah: 'cause. They're inside.
- Christopher: Why is that?
- Sarah: Because me and James live together - and Meaghan too. and Sheila.
We live in the same house. And they they don't live in the same house as we do.
- Christopher: So, you already have friends at your house?
- Sarah: Yeah. And that - that's why.

There was no reason to leave the home to seek out additional friendships. Friends were provided at home.

A possible exception to not having outside friends visit the home would be a volunteer program run in the Ottawa area that matches undergraduate or high school students with adults with intellectual disabilities. Participants are encouraged to see these individuals as “friends” by staff and program organizers (see Best Buddies Canada: <http://www.bestbuddies2.ca>). The Best Buddies program is designed to encourage greater integration into the wider community through “one-to-one friendship”(ibid). Program organizers also organize group events such as pizza parties, magicians, bowling competitions, and banquets with the stated intent of encouraging socialization among program participants. The exception, as noted earlier, is that participants also noted that transportation –students having limited access to vehicles – led to Best Buddies being invited to house activities or simply visiting within the home. The difference between a friend at work – seen in the previous discussion about Madison and Sarah - and a friend from Best Buddies seems to be that Best Buddy friends entered the home.

All research participants at the time of printing had been matched in the Best Buddies program, with the minimum age difference between an individual and his or her

'best buddy' being 12 years, and the maximum age difference being 43 years.

Participants felt this generational difference, suggesting that their youth and unfamiliarity with the environment greatly influenced behaviours. Caleb, for example, expresses frustration with best buddies' insensitivity to the regular Elkwood Heights schedule:

No no, you were asking, like, our best buddies do come and we do, if they are not able to, we say "this is why". And, you know, same to you, is the phone. 'Cause some of the best buddies have it in their heads about 'oh is Monday and Tuesday available' kind of thing. Well no! Those are the two nights that we are busy.

This is not to critique the program – project participants spoke very highly of it. But this program seems a paradigmatic case for understandings of friendship among these five participants.

Like Caleb, I recognize the influence of this generational gap in defining the relationship; undergraduate students are migratory, they have significant time commitments to their academic pursuits and part-time employment, and are perhaps unable to provide long-term friendship. These factors encourage instability and unreliability. With administrators assigning 'buddy-pairs', there is no development of a friendship based on common interests and there seems no real requirement for commitment. Buddies come and go. This particular example of friendship seems to fully capture the larger themes that came up in most discussions of friendships outside of the home: temporary, assigned, and providing an outside connection to the residential care environment.

Family

As was mentioned previously, care staff essential to contacting guardians for consent suggested strained or non-existent familial relationships. This did not come through in the interviews. Each individual presented a positive picture of his or her family. The absence of photographs of family - only Aidan and Caleb included photos of family in this project - would seem a result of staff influence.¹⁴ Indeed, in one case it was suggested that the cameras were deliberately not packed over Christmas holidays so as to avoid them getting misplaced. That said, ‘friends’ and care staff dominated discussions of important people – with most individuals belonging to both categorizations.

Staff

As has been briefly mentioned, both Caleb and Madison were very clear in distinguishing between staff at their prior institutional residence and the staff at Elkgrove Heights. Elkgrove Heights’ staff were presented in a predominantly positive light, with staff from prior residences being referred to in solely negative terms; “*we're treated more like adults and you don't have to have this business with a pink slip [a behavioral protocol] and all this*”(Caleb). The question can be raised, however, how much of the difference can be connected to differing organizational structures between the two residences.

As Caleb notes, staff at the institution were much more bound by protocol and a more formal structured approach, “*[The staff drove me] right up the wall. They said [to family] ‘What are you doing with them [the resident(s)]? How long are you going to have them [the resident(s)]?’ As if it was any of their concerns. That was going too far*

¹⁴ It should be noted that Caleb did not take pictures for this project but instead opted to choose photos from photo albums. He did choose a picture of his brother. Furthermore, three participants expressed frustration about not remembering to take their cameras with them home for Christmas.

as far as I was concerned". Arguably, this was a protocol, like the aforementioned pink slip, and not adopted on an individual level to frustrate residents. However, the manner in which the protocol was engaged seemed to differ and the amount of autonomy provided to the resident seems to differ.

The current residence, in contrast, would seem to allow staff to take a more personal approach, "*Here it's a lot better, you - look you can talk to people, you can say hello to people when they go by, whereas, if you ever did that in an institution, whew, [hand motion of lock and key], yes, lock, lock. Lock you up just for the like of that - mmmm*"(Caleb). In addition, most of the current staff does not have formal training. They have not been exposed to the theories that promoted institutionalization. Aidan noted Elkwood Heights' large dependence on foreign workers and on recent immigrants, and the difference in perspectives that introduces into the home, "*See the different people. People from different countries. They have a different way. We have a different way. You know, you try and understand their culture - and they try to understand our culture. It's hard sometimes. It's hard to get along with everybody sometimes*". This diversity has led to a multitude of perspectives towards care and towards disability entering the home without a larger discussion of what this means.

The identification of staff as 'friends' builds on the above trends emphasized in the discussion of Best Buddies. Because of the demands of the environment, and the high dependence on youth and temporary workers, turnover in the organization is high. Because of shared residence, relationships between staff and residents can be fairly strong. This, of course, makes departures more difficult. Staff – seen as friends because of the design and philosophy of Elkwood Heights – engage in, and emphasize, the same

patterns as the friendships described above: they are provided by the organization; they are, in most cases, temporary; and, staff serve as a medium to the outside community. In viewing staff as friends, and in staff emulating the behaviors of friends, the understandings of friendship held by project participants seem only furthered.

Important People

The second photo project was focused on important people. In coding my interviews and my photographs I found that discussions surrounding care staff and friends largely resulted in responses that could be coded ‘connection to external environment’. Staff differed from ‘friends’ in that they were also coded as ‘encourages behaviors that could be seen as empowering’. Staff appeared to make a greater effort to encourage individuals to pursue interests or hobbies and, as it is their job, in aiding the individual in such pursuits.

This coding is interesting because it led me to question if and how family might be seen in a less empowering or encouraging light. Participants spoke fondly of their families but did not seem to speak of them as empowering or as a connection to the outside world. Visits with family, it appeared, were limited to visiting within the family home and rarely consisted of family visits to the Elkwood Heights’ home. Why were participants slow to initiate discussions about their family but, when questions were raised, enthusiastic and positive in their discourse?¹⁵

To answer this question I returned to the interview transcripts and discussions around family. All five participants reiterated that they are adults. Four out of five

¹⁵ It should be noted that the insistence of care staff about non-existent or limited family relationships remained in the back of my mind – strengthened by limited family photos - until participants challenged these views in the individual interviews.

participants are above fifty years of age. They have been living away from home for a significant time; they are independent, have grown up, and in some cases lost parents and other family members. I argue the absence of a view of family as empowering or a playing a greater connection to the outside world is tied to increasingly limited access to family and to aging.

This argument is strengthened when one talks about participants' childhoods.

Caleb, for example, speaks of his family as supportive and empowering in the past;

I wanted proper schooling. But, of course, back then they were very.. they, uh , they would not let certain people.. and I felt badly. I remember my father had to go up one time and all they told him was just bring pegs for everybody. And, he looked at them, and he said 'what are you saying?'. He said you're just teaching pegs to people. And, that was not what I wanted. I wanted to learn how to read and to write properly. But no no no - they wouldn't.

Aidan builds on this in discussing his relationship with his mother, and the changing role of his siblings as his mother took ill; *"They.. they always try to help me out as best as they can. None of them.. the one of them that really helped look after me the most, my mom did. And, my brother and my sister help me now"*. The role of Aidan's family would appear to have changed with aging and as he has been encouraged to exercise more autonomy over his life. Sarah also makes this quite clear in describing career ambitions that modeled those of her mother, a teacher; *"I wanted to be a teacher like my mother. My mother used to be a teacher, and my father used to deliver the newspaper. He used to work, and he passed away"*. I found myself reflexively asking if this expectation that family be most important was perpetuating a meme of intellectual disability as a perpetual childhood. I will return to this point in chapters four and five.

Photovoice Project Three: "The Work That I Do"

The final Photovoice project was oriented towards the work that participants do. Although it was designed to focus on all aspects of work, participants interpreted it as an opportunity to bring the camera to work. In this way, the camera seemed to break an intracommunity / extracommunity barrier. It served as a means of sharing what one does at work and the people one encounters at work. Of the three photo-projects, participants were most excited about this project. Indeed, even those skeptical about participation during recruitment interviews were tempted to participate when the discussion turned to discussions of their employment outside of the Elkwood Heights community.

A Work / Home Binary

The photos of work were quite diverse but also quite similar to those of home. The photos consisted of workspaces (photo 5), activities (photo 6), and people at work (photo 7). The resulting conversations, however, established a divide between home and work and a sense that the two do not interact with one another. As was mentioned in the paragraph prior there appears to be a barrier between the home and the workplace.



Photo 5

**Photo 6****Photo 7**

It is important to note that none of the participants obtained income from their employment. This was particularly startling in the case of Aidan, who works two jobs and holds significant responsibility in both. Madison would appear to associate her current day program with volunteering, a result of her recent retirement. She understands that the products she makes are sold, but notes that the money raised goes to an overseas organization. Sienna sees her day program as a day program but reports a salary from her previous part time job. Her desire for another part time job seems solely motivated by

the possibility of an increased salary. Caleb was unsure if he received an income – but noted he was more than happy to just help out. When asked if paid work was important to them, Caleb, Madison, and Sarah suggested it was not. Aidan argued that seeking paid employment would challenge the stability offered by the Ontario Disability Support Program. Sienna looked forward to the extra money she suggested a part time job would bring.

Empowerment and Recognition

The point that was strongest throughout these discussions was that work or day programs offered participants opportunities for empowerment and recognition. Caleb, for example, describes a sense of feeling needed, *“if, like, especially there, because they don't have enough staff. That's why the three of us split the difference, because you - they don't have enough staff. Right now there's one away for other reasons I guess. But they like when we help out and they know - and they're all very nice staff”*. Aidan notes that although he is not paid, he has won an award through work, *“This trophy here. I won this one. The first time it was ever presented I won it. It's called the John Smith Memorial for a long time employee who died of a heart attack. I'm the first one to win it. It's for dedication”*. He also noted the creation of a second award named after him, *“That trophy is named after me. Trophy named after me. That's my trophy. Every year the most improved gets the award”*. Sarah also noted work as a place of recognition. She is thanked for her work through a free lunch, *“You know where the gym is - right beside it - that's where I work. I set the table for lunch and I don't have to pay! The rest have to pay!”*

Authority

The experience of work also presented an opportunity for discussions of authority. As alluded to previously, the power structure in discussions of home and in discussions of staff seemed absent. Attempts to challenge participants about this absence resulted in the same response – staff are friends. Attempts to raise discussions around disagreements participants had with staff were also unsuccessful.

At work, however, participants seem more aware of an organizational hierarchy – ranging from direct interactions with support staff to larger government services. Discussions with participants identified a close relationship with support staff, *“This [photo 5] is the, uh, this is where Andrea is. She's my boss. She makes sure I clean the school well. We have a checklist thing where you check it off, check it off, you know”*(Aidan), but increasing frustration as one climbed up the organization ladder. Caleb’s description of the closing of one of his preferred workplaces captures this quite well,

Christopher: Do you have a favorite job Caleb?

Caleb: Yes. But, unfortunately, we had to close it.

Christopher: Where was it?

Caleb: We used to sell, for example, say if you drove out, you say, “Well Caleb, Can I come see your plants?” You'd buy plants for spring if you wanted, drive your car out. Yes, we would charge you, but we wouldn't charge that much. We would explain to you or whoever comes out there, uh, why that price is on it or whatnot. But, then, as I say, the government found out and we had good supervision it wasn't that. Fred was the head supervisor, then Sam, then Marie and Tammy. ()

Once [Fred] came back from a meeting and I said, "What's up?" And he was the one that had to tell us. And I said "Well, why would they

do that?" And he said "I don't know". And the guy wouldn't even come with him to say to the people like myself, and he was... Yeah, well, this guy... Don't know where you got that degree mister - hehe.

This pattern of a 'higher' authority occurred often. Although it is difficult to identify a cause for this belief by participants, the discussions led me to believe that government was (rightly or wrongly) often portrayed to participants as responsible for program alterations. Government and authority was also described as a faceless - male - intangible force. One wonders if 'the guy' Caleb refers to was an individual or if it refers to a larger committee or team that made the decision to cut the program.

Work as Connection to Outside World

Similar to friends, employment and day programs were seen as important because they were a means to get out of the house and engage in social interaction. Arguably, unlike friendships, work presented a more diverse grouping of individuals closer to one's own background. Sienna describes work as a social opportunity in our discussions around Valentine's Day,

Sienna: I might be going to a dance, maybe. Tomorrow, at the [day program].

Christopher: Are you going to know people at the dance?

Sienna: My friend's going, maybe. She might go.

Christopher: Is it during the day or at night?

Sienna: At night. 6:50 it starts.

Aidan took this one step further, suggesting that keeping busy and getting out of the house served as a form of therapy; "*If I don't keep myself busy then I get bored - I get bored you know - and then I start thinking bad thoughts.*" This perspective towards work would seem to also greatly influence participants' views on retirement. Aidan, for

example, reflected on the difference between paid and unpaid work, stating, “*When I get too old with [this job] I’ll probably go back to just volunteer with the [a prior job]..go back to [there]”*.”

There was, however, an oddity in this home / work disconnect which also served to strengthen it. As was established early on in this chapter, one of Caleb and Madison’s frustrations with the institutional setting was the degree of surveillance. Both felt constantly monitored, observed, but not listened too. This frustration seemed absent in the workplace – at work it was ok and expected; “*cause you have to be supervised*”(Caleb). Similarly, Caleb had no problem being in charge of surveillance at one of his programs,

My job is...if somebody gets out. We have some people that they'll try to get out [leave the day program] and they're not supposed to. It's my job to do that. So, basically there's two of them, they will try to get out, they don't speak, I have to page right away, get somebody up to bring them back, because otherwise, if they got out - who is responsible?

This surveillance was often justified by a safety narrative. However, Caleb seems disconnected from the individuals whose safety he is meant to ensure. This interaction with these non-verbal individuals at work also contrasted with the special relationship he described with a friend in the community,

‘cause sometimes I will, um, stay with [her] to keep her company. And she likes that eh, 'cause she understands me and I understand her. She does communicate with her board. And still, I do understand what she says since I do travel with her, I go back and forth to work with her. I travel with her so I know what she's saying very well.

Attempts to discuss this discrepancy with him were quickly dismissed. There was work, and then there was home.

Conclusion

This chapter briefly reviewed the knowledge produced by participants in Photovoice projects on home, important people, and work. It identified a number of significant factors that made people and activities more or less important. Those people associated with connections to the outside world, or people that participants felt were empowering seemed most important. Similarly, work was important because it filled these desires as well. Questions, such as the influence of intergenerational relationships between individuals and 'friends' were also raised, as were questions about the definition of friendship. It was suggested that the high turnover rate of 'friends' prevented any long-term friendships and that 'friends' have come to be seen as mostly fluid. This differed in regard to friends within the home (co-residents) who were seen as dependable and always around.

A Narrative: Gender and Care

The previous narratives looked at how I came to engage critically with disability and my experience in the field. Having looked at the role gender played in the lived experiences of the project participants, this narrative interacts with my experience as a male caregiver and male researcher.

When I accepted a position as a caregiver in a residential care environment, I had no idea what to expect. I pursued the job as a challenge and means of gaining hands on experience; I didn't know if I could be a caregiver.

The adults who resided in the home were not quick to put my insecurities at ease. I endured a few weeks of what coworkers described as "testing my limits" wherein residents challenged my knowledge of the system and how strongly I would keep to protocols. As this went on, I watched as they bonded quickly with the female assistants that were just arriving. At first, I attributed this to a lack of confidence on my part. The new assistants had just as little experience as me but embraced the position with gusto. I was even more confused when colleagues and administrators congratulated me on the speed of the relationships I was developing; I was being welcomed much faster than other male assistants, they noted.

The speed with which I was accepted was perhaps not the only influence of gender over my role. I soon became the 'go-to guy' for 'handyman' tasks. This could perhaps be because I was always willing to try; it was not because of any great skill. I was also consulted for security-oriented tasks. I was asked to set alarm clocks so as to ensure they would go off on time, and similarly to lock doors or check windows. Was this because I was a male assistant? I don't know – but it is in keeping with traditional role expectations.

As a male researcher, the same difficulties and expectations seemed to arise. It took a significant amount of time to form a rapport with research participants and they seemed surprised that all I wanted to do was talk. It appeared they were expecting a more activity-oriented relationship. The cameras served to significantly overcome this obstacle – however even at the conclusion of the project I felt that if I had been a female researcher my data might have been a bit richer. A female may have been able to overcome the outsider status earlier in the project. I was also lucky, in some ways, that the research took place during a citywide transit strike. Participants and I were able to bond over a lamenting of transportation and the unreliability of other services. I was able to relate to concerns about security.

My gender would appear to have played a role in my care-giving and research experience. It did so by affecting the relationships I engaged in, how I was viewed, and expectations of me by participants and residents.

Chapter Four: Mutual Themes and Connections to Gender

Having discussed the three Photovoice projects, I now take a step back and draw out some general themes that these assignments collectively raised. I have termed these themes: ‘Spaces Shaping People’, ‘Internalization of Language’, and ‘A Collective Political We’. Following a discussion of these three generalized themes I will look specifically at the knowledge produced about gender.

General Themes

Spaces Shaping People

As alluded to in the previous chapter, the space in which one encounters an individual would appear to greatly influence expectations of that individual. Individuals encountered in the home would appear to be ‘safe’ people and expected to be attentive and helpful to residents needs;

It used to be when I first came - the assistants, what got me, you'd come home from [a weekend with family] - we'd come home from the weekend and they would be leaving. I said to one chap, He wouldn't ask permission from our director, and I said when will you be back? And he would say ‘oh – goodbye’. He didn't give any explanation, of course. So the poor residents - not putting up with that. So our director came over and I finally told him we can't put up with him. You don't want the like of that (Caleb).

Spaces seem to serve as a ‘cheat sheet’ to the interactions one has with people. Recall the discussion of friends and work in Chapter Three. Madison, noting that those attending the program changed regularly – so often that all participants wore nametags - still insisted they were friends simply for participating.

This pattern continued when one discussed more public settings – such as the bus – but the classification changed from friend to stranger. Participants also noted feeling

hesitant and withdrawn. The most poignant example of this ‘stranger danger’ can be seen in the following discussion between Sarah and Aidan:

Sarah: There were too many people [on the bus]. I couldn't sit down. There was lots of people.

Aidan: Don't talk to strangers! You don't know their reaction. They might grab at you, or snap at you, you know. I wait until they talk to me, I don't talk to them. () I don't want to get in trouble.

It would seem, one could encounter the same individuals in a controlled workplace and they would be approached as friends or as colleagues. Best buddies – for example – because of their association with the home and community are welcomed instead of approached skeptically. However, when approached in a more public setting, a less regulated setting, relationships seem much more hesitant. Indeed, social engagement would seem to be avoided.

Internalization of Language

A second pattern that transcended all three projects was an internalization of community language and community expectations. I found at all stages of the interviews the project participants often used the same choice of language or rationale to describe their world– with this being less true of Sienna (who had been at Elkwood Heights for the shortest period of time). Because of the way these thoughts or sentences were phrased and conveyed it often appeared recited and seemed repetitive. Aidan, for example, who was often a very fast talker slowed down and stated the following in a rather practiced way “*I do my job and () they can talk to me. You know. You know. I don't say bad words. Just be yourself. Talk about better things. About what's going on and all that*”. This relationship between language and behavior, I argue, seems to serve to moderate

behaviors. It has mixed results. Aidan would appear to refrain from bad words so as to encourage integration and prevent a return to a hospitalized setting. This is what he has been told will best allow him to fit in. Caleb would seem to abide by the same behavior, suppressing his frustrations for fear of consequence. The result is a feeling of not being listened to; *“because I know as you were just saying Chris, sometimes I do feel left out, 'cause like ... wait a minute kind of .. and you can't get mad. I'm aware of that.. but it's very difficult sometimes.”* One wonders about the long term effect of this suppression. How does this affect Caleb's self-esteem? How does this affect his relationship with those he feels are leaving him out or prioritizing other individuals? In addition to strict protocols outlined in narrative two (see page 30), internalization of behavioral expectations also seems a tool of behavior modification and – arguably – a tool of normalization.

It should be noted that this internalization of language was also witnessed in community gatherings I was invited to and on communications materials throughout the organization. The framework and objectives of the organization shaped perspectives and approaches to care. References to Elkwood Heights as ‘a community’, would seem one example of this – albeit a very generalized one.¹⁶

A Collective Political We

Initially, I associated project participants' heavy reliance on the pronoun ‘we’ as further evidencing of this collective language. They had internalized a community identity much in the same way they had internalized community language and protocols.

¹⁶ I recognize that this ‘community’ example is not the strongest. However, I am hesitant to provide more detailed examples of this pattern because of how specific this language is to Elkwood Heights. Presenting specific language here would significantly challenge Elkwood Heights' anonymity.

This prioritization of community life can be seen in Aidan's earlier quote about the emphasis on eating together in an almost familial manner (see page 58). However, as my analysis developed, I began to question this reading. The 'collective we' appeared to be used much more specifically. Although it was used to describe intra-community relationships, it also seemed to be employed to describe a political grouping or identification.

This 'collective political we' was perhaps first seen in Caleb and Madison's reflections on the institution and on how that identification with one another has influenced Caleb's own outreach activities. In speaking of bedrooms at the institution versus bedrooms in Elkwood Heights, I asked,

Christopher: Did it feel less like your own space?

Caleb: Yeah.

Madison: We're glad to get out of there.

Caleb: Yeah.

Madison: Yeah.

Caleb: And I just heard recently that that they are going to close it. A friend of mine just called our home one evening.. we were just happening to be finishing supper and I answered the phone and I said what's wrong. He said, well Caleb, he said, I want to be here with your director, I wanna get out. It's driving me crazy. Well I can understand very well what he means, very well. Because I had to live there myself. I know very well what's wrong.

This collective association would appear to be a result of a situational empathy as opposed to directly tied to one's categorization as disabled. Madison and Caleb have

'organized' in response to the structure of the institution and the institution's treatment of them.

The theme of political empowerment can be seen in a number of other places in the interviews. The earlier quote by Sarah lobbying for a change from watching films at work to working on the computer is one example. Caleb's lobbying for a new vehicle is another example. Aidan, furthermore, has begun to lobby for a change in his living situation – hoping to move into his own apartment. This lobbying effort has been strengthened by the fact that some of his close friends within the community have successfully made the transition. He speaks with these friends and gains their encouragement regularly both on the phone and in face-to-face meetings.

Responses to political organizing would also appear positive and empowering. Although it is difficult to assess genuineness, Aidan suggests that Elkwood Heights is supportive of the idea of his moving out as long as he goes about the process slowly. Caleb suggests the organization is receptive to his suggestions of change as well – although notes he has not seen anything being done. Instead, it would seem his efforts have been redirected into other outreach work;

Caleb: Oh! I just found something out now that you brought it up Aidan.. I didn't know myself and – oh! - the new assistant from our place are going to be going to talk to a group of young people. () Yeah, yeah, young young people though Chris. Younger than you! ()
You asked me Chris, what, ok, again. They don't know the first thing about what Elkwood Heights is. So. We've been invited to do that. Introduce ourselves to them - and then they can fire the questions.

Aidan: University students eh?

Caleb: Yes. 'cause they have no clue - PERIOD - what Elkwood Heights is.

The 'collective we' recognizes a collective grouping and a shared identity category: disability. However, much in keeping with the SR model – participants would appear to organize around a shared reality or shared experience. They are not bonded because of reduced function. Instead, they have bonded around the restrictions within various macro levels of society that have come together to create this disability.

It should be noted that this 'collective we' became more interesting as the project developed. As the project progressed an encouragement and excitement about other participants' photos also seemed to grow; participants also began to positively reinforce one another's photo-taking skills. Whereas an important part of the individual interviews was reinforcement and appreciation of the participants' work, this role slowly moved from me as a researcher and became a task adopted by participants' peers. Slowly, as communal reinforcement grew, I became less of a facilitator and the focus group became more a discussion between participants. In the last group interview (on work), for example, participants became aware that I was not participating in the conversation and sought to turn to include me by asking questions about my work, my boss, and other details of my 'non-academic' life.

What's Gender Got to Do With It?

The obvious absence in the discussions above is a conversation about gender. This has been done deliberately so as to allow the discussion to be presented in a cohesive collected way as opposed to spread thinly throughout the prior discussions. This next section can be separated into two parts. First, how did gender interact or intersect with the patterns and themes discussed above? And secondly, what conclusions about gender and disability might be raised?

Gendered Spaces

It should be noted that in early discussions of the project a gendered home environment was denied by project participants. The environment was presented as designed for a 'gender-neutral' individual. Indeed, this would appear in keeping with literature on individuals with disability being portrayed as genderless. Linton notes that in the seventies, "some people would purposefully say women and men with disabilities to provide an extra dimension to the people being described and to decenter the way the disabled were traditionally described" (Linton 1998: 7). One might argue that the dominance of female caregivers served to balance the influence of male administrators in the construction of the environment. In more practical terms, spaces that suggested a more gendered identity were created by participants. Participants all noted, for example, that they had control over their bedrooms – each one confirming that he or she had the opportunity to choose the paint color. As photos 2 and 3 show (see page 59), however, there was a pattern in bedroom color - the boys had blue bedrooms and the girls had pink bedrooms. This – nevertheless- was a gendering of the space by participants and not a gender stereotype forced upon participants.

Gender Roles and Expectations

However, when the conversation turned from gendered spaces to gendered expectations the discourse did change;

Sienna: Boys get more money. () Fred gets 300 dollars.

Aidan: Boys are a lot more [in] control. Girls are supposed to be more sissies.

Christopher: Do you think that's true?

Sarah: No

Sienna: No No

Madison: No

Sienna is identifying a pattern in larger society and grounding it in her own lived experience. If true, it suggests that Fred's extra revenue allows him access to a number of different opportunities that Sienna may not have access to. Aidan, similarly, plays on the idea that men are supposed to be more independent and more assertive. The observation fits with his character and, one wonders, if it motivates his desire towards obtaining his own apartment. What is also interesting is that this discussion of gender occurred at a peer-to-peer level. Short of references to a collective political we, most discussions about people and characteristics often related to friends and staff. The influences of gender – although often subtle and difficult to discuss – were recognized and were recognized as existing at the level of participants' everyday lived experiences.

Sarah painted a much different picture of gender role expectations, suggesting that the behaviors of women were much more regulated and the expectations of women were higher. Where Aidan suggests men are expected to be more assertive, Sarah describes a situation wherein men are able to be more assertive because of fewer behavioral expectations. She describes her male peers as often interrupting without consequence. She describes this both in relation to a male housemate and when discussing the group interview session on 'home'; "*Caleb Martin. Caleb Martin talks all the time. He - uh - he interrupt me. The last time I didn't finish. And then after he interrupt me*". Similarly, she noted frustration that men don't 'follow the rules' such as dressing appropriately for birthday parties, "*yeah, sometimes, sometimes they don't dress properly because, because, because, when, when we have a birthday party, then they don't dress up*". This seeming 'lack of discipline' or 'differing expectations' led Sarah to express frustration

and feelings of disempowerment. It also put me as the researcher in an awkward situation as a facilitator. It did, however, explain how reserved Sarah was in the first group interview. Greater attention directed her way in the second and third interviews led her to open up much more and led to a more positive relationship between her and Caleb.

Relationships with Authority Figures

In addition to gendered relationships amongst peers, a pattern emerged about participant's own expectations of men and women authority figures. As was mentioned earlier, higher degrees of authority seemed to be increasingly recognized as masculine. Male figures were most often presented in a legal or formal aspect. Aidan describes a family relationship where his brother is in charge of his *"cheque you know, my government thing, you know. My card and my money for the month"*, whereas family visits are often with his sister or his mom. Caleb also described his brother in primarily a legal administrative role, *"Oh yes, but he's also my guardian - that's why he wants to know everything if I'm away - see, I'll probably call him before the [grey cup] game tonight and see if, what I'm gonna do for Christmas"*. Madison also suggested a different relationship with her Mom, with her father appearing to only be her mom's husband;

Madison: I lived with my mom first - then she died.

() Then her husband died too.

Christopher: Was her husband your dad?

Madison: Yeah.

Gendered role models have been established by all of the project participants, with males occupying more formal roles and women occupying more traditional caring roles.

Gendered Identities

The question now might be how do these understandings of gender manifest themselves in the project participants? Have they internalized these models and relationships? Do they go beyond recognizing them - do they live them?

It would appear the everyday behaviors of the project participants and the gender roles put forward do shape their expectations of self. However – recognizing the intersectional nature of this study – I also recognize that gender alone might not be the only influencing factor. In discussing the ways the project participants “do” gender – it is important to be mindful of the patterns raised earlier and how they might intersect with these gendered behaviors and identities.

Perhaps the most visible manifestation of these gender patterns is the male / female split that participants described. Recall that males were described as being more assertive and described as holding greater responsibility over more legal functions. They were described as advocates. In contrast, females were described as more attuned to an individual’s emotions and, arguably, aspects of self-realization. While men might be seen as encouraging empowerment through activities, I suggest that women were seen as encouraging empowerment through self-esteem. Men were presented as doers; women were presented as talkers.

More specifically – Madison, Sarah and Sienna all emphasized friendships that engaged in both talking and in listening. As Sarah repeated many times, a good conversation should not include interrupting. Indeed, all three women communicated that these friendships were important to them and that they sought them out.

Similarly, all three women emphasized activities that were important to their own identities, but that might also be connected to (re)producing their gender identities. The

earlier quote about washrooms being Sarah's responsibility was unique in that Sarah clearly communicated that this cleaning provided a sense of value. Furthermore, Madison noted that cleaning the house was her favorite activity;

Christopher: What's your favorite thing to do in the house?

Madison: Clean the house

Christopher: You like cleaning the house?

Madison: Yeah

Aidan's discussion about communal dinners and his frustration with the resulting clean-up suggested he saw little personal value in the task. Caleb (unknowingly) builds on this pattern. In relation to a female peer he notes, "*[I do] the sweeping. Lucy does the cleaning the mats. And Lauren washes and Dean dries. Don't tell her different!*" He goes one step further explaining why Lauren has taken so strongly to after-dinner cleaning, "*Lauren and myself when we, uh, have coffee after our clean up. And you don't tell her different. Believe me, [if] you want her to work*" - connecting the task results to the 'reward' at the end.

This does, however, raise an interesting point. As was alluded to earlier, participants would appear to speak in words that are not necessarily their own, internalizing the language of others. One wonders, to what degree does the internalization of language affect these individual's identities? My data does not appear to offer an answer to this question as it relates to gender. The next chapter will explore this idea in relation to 'perpetual childhood' which, as will be elaborated, is tied to a 'pre-gender' identity. I also note that the qualities associated with both men and women would appear characteristics one would hope for in a good carer. Participants do not suggest a preference for male staff or female staff. However, they see the characteristics

split along gender lines suggesting an effective team needs men and women.

There is one final gender pattern to note. There would appear to be, amongst this group of individuals, a connection between gender and working age. Both Caleb and Aidan have presented work as something they will continue doing until they are no longer welcome. As was noted earlier, Aidan has drafted alternative places of employment for when his current 'employer' no longer needs him; *"When I'm ready maybe. One day. When I'm ready I'll pack it in. When I get too old with [this job] I'll probably go back to just volunteer with the [a prior job].. go back to [there]"*. Caleb goes one step further, suggesting retirement equates to quitting;

I like my job. I like the people. I'm not in any hurry to quit - people have asked me that. I said 'lookit - you're coming to ask me something like that'. I said 'I'm sorry'. The way I look at it the fact that you do have a job - not rush right into the quitting kind of part. I'm not in any rush to quit. I've got good health so far - I'm not in any rush to quit. And.. we do.. they do need help. I can tell right there.

Caleb clearly communicates that work provides him meaning and value. This connection to continued and ongoing employment would seem associated with the 'doer' characterization associated with masculinity. Madison, Sarah and Sienna, in contrast have no concerns about retirement or of moving from 'work' or structured day activities into a different daily routine.

Conclusion

This chapter had two parts. Part one explored mutual themes in the photo-projects and focused largely on the influences of spaces and locations. Participants often associated an individual's personality and character to the place within which he or she was encountered. Participants also seemed internalize and reproduce the language and

behaviors they understood to be used and expected in different spaces. Shared experiences, shared spaces, and shared language would appear to culminate in a sense of a shared political identity.

The second part of this chapter focused more particularly on gender. It establishes that an intersectional relationship between gender and disability would appear to exist, however raises questions about the strength of this relationship. While spaces were not gendered, both institutional frameworks and personal relationships do insert gender into these spaces. Gender did not seem to affect a participant's aspirations or one's political identity. It did not appear to deny participation in certain activities or actions. However, gender would appear to play a role how one expressed her or him self and the importance placed on personal advocacy.

Chapter Five: A Larger Picture through more Generalized Findings

The thesis so far has looked very specifically at the realities of five individuals with intellectual disabilities. It has been very careful to avoid approaching these experiences as a homogenous reflection of life within a residential care environment. This chapter seeks to draw on a variety of literatures to expand these experiences and generalize from them. This will allow the thesis to speak to more people and perhaps increase its usefulness in regard to possible changes within this environment. I also take the opportunity to use the secondary literature to interrogate patterns and themes that were evident but difficult to extrapolate in the analysis – participants' connection to Christmas for example. Christmas was noted and coded because of its repeated conversational appearance. However, the meaning it had for participants was difficult to present in a substantial way other than quantitatively presenting the number of occurrences. A return to the literature has suggested larger patterns into which these occurrences may fit.

To accomplish this, the chapter takes up four themes: claims to normalcy, integration, perpetual childhood, and hierarchy of impairment. The first section seeks to understand how activities like outings to Tim Hortons and the Christmas holiday might serve to connect participants to larger feelings of normalcy, which, arguably, leads to feelings of inclusion. I build on this in the second section, and attempt to unpack the intracommunity / extracommunity tension discussed in Chapter Four. I also engage a bit more with the paradox that participants are dependent on Elkwood Heights' staff to go out into the broader community. In the third section I engage Priestley's (2003) idea of a meme of perpetual childhood in relation to disability – and ask how this perpetual

childhood might affect the gender identities of the project participants. Finally, there appeared amongst project participants a desire to differentiate between one another. So, I look at the idea of a 'hierarchy of impairment' and question whether this hierarchy exists, or whether I am simply misreading a common desire to differentiate oneself. This chapter establishes the complexity of each participants' identities and the intersectional forces that (re)produce both their environment and everyday lives.

Claims to Normalcy

As was mentioned, all five participants expressed a strong connection to Christmas – a connection somewhat mirrored in discussions of Valentine's day – and in discussing trips to Tim Hortons. Responding to why Christmas or Tim Hortons might be important activities is not difficult. The thesis so far would suggest it is because both provide connections to the outside community, recognition for tasks well done, or a recognition of the relationship fostered over the previous year. However, connections to the outside community and personal recognition appeared to be person centred and not tied to events or activities. Christmas and Tim Hortons challenged this pattern. Why did these events gain greater emphasis than those occurring more regularly?

Goffman's *Stigma* offers a less surface reason for the meaning behind this holiday and activity. Goffman notes that, "The stigmatized individual tends to hold the same beliefs about identity that we do; this is a pivotal fact. His deepest feelings about what he is may be his sense of being a "normal person," a human being like anyone else, a person, therefore, who deserves a fair chance and a fair break" (Goffman 2006: 133). If we approach all the participants as a stigmatized group – demonstrated by their positioning as intersectionally invisible – this point is not controversial. All five participants put

forward dreams and goals that seemed initially uninfluenced by labeling as disabled; Aidan, for example, wanted to be a broadcaster and Sarah a teacher. However, Goffman footnotes the point, noting that “Interestingly, a convention seems to have emerged in popular life-story writing where a questionable person proves his claim to normalcy by citing his acquisition of a spouse and children, and, oddly, by attesting to his spending Christmas and Thanksgiving with them” (Goffman 2006:139). Goffman suggests that Christmas and Thanksgiving are activities reinforcing ones belonging to the category of ‘normal’.

With this in mind, one might argue that Christmas and Tim Hortons are more than a means of getting out of the house and engaging the community at large. They are also acts that allow participants to exist in that liminal space between ‘disability’ and ‘ability’. I would argue that as claims to normalcy and inclusion in a larger community, Christmas or Tim Hortons are political acts. Although perhaps not deliberate, they challenge conceptions of who can be ‘normal’ and of defined boundaries. They provide participants opportunities at visibility.

One might expect that this claim to normalcy would also culminate in strong gender identities. Participants might seek to escape categorization as disabled by prioritizing, or making a claim to, a larger gender identity. Participants might perform a ‘hypermasculinity’ or ‘hyperfemininity’. This claim would also allow participants membership in a larger extra-community identity group. The knowledge produced, however, disputes this hypothesis and establishes that this is not the case. Although participants do have gender identities they do not appear to prioritize these identities. Indeed, in keeping with intersectionality, project participants note that their gender

identities are just one of many identities. The significance of this category shifts depending on space and circumstances.

Integration

The thesis makes clear a strong distinction and disconnect between intracommunity expectations and identities, and extracommunity expectations and identities. This can be seen in the tension between the workplace and the home, and also in the tension between how one engages ‘friends’ and ‘strangers’. This friction serves to put forth a paradox: participants who desire increased access to extracommunity events, identities and relationships are most often reliant on paid intracommunity staff to get there. The result, as has been discussed earlier, is a transitioning from ‘staff’ to ‘friend’ – despite staff engaging in required tasks. Participants rely on the ‘inside’ to gain access to the ‘outside’.

Can this pattern be connected to something larger? Engagement with disability literature would suggest so. This paradox appears similar to what Galvin (2003) terms the “paradox of disability culture” speaking primarily of political organization around physical disabilities. In short, Galvin (2003:67) asks: “How can we claim unity without falling into the same exclusionary practices that have served to create our divisive identifications in the first place? Conversely, how can we relinquish the practices of identification that are based on binary oppositions without losing the ability to claim identities at all?” The paradox of disability culture seeks to balance “the need to combine” with “the imperative to let go”(ibid).

Applying Galvin’s paradox to the empirical work serves to generalize the paradox somewhat. We see the “need to combine” resulting in an increase in the delivery of and

access to services and support which participants themselves note as ‘empowering’. The “need to combine” has been effective. However, this grouping has led to a ‘popular’ homogenous understanding of disability that serves to maintain a number of common myths and creates a seemingly separate culture amongst participants (see Galvin 2003:69). This semi-isolation, arguably, is a result of an emphasis on disabled identities, making disability ones primary identity category and overlooking the intersectional nature of identity emphasized and developed through this thesis.¹⁷ Participants suggest they are disconnected from the larger neighbourhood or outside community. They also suggest disconnect from other membership groups – few identify as seniors for example. However, to step away from this claim of disability, to drop that identity so as to gain access to the extracommunity identity (the imperative to let go), would arguably serve to disempower an individual even further and might not necessarily lead to greater integration in the community at large.

What this discussion draws out is a relationship that exists as a result of structural factors. The reliance on staff is a result of how the group home is set up. Participants, arguably, would go out more with non-staff if they had access to such individuals. This access is limited, however, because of the way the home is organized, zoned (in largely residential areas), and because of limited participant access to relationships outside the home. This is the “ongoing dilemma of liberal freedom” Levinson (2005) raised earlier. The structure and organization of the group home environment is better than an institution – but it falls short when compared to full autonomy. One might reply that

¹⁷ I think it has been established that participants are not fully isolated leading to a hesitation to use the term ‘isolation’. Semi-isolation is used to recognize the nuances in their engagement with the community-at-large.

strategic claims to normalcy (the importance of Christmas and Tim Hortons) suggests participants have found other means to transcend categories - but they still require the category of disability for empowerment and services.

Perpetual Childhood

At this point, we have engaged strategic claims to normalcy as a means of challenging the label of disability and examined how the structure of the group home is itself paradoxical: it both provides and limits personal empowerment. This next section picks up on a theme that also came up in the research and can be seen in the following exchange with Madison:

Christopher: The people at work, do you ever invite them over to your house?

Madison: No, they don't walk well, the old people.

What Madison demonstrates is a generational disconnect common amongst participants. All five often referred to themselves as younger than their peers, authority figures, or others in the same generational bracket. Aidan and Sienna, for example, despite a 20 year age difference demonstrated a strong friendship and seemed unaware of the generational divide. This issue of generations can also be seen in the significant age difference between participants and their 'best buddies'. Why is this?

In returning to the literature, authors using a life course model often noted a connection between disability and ideas of 'perpetual childhood' that challenged the autonomy of disabled people; "The social construction of age in Western industrial societies pivots upon an idealised notion of independent adulthood" (Priestly 2000: 426). One becomes an adult not through age but through the completion of a series of transitions: from school to work, from family of origin to family of destination. For persons with disabilities, these transitions would occur at different times and at different

ages. Sometimes they do not occur at all. By completing these stages at different speeds, persons with disabilities engage in different and intergenerational relationships – they don't fit the model. They would also appear to challenge possible generational membership. The move to a culturally constructed adulthood takes longer and, even at that, is not always seen or recognized as sufficient.

Authors such as Shakespeare (1997) and Aspis (1999) are particularly vocal about the influence of this meme in regard to the relationship between disability and sexuality. They, among others, propose a sex-positive approach;

societal perceptions of disability as a state of 'perpetual childhood' determine that information about different kinds of sexual and emotional life may be withheld from disabled young people because they are seen as 'incompetent' to assimilate it and 'may get the wrong idea'. In short, disabled young people are more likely to be confined within the 'sex as a means of reproduction' approach to sex and personal/social education which creates a particular perspective of both boys and girls (Corker 2001: 92).

There is a connection between Madison's references to peers as "the old people", the multitude of intergenerational relationships project participants engaged in, and the meme of perpetual childhood that disability scholars identify in the popular imagination (see Williams and Bendelow 1998; Murphy 1987).

Participants have not escaped this meme of perpetual childhood. Instead, I argue, they have internalized it, leading to a different sense of age and of time (see Owen and Wilson 2006). It is for this reason that they do not always connect with peers and do not always recognize generational memberships. Priestly, however, suggests that this perpetual childhood has greater consequences in that it also purports a gender-neutral view of persons with disabilities – a view Linton (1998) also argues exists. My research,

in part, would challenge these arguments. The research has shown that participants do have gender identities and that they do engage in gendered relationships despite seeing themselves as younger than they are.

The generational theme that flows throughout this thesis is not disconnected from discussions of gender. As Priestly and Linton note – perpetual childhood affects how persons with disabilities are viewed by others, and as Shakespeare and Aspis note this directly affects issues of autonomy and care. Indeed, if we accept the reasoning of Alanen (1994: 37) further study of this relationship would seem encouraged:

The assumption of the pervasiveness of the gender system implies that all social relations are gendered – so feminists claim, and have substantiated the claim by producing much research. To acknowledge this has the effect of changing the focus from one turned exclusively on women to examining how gender shapes and is implicated in all kinds of social phenomena.... Can we accept that all kinds of social phenomena are not only ‘gendered’ but ‘generational’ as well.

What Alanen proposes is outside the scope of this thesis – but the suggestion would seem bolstered by an intersectional relationship between gender, disability, and generation supported by the data produced.

One last point that this discussion of perpetual childhood does bring up, is that paid employment has often been seen as the key transition to adulthood (see Hendey and Pascall 2001). It is a transition in itself and it has been seen as a key to other transitions – such as “householding, partnering and parenting, adult social relations and citizenship”(ibid). The discussions of employment – particularly retirement – can again be perhaps be explained by this meme. Work is important and provides value for participants. It seems to offer a degree of autonomy and a connection to a broader

community. However, participants do not engage in paid work. Put simply, if paid work is key to an independent adulthood, and participants are –for a multitude of reasons not able to obtain paid employment – they may further build on this meme and lose access to a wide variety of opportunities and experiences.

Hierarchy of Impairment

The last theme this chapter addresses is the differentiation participants made between one another. As was mentioned and demonstrated earlier, there was a sense of camaraderie and connection amongst participants – one that built as the project continued. However, there also seemed to be a sense of differentiation that occurred through references to differing levels of autonomy and – arguably – impairment. This could be seen in Caleb’s comments about work and his different relationships with peers at work. This differentiation also arose in personal interactions during group interviews.

In a conversation about ‘help’ and how one responds to an assistant’s offer of ‘help’, Aidan offered the following two statements:

Aidan: I don't need that much help. I'm pretty independent. I can do alot of things by myself - the thing with Jessica or Frederik or Samuel is they need more attention. They need more.. I can do more than they can do.

Aidan: They [assistants] pay attention to the persons that have more problems than we do.

Aidan is clearly differentiating himself from fellow residents by functional limitations. He does not reference the division of attention by need – but by capacity and ‘problems’. This differentiation creates strata of autonomy and situated Aidan into a higher stratum.

The idea of a hierarchy of impairment is not new. A number of quantitative studies have been done to measure public perceptions and ranking of multiple disability

categories. However, the idea of intra-group rankings of disability has been engaged more rarely. Corker *et al.* (1999) comment that ‘informal impairment hierarchies’ can be seen in special schools. Wates (1997:54) notes the subtle nature of such a hierarchy, arguing it is “...often implicit but rarely stated”. Indeed, one of her research participants, a “veteran of a school and college for disabled people”, refers to a “pecking order” (45). It can also be found in earlier research by Bertin (1959) and Mastro *et al* (1996). That said, an argument towards a subtle hierarchy could be drawn out from the discussion in regard to disability studies and the prioritization of physical disability above.

How then, does this impairment hierarchy speak to the larger work? This impairment hierarchy is bolstered in this particular circumstance by the gender norms participants expressed. Aidan’s self-appointment at a higher stratum coincides with his status as a male, which, arguably, encourages outspokenness and personal advocacy. It would also connect with the structure and goals of the group home environment that seeks to encourage autonomy while noting it cannot encourage full autonomy or independence. Structure, gender, function and disability combine to construct and (re)produce this hierarchy.

Conclusion

This final chapter has sought to move from the specificity found in Chapter Three towards more generalized and transferable findings. It has done so by drawing on a further set of secondary literature and by connecting pre-existing patterns to larger more intersectional themes. Discussions of claims to normalcy, for example, demonstrated how participants sought to exist in the liminal space between ability and disability. It also suggested that participants did not see claims to gender as a medium through which

they could engage in extra-community identities or question a 'disabled' label. Gender was not seen as a membership category through which one could express a political category, but seemed more strongly understood by participants as connected to their sex.

By engaging an intra / extra community paradox this chapter connected the particular lived realities of participants to a larger organizational structure. This environment encouraged a number of participants to adopt a variety of behaviors, with these behaviors enforced through consequences. This approach appeared successful. Participants demonstrated a tendency to internalize behavioral expectations – as anyone might do living in such a heavily supervised environment. One wonders, however, the effect this had on individual's gender identities. Instead of allowing participants to express varying gender identity, a gender-neutral environment might actually serve to dissuade participants from adopting a prominent gender identity. Has a largely gender-neutral environment served to neutralize gendered identities?

The discussion of perpetual childhood helped to explain why persons with intellectual disabilities are often seen as genderless. The thesis establishes that participants do not view themselves as genderless. It also establishes that they place limited emphasis on this identity. Ideas of perpetual childhood also explained why participants so often insisted on their adulthood. If perpetual childhood is as prominent a meme as the literature suggests, it would suggest that the recurring theme of generation in this thesis can be found throughout the lived experiences of many individuals with intellectual disabilities.

Finally, the chapter discussed a hierarchy of impairment that highlights the complexity of participant identities while also re-engaging the main theme of

intersectionality. It demonstrates how the environment, by encouraging autonomy, serves to also encourage traditional 'male' characteristics such as assertiveness. In empowering males, it also appears to (re)produce feelings amongst female residents of being overlooked. Men were 'interrupters' because their 'interrupting' was seen as an act of personal advocacy and encouraged, whereas women who interrupted were seen as breaking social norms. This finding too would seem transferable across residential care environments because it stems from a combination of participants lived experiences and an organizational structure which has been reproduced in a variety of cities.

A Narrative: Conclusions and Departures

The conclusion of my employment occurred a few months after the conclusion of this research project. As a result, the study's findings have greatly influenced how I reflect on the job and on the relationships formed while employed there.

Above all else, I am having difficulty separating the employment from the friendships I have formed while employed there. I do not see residents as residents – I see them as friends. I realize that I am engaging in a pattern of behavior that will only serve to continue the friendship pattern detailed in this thesis. I was temporary. I was mobile. And, now that I am not an employee, I am leaving.

The question, of course, is how do we change this? I have made a personal commitment to visit the home whenever I return to Ottawa and to send postcards and updates that can be discussed with the residents. I have encouraged residents to do the same. I do not know if it is possible to go further. Experience has suggested that telephone calls will be ineffective - and impossible with two individuals who are non-verbal. Finding other means of communication is necessary. It is also important to maintain this communication fairly regularly due to the high staff turnover.

I am also wondering if, as a researcher, I have engaged in the same behavior as an employee. The success of this project depended upon the development of rapport. That was obtained – but so was a friendship. In short, I am again engaging in the friendship pattern outlined above. Would this relationship be different if I had engaged the participants in a paid relationship – therefore encouraging a greater separation between researcher participant and researcher? I remain unsure.

The goal of this project was to provide participants with more than a final thesis – it was to provide them skills they can use upon completion. Conversations with participants have suggested that they will use these skills in the future and that they are grateful for the opportunity to participate. I remain hesitant, however, if that is enough. The knowledge that I am perpetuating a trend is unsettling and arming individuals with cameras does not seem to alleviate it.

What to do? I can only hope to build on the results. This project, for example, has outlined for me the multigenerational nature of friendships amongst the project participants. The Best Buddies program was an example of this. On a personal level, I have considered making an ongoing commitment to similar organizations and residences. An act increasingly important as I age that will, in at least one case, serve to challenge the emphasis on younger volunteers. On an academic level, I have become more committed to a participatory and collaborative methodological framework. I recognize that both the time and personal commitment to such a methodology is much greater – but I have also realized that the results of the project, for me, are that much more meaningful.

Conclusion

This thesis started out by putting forward three objectives and three arguments. To conclude the thesis, I evaluate the study's success in achieving these objectives and use the information presented in the past five chapters to further develop these three arguments.

Meeting Three Objectives

I embarked upon this study with three objectives. The first objective was to ensure the realities of persons with intellectual dis/abilities are recognized in discussions of gender. Indeed, I argue that this thesis has accomplished this. Gender has become less of a concept and more tangible through the grounding of the project in three tangible areas of investigation (home, important people, and work). This has resulted in an interesting discussion of different gender roles and different gender expectations. The analysis has gone deeper than this however. These roles and expectations have been extrapolated so as to understand how these factors influence lived realities. This process has allowed a connection to be made between impairment and gender but has also situated discussions of gender and disability in a larger web of intersectional relations. This can be seen most prominently in the way the thesis has engaged relationships between generation, disability and gender.

To ensure participants felt in control of their ideas, the thesis engaged in a rather vigorous effort of consent and ownership. I have attempted to, as much as possible, present the pictures and words of participants with minimal alteration in the final thesis and have gained secondary consent for all properties used. Furthermore, a public showing of participant's work has been arranged in collaboration with participants. They

have selected their favourite or most meaningful prints and have been encouraged to take control over the invitation list. Increasing participants' opportunities to dialogue about this experience, and ensuring the results of this research do not sit idly on a library shelf, will be my responsibility as a researcher.

The second objective was to provide an academic work that can problematize absences of gender in the disability literature and disability in gender literatures. This was accomplished in Chapter Two which provided a detailed examination of disability studies strengths – but also its shortcomings. It was noted that disability studies fell short on empirical works prioritizing the theoretical. In addition, the emphasis on work by disabled scholars led to a significant absence for participation by persons with intellectual disability. This thesis proves that intellectual disability should be included in disability studies because persons with intellectual disability can be engaged and included. Indeed, persons with intellectual disability have much capacity for rich knowledge production – they are just waiting for someone to ask for their participation.

Recognizing the absence of intellectual disability and lived experiences of intellectual disability in the literature, the third objective sought to provide a medium through which persons with intellectual dis/abilities might speak to gender and the role of gender in their everyday lives. It was necessary to find a means through which participants could communicate their realities and which allowed participants to maintain control over these narratives. For this reason, I engaged in participatory Photovoice methodology that revolved around clear tangible themes. It empowered participants by providing positive reinforcement and offering them a 'take-home' skill. It cannot be stressed enough how useful and helpful these photos were in the interviews. However, I

feel it is important to note that it was not just the tangible presence of the photos that assisted in knowledge production. In this particular case, the focus on participant-produced photography recognized participants as adults and as life long learners – creating a unique relationship between researcher and research participant that might not have otherwise been created. The project had at its core the idea of researcher and participant as co-researchers and approached participants as ‘abled-until-proven otherwise’.

That said, anonymity and confidentiality have significant influence over the larger impact of this project. Participants have clearly identified changes they wish to see made to their living arrangements that cannot be expressed without putting the participant’s anonymity and confidentiality at risk. This is a result of the multiple levels of consent necessary for the project and its academic nature. I cannot, therefore, communicate to Elkwood Heights Caleb’s concerns over the van or over his bedroom. I am left hoping Caleb himself will express these concerns. This frustration may be somewhat muted given the fact that Caleb has established himself a vociferous individual. But, as has been suggested by this thesis, this outspoken nature may be made easier by his status as a male in the community. What of females participants who seemed more hesitant to demand change?

Making Three Arguments

In addition to three objectives, this thesis set out three arguments. To conclude, I would like to restate these arguments and expand them.

First, the thesis establishes that empirical research can and should be done amongst persons with intellectual disabilities. Those who have been consulted on earlier

drafts have responded with surprise that the participants consulted were participants with intellectual disabilities. It has been suggested that the presentation of their thoughts as text, and the frankness with which they contributed, was unexpected. Participants, in being published, have sudden ‘credibility’. This sudden credibility would seem to prove a point: empirical research about disability is just as important and can have similarly positive results as theoretical works.

I have also argued that there exists an intersectional relationship between gender and disability. Starting with concrete discourse about participants’ lived realities has allowed for an extrapolation of gender at the level of lived experience. Gender exists alongside a number of intersectional factors that have been detailed in Chapter Three. It is not necessarily the strongest of these factors, but does appear to flow through a number of identity categories. A relationship between disability and perpetual childhood, for example, was established which contributed significantly to an intersectional relationship through generation, gender, and disability. Similarly, a hierarchy of impairment has also come to the forefront, which appears to intersect in some ways with a hierarchy of gender. Gender serves to both maintain and reproduce this hierarchy, and the hierarchy of impairment served to reinforce ideas of men as more vocal self-advocates. The research makes clear that gender and disability are not the only two intersectional categories shaping the everyday lives and everyday identities of the project participants.

Third, I have argued that the project participants are prone to – and indeed ‘qualify’ as – individuals who are intersectionally invisible. This has led me to advocate for more intersectional approaches to disability. In so doing, disabled people will increasingly be visible in a variety of academic disciplines and increasingly represented

in empirical research. Intersectional invisibility, however, should not be read as suggesting project participants were powerless or apolitical. I hope that this thesis makes clear that all of the project participants do have political identities and have, in one way or another, organized themselves. Political agency is important because of its potential for empowerment and for the opportunities it suggests for social scientists in the discipline to affect positive change (see Flyvbjerg 2001).

To conclude, this thesis has met its objectives and made sound arguments. I recognize that the sample engaged was small and that the diversity of the sample can be questioned, however a strong connection to a variety of literatures has allowed some very particular findings to be extrapolated and generalized. The thesis, however, has established that gender does inform the relationships these five individuals engage in. My results may differ in scope and depth from those of a researcher situated in a different intersectional positioning, but I argue the relationship between gender and disability would still come through in his or her research.

This study raises multiple directions for further research. The lack of diversity in my sample also speaks to the lack of diversity in the residents at Elkwood Heights. One might ask why this is. What effect does this have on attitudes towards race and ethnicity? What effect does a more diverse care staff have on a less diverse resident demographic? Similarly, the effect of residence on the relationship between gender and disability, living with one's parents as opposed to a residential care environment, for example would be fascinating. Furthermore, what effect does an arguably standardized revenue among persons with intellectual disability have on class distinctions?

Results of the Member Check

I have opted to conclude this final chapter by conveying the results of the final member check with project participants. This occurred at the completion of the thesis. Participants were presented with the findings and arguments of the thesis and asked for their thoughts. Together we recorded those points participants wished included as their response.

Aidan noted that the spaces in which he met someone did influence how he approached him or her. But, he noted, it was not necessarily shared residence that led to a sense of community. Residents had come to reside together also because of shared health experiences. He noted his own schizophrenia. In regard to paid work, Aidan noted he had no control and wasn't really worried about it. He had enough money because of a supportive family, particularly his brother.

Discussing government and hierarchies of authority, Aidan stated it was important to recognize that the government was getting better. However, he noted that the "*guy in charge*" had to recognize that government is not really providing people enough money to live on. He said this was less of a concern for him because of his family, but that people "*with worse handicaps*" need more money.

Discussing friendships, Aidan noted that there was only one person at Elkwood Heights he could speak to. Interestingly, he did not feel he could speak to the male staff within the home and that the girls "*judge me*". He also noted that although his best buddy was significantly younger, this wasn't necessarily a bad thing. Her youth made her very familiar with computers, allowing her to instruct him on computer use and email. Her age affected their relationship in that they could only "*just be friends*".

Caleb noted a strong sense of solidarity with fellow residents, made particularly clear when we discussed the relationship between Elkwood Heights and larger government agencies. Caleb would seem to hold the government responsible for his treatment in the institution and said he was “*very frustrated*” with them in “*more than one way*”. The conversation visibly frustrated him, which he expressed through a fist jabbing motion. He noted that Elkwood Heights had fostered this sense of solidarity by encouraging friendship and social activities. There were fewer rules governing his behaviors.

Interestingly, when discussing Best Buddies and the difference of age, Caleb suggested that the program wasn’t really that important to him and that his current buddy had been the exception. Caleb “*just go[es] on with what they tell [him] on [his] end*” and described the situation as him doing the best buddy a favor. It was the best buddy who wanted to make new friends. Caleb saw himself as a sort of mentor for the best buddy, but noted that he gets very frustrated when buddies leave because of the personal investment he puts into the relationship.

Caleb also noted that the visible distinction in bedrooms (boys blue / girls pink) is becoming a product of the past. He stated that bedroom colours have become more diverse as new residents join the community.

My discussions with Madison were mostly people oriented. She was less interested in larger organizational structures or in what happened outside of the community. She noted that it was not that she did not want to befriend strangers but that strangers were scary and that the best way to avoid that situation was to walk away. She

also noted that her strong connection to housemates was a result of having been in the institution with two of them. They all knew what it had been like.

In discussing ideas of perpetual childhood Madison got very excited. She stated that she knew exactly what I was talking about and went into significant detail about how a number of assistants treated her that way. When asked if that was something she wanted to change she noted that Elkwood Heights was still better than where she had lived before. It was not perfect, but there were worse possibilities.

Madison suggested that the distinction between blue and pink rooms was not important; she chose pink because it was her favourite color.

My conversation with Sarah was equally enlightening. Sarah noted that she had been in an institution as well – a point not made in prior interviews or reflected in the thesis. The biggest difference between the institution and Elkwood Heights was that at Elkwood Heights she was able to go out more. At the institution, day programs occurred on-site, whereas at Elkwood Heights day programs occurred off-site. She was much happier with her present day activities. Sarah also noted that due to a change with her day-program she was spending more time on the computer, and was very excited by this.

Sarah was very grateful I had noted that men were ‘interrupters’, and repeated how frustrated their interrupting made her. She felt that this prevented her from speaking for herself. She noted that she didn’t mind that she wasn’t paid for her work, because the government sent her a cheque every month. Sarah was also dismissive of discussions about intergenerational relationships. She did not know the age of her buddy or when the buddy’s birthday was, so she was not sure if the buddy really was much younger. When asked about perpetual childhood she noted that she was an adult, and listed a range of

activities that made her one: *“making the coffee, doing the laundry and folding my clothes, doing the dishes”*.

During the member check with Sienna, she questioned my use of the word stranger and suggested it was maybe the wrong word. She might use the word *“acquaintance”* to describe someone she just met. When discussing each point she attempted to ground my finding in a practical example before agreeing or disagreeing. Thus, when discussing gender divisions and a difference in gender expectations she said that this was so because they had told her at a class at her day program that this was how things were. The class was about social skills and self-expression – with her favourite activity being practicing making different faces.

Sienna identified most with the discussions of a perpetual childhood. She noted that this occurred most often when she got in trouble. She noted that she got into trouble for valid reasons but that the responses by assistants made her feel like she *“was two or three”*. She noted that staff were always watching her. She was coming to the conclusion that certain activities that got her in trouble should probably just be stopped because staff *“always find out anyway”*. It is useful to recall that Sienna is relatively new to Elkwood Heights. Sienna concluded the conversation with an expression of thanks and by expressing excitement about the upcoming photo exhibition.

Appendix 1 – Consent Form Template – Participation

Dear Sir or Madame,

My name is Christopher Longtin and I am a Master's student in Sociology at Carleton University. This letter is an invitation to participate in my research project titled *Left out of the Picture: Intersections of Gender and Dis/Ability*. My supervisor in this program is Dr. Janet Siltanen, also a member of the Department of Sociology. Our contact information can be found at the bottom of this letter.

The purpose of this project is to answer the question: What does gender mean to you? And what is gendered about the way you live? "Gender" refers to a person's understanding of how being a boy or girl, man or woman, influences how he or she acts or is expected to act. We will try to answer these questions through pictures and conversations with one another.

What will I have to do?

If you choose to participate in my project, you will do three things per month. First, I will provide you with a camera and ask you to take pictures based on a certain word. For example, the first word will be "Home". When your camera is finished, I will print the film and give you your photos. We will also meet and talk about your pictures. This meeting will take about 45 minutes. If it is ok with you, I will tape record this conversation so I do not forget it. I will also keep a second copy of your pictures to go with the tape recording. After we talk about your pictures, you can choose your three favourites. The next week, before community night, we will meet with four other Participants and share our favourite photos. We can talk with each other about what is the same or different. This will take about an hour. We will do this once in November, once in December, and once in January. If you decide you do not like the project you can stop at any time and decide whether I can keep a copy of your pictures and our conversations, or if they should be destroyed.

Because you will have taken so many good pictures, when we are done we will discuss whether or not we should have a show. We could invite your friends and family to come see the hard work you have done. We could also invite other Elkwood Heights members to participate and submit photography so you are not identified directly with the research.

Later in the year, I will meet with you one last time to explain what I have learned from our conversations. At this time, you can tell me what you think and I will put this in my project.

What will you do with my pictures and my answers?

The pictures you take, and the conversations we have, will help me in writing my master's thesis. A master's thesis is a big project I have to do for school. I may also try to submit a version of the thesis for publication in a journal. A journal is special type of magazine. This will ensure that people get to hear what you have to say.

I might want to print some of your pictures in my project. If I do this, we will have to get permission from anyone in the pictures and I will need you to sign a second form. We will also have to decide if there is anything in the picture we should hide. By signing this form, you are saying that I can use your pictures as long as I get this permission.

What are the risks and benefits of participating in this study?

Participating in this study offers minimal risk. We will be talking about the pictures that you have taken. Sometimes pictures make us feel good, and sometimes pictures make us feel sad. Sometimes we might have difficulty communicating with each other, which might make you feel frustrated. These situations might make you slightly uncomfortable. It is important to know, however, that we can stop at any time, take a break, or choose not to answer some questions. If there is a picture you do not like, we can throw it out.

My project will also have benefits. Sometimes the feelings and experiences of people go unnoticed. This makes people feel left out. Participating in this project will allow you to express yourself. It might also allow us to better understand why things are done in a certain way, or things we would like to change.

Will my identity be kept secret?

If I reference you in my project, I will use pretend names and pretend places. This will allow me to keep your identity confidential. Confidential means I will not tell anyone your name, or anything about you. This means you can share private information without people knowing you shared it.

However, sometimes when we look at pictures or read other peoples words, we guess who might have taken it. Because my project will be available in the library, and I might write about it in articles, it is possible that someone you know might read it and think it sounds like you. I will do as much as I can to keep you anonymous. Because of this, I will not use any direct quotations (what you say) or photographs without your permission.

Also, what we talk about will stay between you and me. Because of the camera, some people might know you are doing a project, but they will only know what you choose to tell them. Please note, however, that the law requires me to report any sign of abuse of specific groups, including people with disabilities in care.

When we meet with other participants, they too might share private information. Signing this form means you will not share their stories, and they will not share yours. I won't include your personal information in the final report or any other papers I write. Your name will not be attached to your answers. The tapes, notes and photos will be kept at my house in a locked box in a locked drawer.

Can I see the final results?

The final paper will be finished by September 2009. I will be meeting with you before to talk about the results and include your thoughts. If you would like a paper copy, you can request one at this time. If you decide later that you would like a copy, you can get one by emailing me at clongtin@connect.carleton.ca

If you have questions, please contact me, Christopher Longtin. My email and phone number are listed at the bottom of the page.

This research has been reviewed and received ethics clearance by the Carleton University Research Ethics Committee. If you have concerns or questions about being involved in this study you can also contact the ethics committee chair. The chair's name and contact information is as follows:

Professor Antonio Gualtieri, Chair

Carleton University Research Ethics Committee

Office of Research Services

Carleton University

1125 Colonel By Drive

Ottawa, Ontario K1S 5B6

Tel: 613-520-2517

E-mail: ethics@carleton.ca

Thank you for considering participating in my project.

I _____ (print name)
understand what the study is about and what I will have to do. I understand that I am
participating in a research project and I voluntarily agree to participate.

Participant's signature

Date

Researcher's signature

Date

Supervisor's signature

Date

Christopher Longtin
MA Candidate,
Department of Sociology
clongtin@connect.carleton.ca
613 520-2582

Supervisor: Dr. Janet Siltanen
Professor,
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janet_siltanen@carleton.ca
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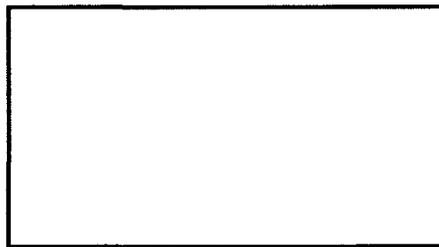
Appendix 2 - Consent Form Template - Publication Participant

Dear participant,

Thank you for all of your hard work in my project. Our conversations and your pictures have been very helpful to me.

Now that I have compiled my data and written my final report, I have come across a number of words and pictures that I think will better allow me to communicate my findings. As we discussed when we first met, sometimes when people who know us well read our words or see our pictures, they can guess who we are even if we use a different name. By signing this letter, you are saying that you are aware of this risk and that I can use these pictures in the publication of [...].

The pictures that I would like to use are:



Sample 1



Sample 2

If you do not wish me to use one of these photos, please cross it out.

If you wish something to be blurred, please circle it.

If you wish something to be removed, please colour over it.

The words that I would like to use are:

[quotation]

If there is a quotation you do not wish me to use, please cross it out.

Thank you again for all of your hard work.

I _____ (print name)
understand what these pictures will be used for and who will be able to see it. I
voluntarily agree to publication.

Participant's signature _____ Date _____

Researcher's signature _____ Date _____

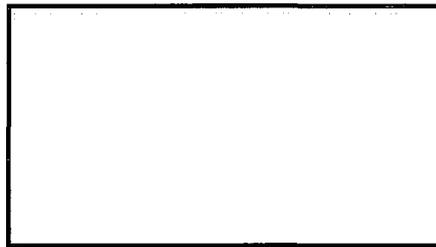
Supervisors signature	Date
Christopher Longtin	Supervisor: Dr. Janet Siltanen
MA Candidate,	Professor,
Department of Sociology	Department of Sociology
clongtin@connect.carleton.ca	janet_siltanen@carleton.ca
613 520-2582	613 520-2600 ext 2795

Appendix 3 - Consent Form Template – Publication (Identifiable Person)

Dear [subject of photo],

My name is Christopher Longtin and I am a Master's student in Sociology at Carleton University. My supervisor in this program is Dr. Janet Siltanen, also a member of the Department of Sociology. Our contact information can be found at the bottom of this letter.

As you are aware, [participant] has taken a picture of you for a project (s)he was involved in. This picture has proven very useful in my research, and I would like to include it in the final publication. That means this photo will become publicly accessible. Further information about the project can be read on the attached Letter of Information. The picture mentioned appears below:



Sample 2

This letter has two purposes. By including the photo, I am presented with the risk of [participant] being identified as a participant in the project. By signing this letter, you will be agreeing to keep [participants]'s participation in the study confidential. Secondly, you consent to my use of the photograph for this publication.

You will notice a third consent box at the bottom of this form. This box allows you to consent to the use of the photograph with certain alterations. You can list these alterations in this form, or use the included marker to circle any items you wish blurred or scratch out any items you wish blacked out.

Thank you for supporting ___ in his or her photography, and for considering allowing me to use these photos in my project.

I _____ (print name) understand that I am privy to information about _____ that places his or her confidentiality at risk. I commit to keeping _____'s involvement in this project confidential.

Subject's signature

Date

I _____ (print name) understand what this picture is to be used for and who will be able to see it. I voluntarily agree to publication.

Subject's signature

Date

I _____ (print name) understand what this picture is to be used for and who will be able to see them. I voluntarily agree to publication if the following alterations are made:

-
-
-

Subject's signature

Date

Researcher's signature

Date

Supervisors signature

Date

Christopher Longtin

MA Candidate,

Department of Sociology

clongtin@connect.carleton.ca

613 520-2582

Supervisor: Dr. Janet Siltanen

Professor,

Department of Sociology

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Appendix 4 – Participant Recruitment Schedule (Group)

Hi, Thank you for allowing me to make a brief presentation to the house tonight. As some of you know, my name is Chris and I'm a Master's student in Sociology at Carleton University. I'm here today to ask if any of you would be willing to participate in a project I have to do to school.

My project asks a big question: What does gender mean to you? And what is gendered about the way you live? "Gender" refers to a person's understanding of how being a boy or girl, man or woman, influences how he or she acts or is expected to act. We will try to answer these questions through pictures and conversations with one another.

So, first I will describe how I will try to answer the question and then I will give you an example.

So, I will attempt to answer the question through taking pictures and talking about them. Those participating in the project will take three sets of pictures (one in November, one in December, and one in January). I will provide you with a camera and ask you to take pictures based on a certain word. For example, in the example the word will be "School".

When your camera is finished, I will print the film and give you your photos. We will also meet and talk about your pictures. This meeting will take about 45 minutes. If it is ok with you, I will tape record this conversation so I do not forget it. I will also keep a second copy of your pictures to go with the tape recording. After we talk about your pictures, you can choose your three favourites.

The next week, before community night, we will meet with four other Participants and share our favourite photos. We can talk with each other about what is the same or different.

Now, this is important - if you decide you do not like the project you can stop at any time and decide whether I can keep a copy of your pictures and our conversations, or if they should be destroyed.

Because you will have taken so many good pictures, when we are done we will discuss whether or not we should have a show. We could invite your friends and family to come see the hard work you have done. We could also invite other residents to participate and submit photography so you are not identified directly with the research.

Later in the year, I will meet with you one last time to explain what I have learned from our conversations. At this time, you can tell me what you think and I will put this in my project.

The pictures you take, and the conversations we have, will help me in writing my master's thesis. A master's thesis is a big project I have to do for school – it is 100 pages long! I may also try to submit a version of the thesis for publication in a journal. A journal is special type of magazine. This will ensure that people get to hear what you have to say.

Participating in this study offers minimal risk. We will be talking about the pictures that you have taken. Sometimes pictures make us feel good, and sometimes pictures make us feel sad. Sometimes we might have difficulty communicating with each other, which might make you feel frustrated. These situations might make you slightly uncomfortable. It is important to know, however, that we can stop at any time, take a break, or choose not to answer some questions. If there is a picture you do not like, we can throw it out.

My project will also have benefits. Sometimes the feelings and experiences of people go unnoticed. This makes people feel left out. Participating in this project will allow you to express yourself. It might also allow us to better understand why things are done in a certain way, or things we would like to change.

If I reference you in my project, I will use pretend names and pretend places. This will allow me to keep your identity confidential. Confidential means I will not tell anyone your name, or anything about you. This means you can share private information without people knowing you shared it.

However, sometimes when we look at pictures or read other peoples words, we guess who might have taken it. Because my project will be available in the library, and I might write about it in articles, it is possible that someone you know might read it and think it sounds like you. I will do as much as I can to keep you anonymous. Because of this, I will not use any direct quotations (what you say) or photographs without your permission.

Also, what we talk about will stay between you and me. Because of the camera, some people might know you are doing a project, but they will only know what you choose to tell them.

Now, to provide you an example of what it is that we are doing, I have taken a camera and taken a bunch of pictures too. My pictures are of “school” – I’ve taken pictures of what is most important to me at school and chosen three to show you today.

So, for example, here is a picture of the library – I took this picture because the library is a place where I spend a lot of time. It's important to me because it allows me to learn new things. What I don't like about the library is that sometimes when I go there I feel disconnected from the world. I feel like I am in a bubble.

However, my office, which you can see in picture number two, is another place where I spend a lot of time writing and thinking. When I look at these two pictures, I realize that I think of my office as a much more lonely space because there is nobody around, even though I can use my cell phone. However, in the library, even though there are people everywhere – I feel disconnected because I cannot use my phone. This has led me to ask why two places that make me feel lonely and disconnected are so important to me.

And finally, this is a picture of the classroom where I used to work last year leading a discussion group. This is important to me because it was a very important part of my school – and it's a place at school that I don't feel lonely. It is a place where I met new people and encountered new ideas.

I noticed, however, that I took three pictures of rooms – and not of people – but the things I liked or did not like about these places were all about people.

What do you think?

So that is my presentation - do you have any questions?

So I am going to go, and let you think about my presentation. I will call tomorrow to see if you would like to participate, and to arrange a time to meet and start this project. Thank you so much for allowing me to share this with you, and I look forward to talking to you soon.

Appendix 5 – Sample Individual and Group Interview Schedules

A) Preliminary Interview / Camera Training (Individual)

R: Hi ____ . Thank you for choosing to participate in this project. Today I just want to review with you the project, talk a little bit about you, and play around with this camera. After we have done this, I will give you your own camera to take home. We'll also discuss the theme for this assignment and can brainstorm a little bit about what it means if you like.

R: Is it ok if I use the tape recorder so I can remember what we talk about?

R: And you know that we can stop at any time, take a break, and talk about something else if you want to.

R: I also want to remind you that everything we talk about here is confidential. Do you remember what confidential means?

R: Right, whatever we talk about stays between you and me. Nobody else will know what we talk about unless you tell them.

R: Is this an ok place to have this conversation? Can you think of any other places where we might

R: So.. what was it that made you want to participate in this project?

R: How long have you lived here?

R: Ok, so let's draw a comic strip about how you came to live here. What might we include...

R: Can you tell me about your house? Where you live?

R: How old are you?

R: Do you have any siblings?

R: Are you married?

R: What do you do during the week?

R: Hmm.. what if we try to fill out a calendar? Will that help? What might we include? Monday.. Tuesday.. etc.

R: What are some of your favourite things? Do you have any collections?

R: I would like to talk about the camera. Would you like to try?

R: Cool, how might our camera and comic strip go together?

B) Sample Personal Interview

R: Hi _____, how was your week?

R: Is it ok if I use the tape recorder so I can remember what we talk about?

R: I just wanted to remind you that we can stop at any time, take a break, or talk about something else if you want. You're the decision maker here. We can stop at any time.

R: How did you find this weeks assignment?

R: What did you like? What didn't you like?

R: Can we talk about your pictures?

R: What do you think about this photo?

R: Where was this photo taken?

R: When was this photo taken?

R: Why did you choose to photograph _____ ?

R: What is the main thing in this photo?

R: What is the happening in this photo?

R: If you had a magic wand what would you change about it?

R: When you were in this place how did you usually feel? What sounds did you hear? See? Smell

R: What did you like the most/least about this place / situation?

R: What do you think other people like about this place?

R: Do you think girls/boys older/younger like to do this in the same way? Why? Why not?

R: Can you choose your three favourite pictures? Why are these your favourites?

R: Are there any photos you do not like? Why?

R: If we wanted to use these pictures to tell a story about “the weeks theme”, how might we arrange them?

C) Sample Focus Group Interview

R: Is it ok if I use the tape recorder so I can remember what we talk about?

R: I just wanted to remind you that we can stop at any time, take a break, or talk about something else if you want. You are the decision makers here. I also wanted to remind you that the things we talk about here, and the stories we tell, are confidential. Do you remember what this means? So we keep each other's stories to ourselves and respect one another's stories.

R: So, to decide who goes first, we will choose a number out of this hat. Number one starts, number two goes second, etc. So that we can better see the pictures, I am going to project them on the screen.

R: So _____, do you want to go first? Can you tell us about this picture? Why it is important to you? What does everyone else like about this picture? What is your second picture...”

R: Looking at both _____ and _____'s pictures, is there anything we saw that was the same? Anything different?

R: Now we have seen three groups of pictures. We noticed that in _____ and _____ there was this similarity. Is it here too?

R: If we wanted to use these pictures to tell a story about “the weeks theme”, how might we arrange them?

R: So, I thought for the next project we might use the word “home/work/family”. What do you think of that? Do you have any questions about the camera? Do you want to participate next week

Appendix 6 – Short Description of Sample

- Aidan is a male in his forties who has lived within Elkwood Heights for close to ten years. His siblings enrolled him following a brief hospitalization and the deteriorating health of his mother.
- Caleb is a male in his fifties who began living in a group home environment approximately 30 years ago. It is unclear if he has been with Elkwood Heights for that entire time. Prior to residence in this environment he had been in an institution.
- Madison came to reside at Elkwood Heights following institutionalization. She is in her sixties and retired.
- Sarah is in her sixties and has a diverse residential history that includes a variety of group homes and a period of institutionalization.
- Sienna is in her thirties and has only recently taken up residence within the home and the Elkwood Heights' community. She was the youngest of the participants and provided an interesting insight into generational influences.

Appendix 7 – Final Members Check

What I found out about Home:

Spaces Shaping People

The spaces where we live and work appear to influence the relationships we have. This seemed particularly clear in our discussions. When we talked about home or work your conversations were often about friendship – even with people you did not know that well. But when we talked about new spaces and places – like the bus or the mall – it seemed like people were more likely to be strangers than they were to be friends. It seemed that where you met someone influenced your expectations of them.

A Collective Political We

It also seemed like all five of you were connected in shared experiences of disability. You had all been treated the same way because of it (Caleb/Madison institution) and seemed to identify and group yourself because of similar residences and experiences. You seemed to alternate between recognizing staff as ‘friends’ and recognizing that staff sometimes held an unequal power imbalance. Where you encountered staff seemed to make a big difference.

What I found out about Work:

Work / Home

I found it odd that there was such a disconnect between our conversations about work and our conversations about home. You made it clear that work was very important to you and provided an opportunity for empowerment and recognition. It seemed like work was important because it made you feel important. You described your job as one of significant responsibility and I found it troubling that you were not paid for it.

Authority

It seemed that relationships of authority “people who are the boss” existed mostly outside of your home and were often ‘faceless’ and ‘male’. I also read a sense of frustration with government from our talks. I wondered how you distinguished between policies set out by Elkwood Heights and those by the government – and if you ever felt that Elkwood Heights cited the government to justify decisions you did not like.

What I found out about Important People:

Internalization of Language and Behavior

In some of our discussions, it seemed like you recognized a difference between how you wanted to behave and how you are supposed to behave. You expressed this verbally and usually quite deliberately. I wondered how saying something out loud affected how you acted – and if by repeating what someone else said helped you to make it ‘true’.

I also noticed that there was a specific type of language engaged by Elkwood Heights that sometime carries over into how you see yourself or see others. I wondered how that language originated and how it shaped how you saw yourself. Do you think you have changed how you see yourself since moving in? Do you think if you did not fit in – they would ask you to leave/ would not have accepted you?

Family / Staff / Friends

I also found it unusual that so many of your friends (like --, your best buddy) were so much younger than you! What do you think of that?

It seemed like people that were important to you were people that empowered you (made you feel good about yourself) or that you were able to go out of the house with. What do you think?

What I found out about gender and disability:

Gendered Expectations

I found that there were some common patterns between the way men and women were seen. I found that men were often presented more often as “doers” – people you go do activities with. Women were often presented as “talkers” – people you have a conversation with.

I also found that there was a division of roles. Men were often described as more assertive, more outgoing, and often associated with more legal stuff – like guardians. Females were often associated with closed weekends and empowerment. Females were consulted for emotional things.

Gendered Space

It seemed that Elkwood Heights does not build gender into environments but that the expectations we listed above did inform the house. So, it seemed like men were responsible for certain things in the house that maintained those roles. I also noticed that all the girls had pink bedrooms and all the boys had blue bedrooms. I wondered what motivated those color choices?

Perpetual Childhood

There were times when I wondered if you were ever treated as a child as opposed to an adult and how that affected your relationships. It would seem to deny a

gender or sexual identity. You often reasserted your adulthood and I wondered how that affected how you saw yourself and affected your relationships with others.

You also seemed to refer to others that are the same age as you as older. I was curious why you did this.

Do you think that best buddies encourage this idea that you are young?

Gender Identities

There also seemed to be a difference between how seeing oneself as a man or a woman affected your behavior. Do you think that it is easier to be assertive, vocal, and political as a man than it is as a woman? Do you think this led the women in the study to be more reserved? Do you think this led the men in the study to be more represented?

Hierarchy of Impairment

It seemed that sometimes distinctions were made between different people based on what they could or could not do. Do you feel that at Elkwood Heights people with different needs are treated differently? Do you think that you/residents treat fellow residents differently? Do you think that this is fair?

I found that often because women were more reserved, they seemed to be referenced as less independent – what do you think of that?

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