Pictures, actions and words: Using photo elicitation to explore the lived experience of

outdoor recreation for a person with a developmental disability

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Abstract

The purpose of the research was to document the lived experience of outdoor recreation from the perspective of a 19 year old male with a developmental disability and to explore photo elicitation as a method of eliciting narrative from a person with communication difficulties.

Using a phenomenological framework guided by the social model of disability this research incorporated multiple data collection methods. Participant generated photographs and participant observations took place during a series of outdoor activities and were supported by formal photograph-based interviews with the research participant. Additionally, data gained from a formal interview with the research participant's mother, emails exchanged between his mother and researcher as well as a reflective journal kept by the researcher further informed the study.

The lived experience of outdoor recreation for the research participant emerged as a cyclical process involving anticipation before the activity, engagement and disengagement during the activity as well as recollection after the activity. Levels of engagement were moderated by the amount of autonomy the research participant had within the activity, the presence of people with whom the research participant had an established relationship with, and opportunities to photograph and interact with animals. Supporting the research participant, whose behaviours were sometimes atypical, within

the outdoor recreation activities required the research participant's family members and the researcher to negotiate a line of social acceptability involving context specific social norms that shifted during each outdoor activity. The line of social acceptability emerged as a primary factor in the integration of people with developmental disabilities into community based outdoor recreation programming.

This research concludes that outdoor recreation has the potential to provide engaging experiences for people with developmental disabilities within community based recreation programs provided their supports are able to negotiate the line of social acceptability. Photo elicitation provided valuable insight into the research participant's preferences, however, adhering to ethical photo elicitation guidelines required that the researcher assist the research participant while photos were being taken. Furthermore, interpreting the meaning of the participant's pictures, actions required some translation from his mother as well as supporting descriptive data from participant observations recorded during each outdoor activity.

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CHAPTER 1

Introduction

The end result of an outdoor recreation experience is often a life enriching story

(Patterson, Watson, Williams & Roggenbuck, 1998). It is a story that develops within

the experience (Lee & Dattilo, 1994) and creates meanings that can evolve and change

over time (Patterson et al., 1998; Watkins & Bond, 2007). Some of the meanings

associated with outdoor recreation experiences involve spirituality, self discovery and

connections with others (Loeffler, 2004) as well as closeness to nature and overcoming

the unique challenges presented in outdoor environments (Davidson, 2001; Patterson et

al., 1998). Qualitative accounts of outdoor recreation experiences and meanings are

becoming more prevalent for non-disabled people (Lee & Dattilo, 1994; Loeffler, 2004;

Patterson et al., 1998; Schmidt & Little, 2007). However, in-depth qualitative research

examining the experience of outdoor recreation for people with disabilities has been

very limited (Devine & O'Brien, 2007; Gibson, 2000; Rose & Massey, 1993).

In my two years of work developing and facilitating recreational activities in a

residential care facility for people considered to have severe and profound

developmental disabilities, I often wondered how outdoor recreation was experienced by

the people I served considering the amount of support and resources required for these

activities. Although the people I served expressed themselves in ways that were often

difficult for me to interpret, my co-workers and I were generally able to see that some of

the people greatly enjoyed outdoor recreation experiences and others did not. In searching for related literature and talking with various experts, I attempted to engage in the process of understanding how outdoor recreation was experienced by the people I served. Although there are some exceptions (Devine & O'Brien, 2007; Rose & Massey, 1993), it became apparent to me that little research attempted to engage in dialogue with people who have disabilities to examine the nature of their outdoor experiences.

Guided by legislation concerning the rights of people with disabilities, the last decade of outdoor recreation research has primarily focused on issues of accessibility, measuring preferences for natural areas and measuring the effects of outdoor recreation experiences on people with disabilities (Anderson, Schleien, McAvoy, Lais, & Seligman,, 2001; Brown, Kaplan & Quanderer, 1999; Burns & Graefe, 2007; McAvoy, 2001; McAvoy, Smith & Rynders, 2006). While research findings indicating that people with disabilities have preferences for outdoor environments and experiences that are similar to the rest of the population (Brown et al., 1999; Burns & Graefe, 2007; McAvoy, 2001) are valuable information, these types of findings raise a number of questions. For instance, when a study uses the term, "people with disabilities", what population is being referred to? Can these findings be generalized to people with all variations of both developmental and physical disabilities? How did the researchers account for variations in the cognitive abilities of their participants in their methodologies? What was the

social context of the outdoor experiences and how did these experiences unfold for the research participants?

Rationale

There are few studies that provide insight into how outdoor recreation is actually experienced by people with disabilities. These studies include a series of brief, focused interviews done by McAvoy, Smith and Rynders (2006), an examination of two mountaineering trips for people with learning disabilities (Rose & Massey, 1993), a study on the camping experience of a deaf/blind man (Gibson, 2000) and a study on the social aspects of an inclusive camp experience (Devine & O'Brien, 2007). I am unaware of any research that examines the lived experience of outdoor recreation for people with developmental disabilities that is primarily informed by the perspectives of people with developmental disabilities.

The value in examining the perspectives of people with disabilities is apparent in literature grounded in social constructivism (Devine, 2004; Devine & Dattilo, 2001; Devine & O'Brien, 2007) as well as the social model of disability (Coles, 2001; Pedlar et al., 1999; Tregaskis, 2004). Research has identified that there are social barriers to life enriching aspects of outdoor recreation activities for people with disabilities (Burns & Graefe, 2007; Devine & O'Brien, Dillenschnieder, 2007; Ewert, 1989). Furthermore, the experience of social barriers for people with disabilities and their supports within a

recreation context, including outdoor recreation, is located within the larger societal

construction of disability (Devine, 2004; Devine & O'Brien, 2007). Therefore, this

research provides insight into the larger social context of disability as it is negotiated

within the lived experience of outdoor recreation from the perspective of the person with

a developmental disability. "People with disabilities have experiences, by virtue of their

disabilities, which non-disabled people do not have…which are sources of knowledge

that is not directly accessible to non-disabled people.…Much of it would enrich and

expand our culture, and some of it has the potential to change our thinking and our ways

of life profoundly" (Wendell, 1996, p. 68-69). As an emergent, subjective and dynamic

experiential context (Loeffler, 2004; Patterson et al., 1998; Watkins & Bond, 2007)

outdoor recreation provides a unique venue in which to explore lived experience.

By examining literature that explores the process of conducting research with

people who have disabilities, it is apparent that engaging in this type of research process

is challenging (Finlay & Lyons, 2001; Kitchin, 2000; Knox, Mok & Parmenter, 2000;

Lennox et al., 2005; Rodgers, 1999; Stone & Priestley, 1996; Tregaskis, 2004;

Walmsley, 2001). A brief overview of these challenges includes overcoming various

barriers to recruitment and ethical issues inherent in working with populations that are

deemed unable to speak for themselves (Knox et al., 2000; Lennox et al., 2005; Rodgers,

1999), creating research relationships and modes of communication that facilitate

authentic data (Rodgers, 1999; Tregaskis, 2004) and using data collection and

dissemination methods that are congruent with the abilities of research participants

(Dyches, Cichella, Olsen & Mandleco, 2004; Finlay & Lyons, 2001; Kitchin, 2000).

Through a process of discussion, reading and reflection suggested by Moustakas

(1994), as the phenomenological technique for formulating questions and designing

research, I selected photo elicitation to address the challenges of creating and collecting

authentic data. The method of photo elicitation was largely informed by Photovoice

methodology which was developed as a tool to assist communities in documenting their

strengths and challenges through photography and critical reflection to facilitate social

change (Wang & Burris, 1997). Photovoice has been used with various populations in

the field of health care to document life experiences (Rampton et al., 2007; Thompson et

al., 2008) and has the potential to address some of the aforementioned challenges in

conducting research with people who have developmental disabilities.

Purpose

The purpose of this study is twofold. The initial intent is to gain insight and

understanding into the lived experience of outdoor recreation for a person with a

developmental disability from a phenomenological perspective grounded in the social

model of disability. The second is to pilot photo elicitation as a data collection technique

with the potential to overcome potential barriers to communication with people who have developmental disabilities. The questions guiding this study are:

1. What is the lived experience of outdoor recreation for a person with a developmental disability?

2. Is photo elicitation a useful approach for including the perspectives of people with developmental disabilities in academic research?

Operational Definitions

Outdoor Recreation

In this study outdoor recreation is defined as purposeful recreation that takes place in a nature based setting. The purpose for defining outdoor recreation in such a broad sense is to avoid assumptions inherent in narrow characterizations of outdoor recreation and allow research participants to select, participate and create meaning from experiences without classifying or making presumptions beforehand (Moustakas, 1994).

Developmental Disability

The meaning of developmental disability, from a semantic perspective, is "something in the way a person grows and changes over time that deprives him or her of developing the abilities to perform or accomplish specific things" (Brown, 2003, p. 19). People with developmental disabilities are characterized as "people with lower intellectual functioning who need some type of specialized assistance to carry out the practical and social activities of daily living." (Brown, 2003, p. 21). The reference to

lower intellectual functioning often results in the terms developmental disabilities and intellectual disabilities being used interchangeably (Brown, 2003). I have chosen to use the term 'developmental disabilities' as opposed to intellectual disabilities because often people who are diagnosed with various disabilities, such as Autism Spectrum Disorder, can still have a high degree of intellectual functioning but may require support in understanding social contexts or in communication (Brown, 2003). Furthermore, the term "developmental" has connotations that fit the social model of disability. While there may be specific biological traits that inhibit certain developmental processes, social structures can deny people with disabilities the opportunity to have experiences that non-disabled people have during their developmental phases, thereby inhibiting people with disabilities from reaching their full potential as human beings (Tregaskis, 2004; Wendell, 1996).

CHAPTER 2

Literature Review

To fully shape my perspective before conducting the research and to gain insight

into the broader context of developmental disability with respect to recreation and

leisure, I have chosen to examine literature that addresses several topics. In reading

leisure focused literature that documents the perspectives of families which include

people with developmental disabilities as well as literature that critically examines

community agencies providing supports for people with developmental disabilities, my

intent was to gain insight into the societal structures that people with developmental

disabilities rely on for support. The insight provided by this literature can be used as a

lens to view research regarding outdoor recreation and people with disabilities within

what is known about the social construction of disability. Lastly, an examination of

challenges in doing research with people who have developmental disabilities and a

summary of Photovoice methodology as a technique to overcome these difficulties is

presented.

Disability and Leisure

As published accounts of the outdoor recreation experience for people with

developmental disabilities are limited, it was necessary to examine literature exploring

leisure and recreation for people with disabilities to inform this study and provide

context. Literature that discusses leisure and recreation based on normalization and social role valorization suggests that people with disabilities have been denied access to valued roles in society through institutionalization and segregation (McGill, 1996; Hutchison & McGill, 1992). As opportunities for meaningful and satisfying employment are either absent or difficult to access, both physically and socially, for people with developmental disabilities (Pedlar et al., 1999; Wendell, 1996), leisure and recreation can become the central focus in their lives (Devine, 2004; Tregaskis, 2004). Therefore, leisure experiences and contexts have often been used to examine how people with and without disabilities socially construct and react to the concept of disability (Devine, 2004; Devine & Dattilo, 2001; Devine & O'Brien, 2007; Hutchison & Potschaske, 1998; Pedlar et al. 1999; Tregaskis, 2004).

Studies grounded in social constructivism (Devine, 2004; Devine & Dattilo, 2001; Devine & O'Brien) have used leisure contexts to understand the experience of the disability community's interaction within society. Leisure contexts elicit underlying issues that may be present in everyday life, suggesting that the informal role of leisure may be a better indicator of societal norms than work or education contexts. Devine (2004) found that varying leisure contexts could connect, distance or maintain neutrality between people with and without disabilities depending on how the people with disabilities were perceived and included in activities. Several of Devine's participants

discussed a hierarchy of disability, where some disabilities were perceived by non-disabled peers as being easier to accommodate, which is an indicator of how differing types and degrees of disability are rooted in a socially constructed value system (Wendell, 1996).

It is apparent from this brief review that people with developmental disabilities are currently reliant on various aspects of society to support them, whether it is physically, emotionally or socially, to actively participate in leisure activities (Hutchison & McGill, 1992; Pedlar et al., 1999). Most non-disabled people rely on support from various sources and agencies to develop as human beings, including family, healthcare professionals, the education system and public transportation system. While non-disabled people often take these forms of social support for granted, similar social support required by people with disabilities is viewed as either charity or a handout to compensate for being unable to perform at the level accepted by society (Wendell, 1996). Therefore, to examine the socially constructed disparities between the rights of the disabled and non-disabled, it is necessary to review literature based on two of the main societal structures supporting people with developmental disabilities: family and community based organizations.

Disability and Family

Studies examining the experiences and stories of families that include a person with a developmental disability provide insight into the negotiation of socially constructed values related to disability (Devine, 2004; Vanier, 1998). With this negotiation comes the process of planning and forethought required to structure life for the inclusion of a person with a disability. By examining the perspectives of parents supporting a person with a disability (Lassetter et al., 2007; Mactavish et al., 1997, Mactavish & Scheien, 2004; Mactavish et al., 2007) we can begin to examine both the struggles and joys associated with the current social paradigm which frames the relationship between society and people with disabilities.

Mactavish and colleagues (1997, 2004, 2007) have extensively explored the experiences of families that include a person with an intellectual disability. While families that support an individual with an intellectual disability do not, "inherently differ from other families, [they often have] unique and…extended…care-giving responsibilities" (Mactavish et al., 2007, p. 129). Family-based leisure activities that include a family member with an intellectual disability often require extra planning, well organized family scheduling and the ability to make accommodations for differing levels of ability within the family (Mactavish, Schleien & Tabourne, 1997, Mactavish & Scheien, 2004; Mactavish et al., 2007). The nature of these extended logistical responsibilities are adequately described by one participant in Mactavish and Schleien's

(2004) study on parents' perspectives regarding family recreation that include a person with an intellectual disability.

> Planning, planning planning! That's what it takes to get any family recreation activity going in our family – probably in any family with a kid with a disability. On the upside this is one way of making sure that everybody has a good time. On the downside, nothing is ever very spontaneous… (p. 132)

In their photo-based analysis of parents' experiences raising children with disabilities, Lassetter, Mandleco and Roper (2007) asked parents to reflect on what they did not photograph; through this study they elicited some important themes. Parents discussed the process of accepting that their child has a disability, concern for the future, joys and struggles unique to raising a child with a disability, balancing good and bad times as well as feelings that their child and family structure was more "normal" than not. The importance of relationships within the family structure is evident in photograph-based studies done by Rampton et al. (2007) and Dyches et al. (2004). In their studies, children with a disability and siblings of children with disabilities took more photographs of people, mostly family members, than anything else. The importance of family is characterized in the following two participants' comments, elicited by the photos:

"They're my family. I love them so much I can't stand it. " (Dyches et al., 2004, p.178)

"Because it's my Mom and she's one of my best friends. She's the one that I can talk to the most." (Rampton et al., 2007, p. 431).

Some families felt that the presence of a child with a disability separated them from society. For parents of children with autism, negotiating the service system and supports necessary for their child made them feel that they were living in a separate world from typical parents (Woodgate, Ateah, & Secco, 2008). In Grey (2002), parents of children with autism indicated that their children's embarrassing public behaviours, such as yelling and throwing objects, caused them psychological distress and separated them from their social relations. Grey (2002) noted that the power of social stigmatization, both felt and enacted, had a strong influence on the parents of children with autism.

In a study on perceived constraints to outdoor recreation for households that include a member with a disability, Burns and Graefe (2007) found that some, but not all, households were able to overcome constraints and participate in recreation at a frequency similar to households that did not include a member with a disability. In identifying that some households were able to overcome constraints and some were not, Burns and Graefe (2007) suggest that there is a need to understand the variables associated with the ability to overcome perceived constraints to outdoor recreation.

In the light of the aforementioned qualitative accounts of leisure experiences for families with disabilities, one of the variables associated with overcoming perceived constraints to outdoor recreation, as a form of leisure, is the perceptions of caregivers and supports. Within the larger social context, it is apparent that people with developmental disabilities currently require support and facilitation to fully participate in leisure activities. While this support is often provided by family members, there are also other venues within our societal structure designed to support people with developmental disabilities, such as community supports.

Disability and Community Supports

Many people with disabilities reside in either long term care facilities or in community-based group living accommodations and are supported by staff (Groce, 2006). In Dupuis et al.'s (2005) examination of community access recreation programs in long-term care facilities, it was evident that choice of, access to and participation in leisure activities was largely determined by the perceptions and mindsets of staff in charge of leisure programming. Staff stated that they felt residents participated in recreation primarily to relieve boredom and to fill time.

Hutchison and Potschaske (1998) documented the process of social change from the perspective of institutional recreation providers who were supporting residents as they prepared for deinstitutionalization and the resulting move into community living

contexts. After conducting interviews with recreation managers and staff, Hutchison and

Potschaske (1998) concluded that the process of social change meant to occur with

deinstitutionalization is more than a physical process but a state of mind involving open

communication, empathy, responding to peoples' needs and a continual effort to stay

motivated and flexible. With regards to people with intellectual disabilities moving into

community living arrangements, such as group homes, one community service manager

stated, "They are like institutions, smaller though, but still like institutions. I think there

needs to be another whole change process to deinstitutionalize group homes. "

(Hutchison & Potschaske, 1998, pp. 137). While the physical setting has changed, the

remnants of an institutional mindset remain embedded in the practice of service delivery.

One example of the institutional mindset is explored by Claire Tregaskis (2004),

in her profound and in-depth examination of the social interface between disabled and

non-disabled people in a community leisure centre. She found that the social services

staff providing leisure were regularly oppressive towards people with disabilities.

Despite a handful of exceptions, Tregaskis (2004) found that many leisure activities

were sedentary and diversionary where the role of staff was to monitor people with

disabilities and ensure that they remained "under control".

Hayden et al. (1996) conducted a study comparing the leisure activities of people

with intellectual disabilities who left an institution to live in the community to those who

stayed in the institution. The type and location of leisure activities between the two groups remained relatively similar: sedentary, in-house and segregated from the community. Rogers et al.'s (1998) study on the experience of leisure lifestyle in older adults with intellectual disabilities contained accounts of engagement and satisfaction in meaningful leisure experiences when group homes and institutions offered a wide array of recreational activities and provided choices. Pedlar et al. (1999) examined the nature of leisure related social relationships for people with developmental disabilities through in-depth interviews. Many of the respondents indicated that building social connections with both disabled and non-disabled people was often difficult because many aspects of their lives were controlled by the staff and administration of their community support system. As living, work, leisure and staffing arrangements shifted within the agency, people with developmental disabilities were often disconnected from valuable social connections that were developing in their lives.

In light of these findings (Dupuis et al., 2005; Hayden et al., 1996; Hutchinson & Potschaske, 1998; Pedlar et al., 1999; Tregaskis, 2004), it is apparent that much of the disability community resides in group living settings which may be separated, in some way, from society as a whole. While major institutions are disbanding into the community from a physical standpoint, the process of social integration through leisure is still dependent upon the support provided by staff. Therefore, the access to and quality

of leisure experiences for people with intellectual disabilities is tied to the perceptions

and constraints experienced by their community supports at both the administrative and

front line levels of service delivery.

Often, agency staff who support people with developmental disabilities

recognize the need to advocate for the people they serve, but are frequently overloaded

with a plethora of other responsibilities and, therefore, are unable to engage in in-depth

advocacy research and/or campaigns (Lennox et al, 2005). By gaining an understanding

how a person with a developmental disability experiences outdoor recreation and

potentially expresses his/her experience through Photovoice, this study is an attempt to

assist both people with developmental disabilities in advocating for themselves and

agency staff in gaining a greater understanding of the people they serve.

Outdoor Experiences and People with Disabilities

Lassetter et al. (2007) provides a starting point in narrowing the literature to

focus on outdoor leisure experiences for people with disabilities. When Lassetter et al.

(2007) analyzed photographs of elements that were meaningful in the lives of parents

with a child who has an intellectual disability, over half of the "active" activities

photographed were based in the outdoors. Furthermore, McAvoy (2001) suggests that

people with disabilities value, participate in and benefit from outdoor recreation just as

much or more than the general population. Burns and Graefe (2007) supplement this

statement in finding that the levels of interest for participating in outdoor recreation were similar in households that did and did not contain a person with a disability.

Sources of literature that support McAvoy (2001) generally attempt to document the effects of outdoor programming and experiences under the premise that outdoor recreation is a transaction providing benefits that contribute both to the process of social change as well as to the well-being and self motivation of participants with disabilities (Anderson et al., 2001; McAvoy, Smith & Rynders, 2006; Rose & Massey, 1993; Scholl et al. 2003). Scholl et al. (2003) found that a wilderness trip for families with an intellectually disabled child increased family cohesion and bonding, while helping families to see past their perceived constraints. Anderson et al. (2001) found that inclusive outdoor trip experiences resulted in social growth for both people with and without disabilities.

McAvoy et al. (2006) examined the effects of a wilderness training program designed for people with cognitive disabilities whose behavioural characteristics prevent them from being ready to participate fully in wilderness experiences. The participants, who had cognitive disabilities and required substantial accommodation, demonstrated growth in both social and task-related skills (McAvoy et al., 2006); however, qualitative statements that documented the experience of the program were largely provided by

staff, and thus the perspectives of the caregivers primarily informed the study as opposed to the participants with disabilities.

In focusing on the effects of outdoor recreation, the aforementioned research has generally bypassed documenting the experience and meanings associated with outdoor recreation from the perspective of people with developmental disabilities. One exception is Rose and Massey (1993) who examined mountaineering trips that included people with developmental disabilities and their support staff. They included the perspectives of people with disabilities and noticed that the challenging environment facilitated a role reversal where people with disabilities were supporting their support staff to continue climbing. Although the authors identified that outdoor adventure should not be referred to as "therapy" for people with disabilities, the focus of their conclusions remained oriented on the psychological and physical benefits and outcomes of outdoor adventure participation.

While there is a call for studies that shed light on how elements of outdoor programming affect greater inclusion (McAvoy et al., 2006) and how people with disabilities are able to overcome barriers to participation (Burns & Graefe, 2007), the use of qualitative data in outdoor studies has generally focused on supporting quantitative data that documents the effects of outdoor experiences (Anderson et al., 2001; McAvoy, Smith & Rynders, 2006; Rose & Massey, 1993; Scholl et al., 2003)

limiting the authentic perspectives of people with disabilities or necessary contextual

information (Devine 2004; Devine & O'Brien, 2007). Although this is not openly stated,

the effect based approach to research is indicative of philosophical assumptions inherent

in the medical model of disability where disability is considered a disorder or problem

that needs be changed or fixed (Bach, 2003; Wendell, 1996).

The social model of disability has also been used to examine the outdoor

recreation experiences of people with disabilities. As an alternative to the medical model

of disability, the social perspective towards the conceptualization of disability was

identified within early outdoor recreation research (Ewert, 1989; Hammitt, 1980; West,

1981) however the discourse remains relatively undeveloped. Using the social model of

disability shifts the focus of the research from how outdoor experiences change people

with disabilities to how the social structure and context of outdoor recreation

experiences can be changed to create a more physically and socially accessible

environment.

One of the sole examinations of social context with respect to outdoor recreation

from the perspective of both people with and without developmental disabilities is

Devine and O'Brien's (2007) study on the experience of inclusion in a camp setting. The

experiences of both non-disabled and disabled campers ranged from having fun and

making friends to weird and uncomfortable based on the variations in the leisure context

(Devine & O'Brien, 2007). The attitudes of both staff and non-disabled campers as well as the physical and social accessibility of outdoor activities had a large role to play in how disabled campers experienced the process of inclusion. These attitudes and experiences often shifted and changed over the course of the camp experience and thus the value of in-depth qualitative interviews in uncovering contextual variables in outdoor recreation experiences is apparent. Devine and O'Brien (2007) have provided valuable insights into how people with developmental disabilities experience inclusion from a social perspective and call for further research examining the experience of recreation and camp experiences for people with disabilities to improve programming and service delivery.

This research seeks to recognize the voice of people with developmental disabilities within the field of outdoor recreation research. People with developmental disabilities are legitimate research partners who should be informing the academic field along with the caregivers and family members with whom their lives and supports are intimately tied.

Challenges of the Disabled/Non-Disabled Research Relationship

As a non-disabled researcher studying the experiences of people with developmental disabilities, there are definite challenges to engaging in the process of research. In discussing these challenges, the intent is to shed light on both the social and

methodological structures that inhibit people with developmental disabilities from fully

engaging in the research process. Considering the amount of effort required for a non-

disabled researcher to gain access to people with developmental disabilities through the

organizations that serve them, I can imagine how difficult it might be for a person with a

developmental disability, served by these agencies, to gain access to a researcher for

their own purposes, as is the goal of emancipatory research (Kitchen, 2000; Knox, Mok

& Parmenter, 2000; Stone & Priestley, 1996; Walmsley, 2001). As indicated by the

previous statement, challenges arising in the process of conducting research with people

who have developmental disabilities revolve around issues related to recruitment,

informed consent, data collection, analysis and dissemination.

Since people with developmental disabilities are often not present in traditional

workplace or recreational settings, techniques of recruitment such as advertising and

posters are generally ineffectual (Lennox et al., 2005; Pedlar et al., 1999; Tregaskis,

2004). This situation is compounded by the fact that many people with developmental

disabilities are deemed unable to legally consent to participate in research projects and

require the consent of a designated third party (Lennox et al., 2005; Rodgers, 1999).

Therefore, access to people with developmental disabilities, for the purposes of research,

lies with both third party caregivers and/or organizations that serve people with

developmental disabilities (Lennox et al., 2005). Organizations that have access to

people with developmental disabilities can often block access to potential participants due to either an immense workload or administrative attitudes that are not congruent with the research objectives and/or methodology (Lennox et al., 2005; Rodgers et al., 1999).

In a descriptive self analysis of his research experiences with an organization serving people with disabilities, Colin Barnes (1992), describes how an organization's perceptions of a research project combined with personal connections within the agency are key factors in gaining access to environments that contain people with developmental disabilities. Within the proposal phase of my research, I spoke with eight different administrators at four separate organizations, and experienced many of the barriers presented in the aforementioned literature. As a result I ended up initiating the research through a personal contact as documented with my methodology.

Although the perspectives of both the researcher and organizations are important, research objectives must also be balanced with the views of the potential research participants. Disabled research participants, in a study done by Kitchin (2000), state that people with disabilities are often mistrustful of researchers due to previous research projects that have used unsuitable methodologies, misinterpreted data in analysis, failed to disseminate research in an accessible format as well as failed to create positive change as a result of the research. In addition, Tregaskis (2004) points out that people with

disabilities seem to take the privacy and confidentiality of research data pertaining to them more seriously than non-disabled research participants. She goes on to suggest that since the personal stories of people with disabilities often remain unheard and devalued, the written account of these stories is much more powerful to people with disabilities than it is to non-disabled people.

In designing a methodology and recruiting people with developmental disabilities, it is necessary to create a research environment where the research participants are able to comfortably discuss their thoughts and experiences on issues that are relevant to their lives. For individuals who are unable to communicate within a traditional interview format, participant observation of various behaviours and actions as communication has been used in numerous research contexts (Cocks, 2006; Rabiee, Sloper & Beresford, 2005; Spitzer, 2006).

Many people with disabilities that affect their cognitive functioning are deemed legally unable to consent to participate in research and thus a third party caregiver or guardian is required to provide consent to research participations (Lennox et al., 2005; Rodgers, 1999; Wiersma, 2003). This ethical procedure protects people with developmental disabilities who may be vulnerable and thus coerced into research, but it can also prevent people with developmental disabilities from participating in research that might be worthwhile for the potential participants based on the third party care

giver's perspective (Lennox et al., 2005). In developing both information and consent

forms, it is ideal for the researcher to develop and deliver forms that address the process

of research and ethical implications in a format that is suited to the abilities of the

potential research participants (Wang & Burris, 1997). To supplement written consent

both Rodgers (1999) and Knox et al. (2000) state that the concept of informed consent

should be ongoing throughout the process of research with people who have

developmental disabilities. Therefore, while gaining third party consent is necessary, the

assent of potential research participants is paramount throughout the entire time frame of

the research process.

Data collection procedures for research including people with developmental

disabilities have been examined extensively (Eckhardt & Anastas, 2007; Finlay & Lyons,

2001;Kitchin, 2000; Malik, Ashton-Shaeffer & Kleiber, 1991; Rodgers, 1999; Sigelman

et al., 1982). Initial research into interviewing techniques used with people who have

developmental disabilities are largely guided by positivistic frameworks that seek yes/no

answers or likert scale type responses (Malik et al., 1991; Sigelman et al., 1982). These

studies indicate that people with developmental disabilities have a tendency to acquiesce

to questions posed in an interview, in other words, they usually say yes or agree with

what they feel the researcher wants. A tendency to always pick the last answer when

presented a series of response options was also indicated (Sigelman et al., 1982). These

types of positivistic frameworks have been highly criticized by both critical disability researchers (Kitchin, 2000; Rodgers, 1999) as well as psychologists (Finlay & Lyons, 2001). The participants with disabilities in Kitchin's (2000) study stated that research questionnaires, "were often poorly presented, poorly conceived, limited their responses, and lead to a limited understanding of the subject which they seek to address." (p. 42).

Finlay and Lyons (2001) state that traditional methodological instruments, both qualitative and quantitative, used with the non disabled population are often inappropriate for people with developmental disabilities due to the abstract reasoning necessary in making quantitative scale judgments, answering socially reflective questions and providing reliable, valid data. It is interesting to contrast both Kitchin (2000) and Finlay and Lyons' (2001) articles; Kitchin's (2000) participants with disabilities felt that they were unable to give accurate responses within certain methodologies while Finlay and Lyons (2001) were concerned with the inability of certain methodologies to collect valid data. This distinction provides a window into how the social model of disability differs from more positivistic models.

Knox et al. (2000), Pedlar et al., (1999) and Rodgers (1999) all demonstrate through their research that people with developmental disabilities have the ability to reflect on issues and provide articulate, insightful answers to open-ended questions when provided with the appropriate methodological means. These means include qualitative

methods in the form of open ended questions that can be reframed or reworded to examine the phenomena from different viewpoints (Finlay & Lyons, 2001; Kitchin, 2000; Rodgers, 1999), using cues, such as photographs, to assist participants in reflecting on issues and responding to questions (Dyches et al., 2004; Rodgers, 1999), and developing a rapport with participants so that they feel comfortable telling their stories (Kitchin, 2000; Tregaskis, 2004). In essence, methodologies that "work" with people who have developmental disabilities seek not to prove or disprove theory but to assist people with developmental disabilities in telling their stories so that a wider audience can gain knowledge from their experiences.

Photo Elicitation

Using photographs as data to access the experience of research participants has been widely used in the social sciences (Collier & Collier, 1986; Hagedorn, 1994) and there are several texts published on the topic summarized by Harrison (2002). Despite its use in other fields of inquiry, outdoor recreation research has been slow to adopt the use of photography as a form of data elicitation, although the body of photo-based leisure literature is growing. For example, photographs as a means for visual analysis or as a catalyst to elicit narratives have been used to understand the social construction of photography for backpackers (Cederholm, 2004), elicit the meanings of outdoor adventure experiences for college students (Loeffler, 2004) and elicit meanings associated with tenting at an agricultural fair (Kyle & Chick, 2007). In doing what may

be the first photo elicitation based study on outdoor experiences, Loeffler (2004) states that, "photo elicitation proved to be a powerful tool." (p. 551). In discussing holiday and leisure photography, Pierre Bordieu (1990) states, "popular photography is trying to consecrate the unique encounter…between a person and a consecrated place, between an exceptional moment in one's life and a place that is exceptional by virtue of its high symbolic yield" (p. 36). In light of both Loeffler and Bordieu's statements, eliciting the meanings behind leisure-based photos has great value as a method for understanding the dynamic and contextual nature of outdoor recreation.

Photo elicitation has been used in health research to gain unique, insider insight into the perspectives of various populations in the fields of disability, mental health, nursing and health education (Dyches et al., 2004; Lassetter et al., 2007; Rampton et al., 2007; Thompson et al., 2008). Photovoice is a form of photo elicitation developed by social action researchers Caroline Wang and Mary Ann Burris (1994) and guided by Freirian principles (Freire, 2000). Photovoice is a community-based participatory action research method that "can affirm the ingenuity and perspective of society's most vulnerable populations"(Wang & Burris, 1997, p. 372) by highlighting and building on the strengths of these communities (Israel et al., 2003; Wang & Burris, 1997).

Critical reflection on community strengths and difficulties, as part of the Photovoice process, is used to create communication and dialogue with figures of power

as well as broader society as a means to affect change (Wang & Burris, 1994). While a critical view of how the disability community is positioned within society is necessary, the purpose of this study is not solely to be critical, but also to gain an understanding of and appreciation for, "what people [with intellectual disabilities] themselves regard as important in their lives and social or cultural worlds [and how this] may be different to how others...have viewed them" (Harrison, 2002, p. 94).

As a tool for understanding the meanings of leisure experiences for people with developmental disabilities, using participant generated photographs as data is ideal in that it transfers authority over the data from researchers to participants (Carlson, Engebretson & Chamberlain, 2006; Wang & Burris, 1997). By accepting that people with developmental disabilities are able to document, reflect on, communicate and analyze their own experiences (Dyches et al., 2004; Rodgers, 1999; Walmsley, 2001), this study is congruent with the social model of disability, which is concerned with shifting power from the 'expert' researcher to the participants (Kitchin, 2000; Knox, Mok & Parmenter, 2000). By combining suggestions from both reflexive and literature-based accounts of research with people who have developmental disabilities (Finlay & Lyons, 2001; Rodgers, 1999), it appears that using open-ended interview questions that allow for rephrasing and comprehension prompted by visual cues such as photographs (Dyches et al., 2004; Rodgers, 1999) is one of the most effective methods for collecting

authentic data. Photo elicitation is a research method that combines open-ended interview questions with photographic cues. It is designed to move toward comprehension through meaningful interactions with the person participating in the research (Wang & Burris, 1997), and therefore meets the criteria for an effective methodology with regards to this study.

Theoretical Framework

The concept of lived experience is derived from the phenomenological approach to scientific inquiry (Creswell, 2007, Moustakas, 1994; van Manen, 1997). The aim of phenomenological research is to, "transform lived experience into the textual expression of its essence" (Van Manen, 1997, p.36). Phenomenology rejects the notion of an objective reality that is experienced by all people and suggests that the meaning of an experience is married to the subjective interpretation of that experience by the individual experiencing it (Patton, 2002). While there is a universal order to the structures which mediate human experience, each individuals experience is infinitely unique within those structures. By attempting to avoid presuppositions inherent in theory driven, positivistic studies, a phenomenological approach creates an opportunity to capture the lived experience of a person or group of people through the rigorous analysis of individual experiences and an amalgamation of thematic elements (Patton, 2002; Van Manen, 1997). Phenomenological methods create the possibility of gaining access to the lived experience of outdoor recreation for a person with a developmental disability through

the elicitation of his/her interpretations and recollections of this experience (Patton, 2002). Through textual, thematic analysis of the research participant's accounts of their experiences, insight can be gained into their lived experience and related to the collective reality of the outdoor recreation experiences for people with developmental disabilities. However, to do this it is also necessary to thoroughly examine the nature of language and communication for the group of people involved in the study (van Manen, 1997).

The epistemological foundation of this study is rooted in the social model of disability where 'disability' is considered as a subjective phenomenon socially constructed by, "the legal, social, economic, and political structures that calculate value and status on the basis of difference" (Bach, 2003, p. 34). The implications of using the social model in a phenomenological study are that the research relationship is a partnership between the participants and the researcher (Stone & Priestley, 2001; Walmsley, 2001). In this study the participant shares his/her experiences (Stone & Priestley, 2001) with the researcher and together they develop a methodological technique to share the participant's reality with a wide audience with the intent of affecting social change (Kitchin, 2000).

CHAPTER 3

Methods

This research involved several phases that are informed by phenomenological

guidelines found within the literature of Moustakas (1994) and van Manen (1997). The

methodological framework for photo elicitation was primarily informed by Wang and

Burris (1997). A brief overview of the study, covered in this section includes: recruiting

a participant, ethical procedures, photography training, data collection, data analysis

procedures and dissemination.

Recruiting a Participant

Initially I attempted to recruit participants from local organizations who provided

recreation services for people with developmental disabilities. However, I experienced

difficulties similar to those expressed by Lennox et al (2005). Some of the issues I

experienced include:

- Lack of time and resources to facilitate research participation

- Administrative barriers to accessing research participants such as staff

  changeover and complex communication structures

- Inability to support outdoor recreation activities within the service model

  framework

After contacting several organizations I called the parent, Sabrina, of a young man,

James, with a developmental disability that I knew personally. I asked if they would be

willing to participate in the research. Sabrina was interested in the research for several reasons:

- Her son was interested in outdoor activities and this was a chance to try some new things.

- He was 19 years of age and is therefore one year over the cut off age, 18, to participate in local, specialized summer recreation programming.

- She was interested in finding out about how her son would communicate and what we would learn through the process.

When I received informal agreement from Sabrina I sought and obtained ethical approval for the study through Lakehead University. I then set up a meeting with Sabrina and James to formally discuss the study and seek informed consent and assent.

Ethical Procedures

One of the ethical considerations arising from this study included the process of informed consent and assent with a person who has a developmental disability (Cocks, 2006; Finlay & Lyons, 2001). While James' parent, who is considered by law a third party caregiver, was the only person would could legally consent to his involvement in the research I wanted to ensure that James understood the research process and assented to participate in the research.

During my first formal meeting with James and Sabrina, after obtaining ethical approval, I presented the research verbally (see Appendix A) as well as in written format (see Appendix B & C). I then presented a consent form to James' parent Sabrina (see Appendix E) and an assent form to James (Appendix D). The assent form was identified by Sabrina and I as being too complicated to meet James' cognitive needs (Wang & Burris, 1997) and so I verbally and experientially went through the research process with James. I told James that we would do activities together outside and that he would take pictures during the activity and we would look at the pictures and talk about them later. I conducted a brief experiential activity that involved taking a picture of something that was important to him and then both showing and describing the picture to me (Dyches et al., 2004). I then proposed that we do a trial run of the entire research methodology so that James could experience each part of the research as a component of informed assent. If he was willing to participate in each component of the research then I would interpret this as assenting to participate (Cocks, 2006; Morris, 2003; Spitzer, 2003). Sabrina, James and I agreed to go on a hike around his neighbourhood for this trial activity.

A few days after the formal meeting, James, Sabrina and I conducted the trial activity. During the trial activity, James took both independent as well as prompted pictures of things during the walk. Pictures were uploaded onto a laptop and I conducted the interview with James while Sabrina sat close by and watched, sometimes helping

James to communicate. The interview process involved James using a mouse to click through his pictures, one at a time, on the computer in a slideshow format and when he stopped on a picture we talked about it. I audio recorded the interview and let James listen to a portion of the audio recording so that he was aware that he was being recorded and that I could listen to it again. After going through the entire research process with James, I felt that I had obtained his informed assent.

After obtaining James' informed assent, I presented a list of outdoor recreation options available in the community with dates as well as the associated costs to both Sabrina and James. I asked them if there were any outdoor recreation activities that they already participated in that could be used for the study. Due to James' age he was too old to participate in his traditional summer programming, therefore we selected activities solely from my list of options. After discussing the types of activities that were available and that James would be interested in we selected horseback riding, kayaking, canoeing and rock climbing.

Issues addressed within the verbal and written consent/assent process involved discussing the use of pictures in public dissemination of the research data (Wang & Redwood-Jones, 2001). Sabrina and James identified that the pictures taken during the study were not 'private' pictures and this was considered as assent and consent. Due to the fact that James was one participant, I was unable to provide assurance of anonymity

as both the participant and I participated in various group activities in the outdoors. All

data used in this study was kept strictly confidential and only viewed by me. With the

exception of presentations where both the participant and parent are present,

pseudonyms were be used to disguise the names of participants in all forms of academic

and professional dissemination.

Photography Training

Part of typical Photovoice training, as a form of photo elicitation, involves

discussing the care and use of cameras as well as the ethical issues inherent within the

methodology (Wang & Redwood-Jones, 2001). I adapted these guidelines to suit this

study. The ethical issues are:

- Obtaining the consent of people who were not participating in the research

  before taking their photograph.

- Safety concerns overrode the importance of the study. Whenever a choice needed

  to be made between meeting research objectives and safety concerns, safety

  always prevailed.

- Understanding that photographs taken by a research participant belong to

  him/her and that the researcher was borrowing them for the research.

Before the start of each outdoor activity within this research, James and I would inform

all of the program participants about the nature of this research. We would then provide

consent forms (Appendix H) to program participants who were willing to be photographed. Traditionally, within Photovoice methodology, the research participant approaches a potential subject with information and obtains consent before taking their photograph (Wang & Redwood-Jones, 2001). I was unable to find a way to adequately describe this ethical procedure to James in a way that translated into awareness on his part. Therefore, to address the issue, I chose to inform all program participants about the research before the activity began. As a result of this procedure, there were two pictures which accidentally contained identifiable subjects who had not consented to be photographed. These two pictures were not used in the study.

To address the care and use of cameras, I provided James with a waterproof and shockproof camera. At the start of each activity I would set the camera up to compliment the light conditions and he was well versed in taking pictures with a digital camera. Towards the end of the research he reviewed his pictures on the camera to see if the picture he had just taken was to his liking.

Data Collection

Data collection occurred over July, August and September, 2008, in several forms: participant photography, participant interviews, participant observations in the form of field notes, a formal interview and email correspondence with James' mother and my personal reflective journal. During the data collection period, James and I participated in

several outdoor activities lasting from one to five hours. They were, at times, accompanied by members of his family. The activities are not listed in the order they occurred.

- Two sessions of horseback riding both accompanied by his mother

- Two sessions of kayaking both accompanied by his sister

- One session of canoeing

- One session of indoor rock climbing accompanied by his mother

- One session of outdoor rock climbing accompanied by his mother

James had no previous experience with any of the selected activities.

Participant Photography

James took photographs during each activity with an Olympus Stylus 790SW digital camera attached to a sling around his neck. During the first three activities Sabrina and I would prompt James to take pictures at various times. I would use the prompt, "Is there anything here you would like to take a picture of?" a couple of times during the activities and at the end of the activity I would ask James if there was anything he would like to photograph before we went home. After the fourth activity, Sabrina and I realized that James was taking pictures on his own without being prompted. Consequently, we both stopped prompting him to take pictures. I made note of which photographs he took independently and which photographs involved prompting

in my field notes. At the end of each activity I retrieved the camera from James and review his pictures to ensure that he had not accidentally included and identifiable picture of someone who did not consent to be photographed during the activity.

Participant Observation

During each outdoor activity, I acted as a participant observer collecting data in the form of field notes both written and dictated on a digital voice recorder. I observed and took field notes in point form during the activity in order to be as present as possible during the outdoor experience (Moustakas, 1994). Immediately after each activity I rewrote the field notes in more detail.

Field notes were guided by a sensitivity framework (see Appendix I) and contained descriptive information on the physical and social setting, the activities that took place during the experience and direct quotations from James and his mother (Patton, 2002). The intent of these observations was to gain access to the physical and social context of James' lifeworld (van Manen, 1997) by participating in the experience alongside. While the role of being a full participant is limited, in that the researcher is non disabled, there is value in the contextual data and reflections taken from an outsider's perspective (Patton, 2002; Stone & Priestly, 1996). For documenting the communication of people who do not primarily use speech for communication, participant observation has been identified as an effective research method for creating

dialogue that could not take place during interviews (Cocks, 2008; Morris, 2003; Rabiee,

Sloper & Beresford, 2005; Spitzer, 2006).

I also used a reflective journal alongside my field notes to document insights,

interpretations, feelings, thoughts and emotions as the data collection process unfolded

(Patton, 2002). I used the field notes and reflective journal to provide contextual data,

account for and documenting personal reflexivity, as well as to guided the interview

process (Patton, 2002).

Individual Interviews

One to two days after each outdoor activity I conducted an interview with James in

his home, based on the photographs that he had taken. I uploaded his pictures onto my

lap top computer and created a slide show for him to view. After the first two interviews

James referred to me as "Andrew, black computer" and helped me set up the computer

and plug in the computer mouse. James used the mouse to look through his pictures and

answer interview questions (Appendix F). I asked interview questions when he stopped

on a certain pictures using a semi-structured, flexible interview format (Dyches et al.

2004; Finlay & Lyons, 2001; Rodgers, 1999; Rogers et al., 1998; Wyngaarden, 1981). I

often altered, rephrased or omitted questions (Finlay & Lyons, 2001; Rodgers, 1999) in

an attempt to assist James in understanding the question or to avoid frustrating him with

a question he could not answer. James was able to direct how long he talked about a

picture by switching the picture when he had finished talking about it. During every interview he went through all of his pictures several times, including any pictures from past activities. During the interviews I had a set of picture symbols depicting emotions to potentially use as an aid (see Appendix J); however when I pointed them out to James he simply read each emotion out in the order they were shown on the page and so it was not an effective tool for eliciting data. The interviews were audio taped on a digital voice recorder to document James' unique narrative style and assisted in recalling exactly what was said during the interview (Finlay & Lyons, 2001; Lennox et al., 2005; Rodgers, 1999).

Formal Interview and Email with Parent

Email correspondence between Sabrina and I occurred throughout the research either for organizational logistics or to share something that James had expressed when the other person was not present. Reflective journal entries occurred throughout the research. Finally, I conducted a formal, audio recorded interview with Sabrina three weeks after James and I finished the last outdoor experience to gain her insight into how James expressed himself with respect to his outdoor activities.

Analysis

Analysis of the data was guided by both Moustakas (1994) and van Manen (1997). I used both because I found that the processes of epoche and bracketing (Moustakas, 1994) were necessary in documenting and working around my personal

reflexivity, similar to Forster and Iacono (2008). The existentials of lived experience contained within van Manen (1997), lived time, lived space, lived body and lived relations, provided theoretical guidance in regards to the structures of lived experience as mediators of the thick descriptive components, or texture, of lived experience. Data analysis consisted of several phases: organizing, epoche, bracketing, horizonalization, imaginative variation and synthesis

Organizing

The first part of collaborative analysis was when James analyzed the data by focusing his attention and responses to key photographs during the individual interviews, essentially sorting and picking out important parts of his experience.

After all the individual interviews were conducted, I personally transcribed all of the audio recorded interviews verbatim to familiarize myself with the data as well as to account for the unique characteristics of the interview data (Finlay & Lyons, 2001; Patton, 2002; Rodgers, 1999). I organized the transcripts by date and activity and matched each transcript with the corresponding field notes, reflective entry, photographs and email correspondence. After transcribing and organizing the data, I read through each transcript twice and made preliminary codes and margin notes out of anecdotes or statements related to the phenomenon of outdoor experiences (Creswell, 2007; Moustakas, 1994).

Epoche

Engaging in the process epoche, as described by Moustakas (1994), requires recognizing one's personal philosophy as well as personal and political stances so that they can be transcended before analyzing components of lived experience. What follows is a textual account that I wrote during the process of epoche to document and recognize my personal and political stances.

Personal

As a recreation provider working in long term care for people with severe and profound developmental disabilities, I spent a substantial amount of time trying to organize meaningful leisure and communicate with people who were non-verbal and often had unintelligible facial expressions. Through the support of staff and management I was able to organize and participate in several outdoor based vacations with some of the people I supported. These were quite profound experiences for me and a chance to live alongside people who regularly see multiple staff rotations, nurses, medications and various sorts of therapy within a single day. I believe that people with developmental disabilities, no matter how profound, can communicate, make choices and participate in society, but the idea of 'inclusion' requires a greater societal paradigm shift than often is assumed.

Political

From a political standpoint, my intent with this project is to introduce the social model of disability, or emancipatory paradigm of research to the field of outdoor recreation. The contents of seminal journals in the outdoor recreation industry such as Journal of Experiential Education, Adventure Education and other sources have not yet embraced this paradigm. The numerous articles on methodologies for conducting research with people who have disabilities seems to generally be ignored, and thus, research and education for outdoor professionals with respect to inclusion and disability is substandard.

Undergoing the process of documenting my personal and political agenda, to truly understand where I am oriented was profound in that I could transcend or leave that viewpoint and attempt to engage, to feel, to experience James' lifeworld as best I could. As I engaged in the process of epoche it became increasingly apparent that despite many data sources, despite all the research time and effort involved, I could only get a bare glimpse into the richness of the research participant's lifeworld. I would describe it as being similar to viewing a painting where the painting is the data or expression of the artist's experience. Through that painting one can glimpse the complexity of the artist's mind and perspective, but never understand the whole: although perhaps we are not meant to.

that is less clouded by personal biases (Moustakas, 1994). The process of epoche is not confined simply to one stage of the data analysis process, but must be continually engaged in throughout each step (Moustakas, 1994). Using epoche allowed me to engage in the process of bracketing and provided a strong orientation towards James' experiences.

Bracketing

Although described by Moustakas (1994), Patton (2002) provided an important insight into the process of bracketing. Husserl, one of the pioneers of phenomenology and conceptual originator of bracketing, was primarily a mathematician (Patton, 2002). When using bracketing in a mathematical equation, the focus is on the equation contained within the brackets and everything outside of the brackets is ignored until the work within the brackets is completed. Therefore, bracketing when combined with epoche involves placing brackets around the data describing James lived experience and ignoring issues outside the brackets including personal and political preconceptions documented within the process of epoche (Patton, 2002).

I found that bracketing was a constant process during analysis. Often my preconceptions would frame the data and I would begin to develop a theme that had little to do with James actual experience. At times I would develop a theme based on an assumption only to bracket James experience and realize that I had created a potentially invalid theme.

Horizonalization

As a process of phenomenological reduction, horizonalization, involved describing the texture of James' lived experience and continually moving between description and reflection until new horizons of experience began to appear (Moustakas, 1994). Through each reflection and description, inherent meanings within the data shifted and new horizon of meaning would unfold. According to Moustakas (1994) there are limitless horizons to an experience, thus that we can never find them all. One important aspect of horizonalization is to consider each horizon as similar in value, that each horizon is equal as a component of lived experience

The process of horizonalization began by examining and sorting James' pictures based on the interview transcripts. I also listened to each interview to capture his affect when speaking about the pictures. I thematically coded each grouping of pictures as related to the phenomenon of James' lived experience of outdoor recreation. I used the codes derived from data directly obtained from James to examine through the process of open coding the field notes, parental interviews and email correspondence while allowing new themes related to the social context surrounding James to emerge. After creating a list of themes I reduced each theme into a broader categorical framework, or horizon of meaning, that served as a classification scheme to further examine the data (Moustakas, 1994; Patton, 2002). The classification scheme was used to start writing

thick, textural descriptions of James' outdoor experiences within each identified horizon

of meaning.

Imaginative Variation

The process of imagination variation involves examining each thematic aspect of

lived experience to explore its varied meanings (Moustakas, 1994). To guide

imaginative variation I examined each of my identified horizons of meaning within the

structural framework of van Manen's

(1997) existential: lived body, lived

space, lived time and lived relations.

The process of imaginative variation

was less of a structured recipe and

more of a guided, repetitive process,
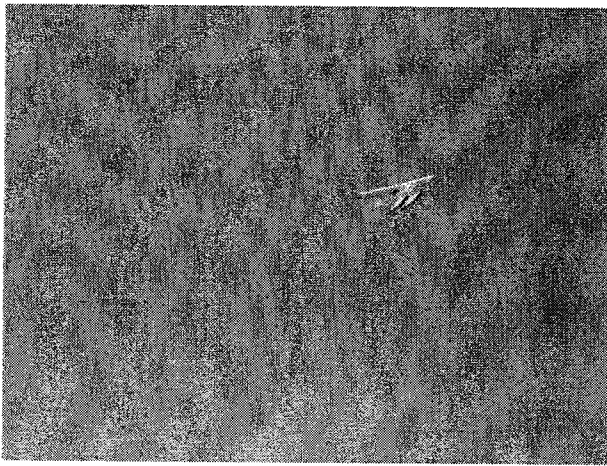
Figure 1. Picture of a float plane

shifting between texture and structures,

imagining variation and constantly attempting to remain bracketed. For example, a

picture of a float plane (see Figure 1) similar to the plane within one of James' favorite

movies, *Alaska,* took on meanings through imaginative variation. These included: a love

of planes, the ability to accurately and independently document things of importance in

his life, living the reality of a favorite movie and learning to communicate through

media. Often movies would assist James in bridging the gap between the world inside

James' mind and the world experienced by nondisabled people through learning new

phrases and ways to express himself. The plane was a representation of these meanings explored through imaginative variation.

Synthesis

The final phase of analysis was synthesis. Synthesis involved combining the texture and structure of James' lived experienced into an expression of its essence. Through the process of imaginative variation and horizonalization I had written textural descriptions of James lived experience within the structures of human lived experience using van Manen's (1997) existentials. Through phenomenological reflection, writing and rewriting (van Manen, 1997) I used both structural and textural descriptions in combination to narrate the essence of a phenomenon using both what was experienced as well as how it was experienced (Creswell, 2007). During the writing of the thesis I conducted three member checks (Creswell, 2007) with the third party caregiver. The first was conducted during theme development, the second was conducted once the themes were complete and another when the initial draft of the thesis was complete to ensure that I was portraying the lived experience as accurately as possible.

CHAPTER 4

Discussion

The purpose of this research was to gain insight into the lived experience of outdoor recreation for a person with a developmental disability and also to explore photo elicitation as a method for including the perspective of a person with a developmental disability within the research process. To present and discuss the findings of this research I will discuss my *analysis and interpretation* of the research data that resulted in the creation of thematic elements related to James' lived experience of outdoor recreation: The Self, Phases of Outdoor Recreation, The Social Line of Acceptability, Relationships/Support and Autonomy. Each thematic element is then discussed through an integration of both research data and theory.

Analysis and Interpretation

One of the main issues during this research was to ensure that James' voice was the primary voice informing the development of themes and results. However to examine the social context within which James experienced outdoor recreation I often relied on data that was not directly provided by James to understand how the social context shaped his lived experience. I am unsure to what extent James was aware of the social context and norms that surrounded him but I observed that they impacted his lived experience, both directly and indirectly.

Through repetitious examination of pictures, interview transcripts and direct quotes from my field journal I reduced a long list of potential themes down to three core elements: animals, his social relationships and his level of engagement in each individual outdoor activity. When I began to incorporate my participant observations, field notes, reflective journal as well as interview and email data from James' mother, Sabrina, two indirect themes became apparent: social gaps related to socially constructed differences between people with disabilities and the non-disabled and my own methodological learning in relation to the research relationship shared between myself and the family.

After developing an initial set of themes I began to write and rewrite descriptions of how various horizons of meaning relate James' outdoor recreation experience to theory. During this process it became apparent through phenomenological reflection (van Manen, 1997) that each thematic element fit within the components of van Manen's (1997) lifeworld called existentials. The four existential components of lifeworld make up the shared aspects of human lived experience and relate closely to what Moustakas (1994) describes as the structures of lived experience. The texture or detailed description of experience fits within the structures of human experience (Moustakas, 1994) which van Manen (1997) characterizes as existentials of the lifeworld. These existentials are named lived body, lived time, lived relations and lived space.

The existential of *lived body* refers to the corporeal body as a mediating factor in lived experience (van Manen, 1997). As I wrote and reflected I found that the human body contains within it personality and character that seemed dampened and unrealized by simply discussing it within the body. Also, despite my observational data, I could not assume to provide a thick description of how James experienced outdoor recreation through his body because he could not tell me. I wanted to provide the reader with what James shared of himself and how that could be interpreted, since in some cases, interpretation is all both his mother and I could do to understand his experience (Ferguson, 2000).

The existential of *lived time* provided an opportunity to explore how James experienced each activity through his behaviour and communication in the time before, during and after each activity. Within the existential of *lived relations*, social aspects such relationships with his family, myself and others, as well as communication and social gaps could be explored as they are all a component of people living in relation to each other. The existential of *lived space* provided the framework for exploring the factors that mediated James' experience within various environments.

The results of this research include five separate themes considered horizons of

meaning within phenomenological studies (Moustakas, 1994). These themes are The
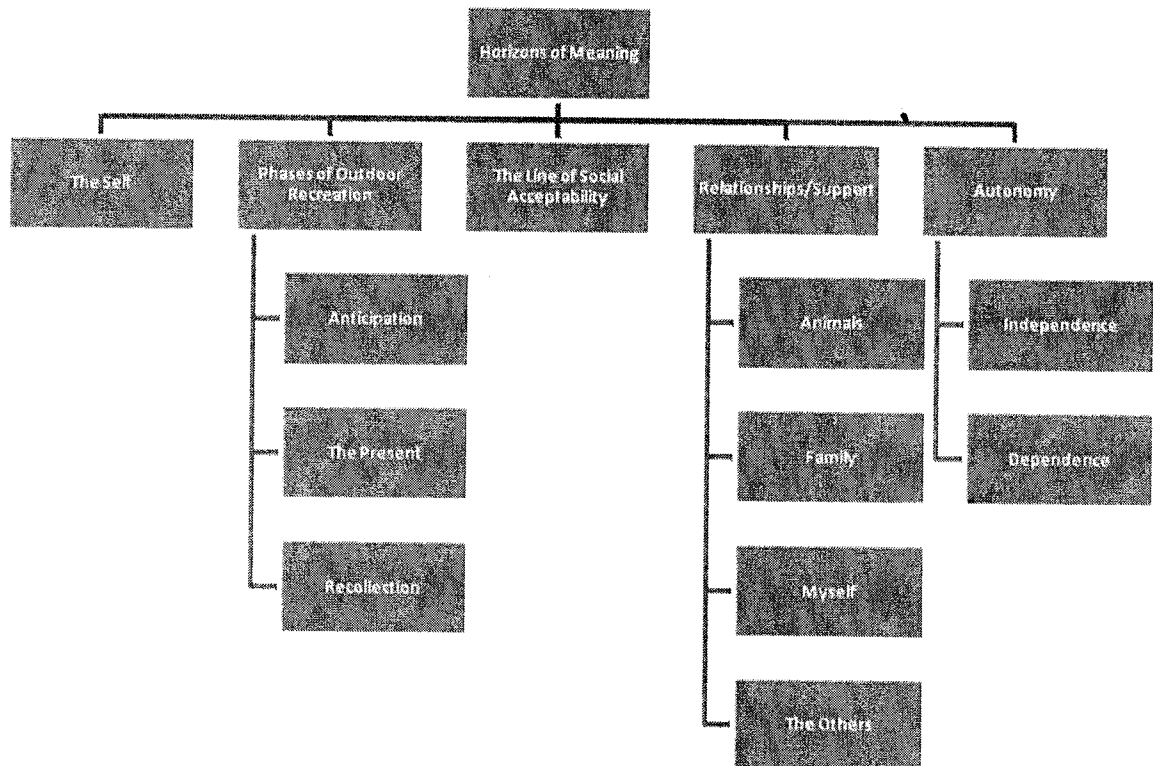
Figure 2. Research Themes

Self, Phases of Outdoor Recreation, The Line of Social Acceptability,

Relationships/Support and Autonomy (See Figure 2).

While initially I developed the themes solely from interpretations of James'

pictures, words and actions they became richer and more complex as I integrated field

notes, reflective journal entries as well as formal interview and email data from his

mother, Sabrina. The result is a discussion and exposition of results that I wove together

using all sources of data as well as academic research to describe the results of this

research within a tapestry of theory and data.

The Self provides insight into the type of person James is as well as how he

communicates and the challenges he faces on the road to adulthood within the social

context of the study. I used James' photographs (Figure 2 & 11) combined with

background information from Sabrina and observations of James' behaviour gained

from my field notes to provide the reader with a snapshot of James' personality as the

basis for presenting horizons of meaning based on his experiences.

The Phases of Outdoor Recreation were initially inspired by examining the

content and amount of photographs James took during an activity and combining it with

observations of his behaviour from my field notes and his affect during the interviews.

During some activities James seemed disinterested and took very few pictures. "James

seemed quiet throughout the ride....Quiet and he was looking around at the ground near

him" (Field notes, August 9). During other activities James was excited and talkative

and took quite a few pictures. "Once in boat, he was talking away...'Hello', 'It's hot',

'Wait up' (he was really excited)" (Field notes, August 12). As I began to explore the

differences in James' affect, which I characterized as engagement, Sabrina informed me

of situations where James had discussed both looking forward to future activities as well

as experiences from previous activities that he enjoyed. His anticipation and recollection

of activities related strongly to his observed level of engagement during activity and therefore the Phases of Outdoor Recreation seemed a suitable descriptor for discussing the cyclical process of James' outdoor recreation experiences.

The Line of Social Acceptability as a horizon of meaning began when Sabrina suggested during our first meeting that "Some parents wish their child [with a developmental disability] would disappear, they do what is easiest" (Field Notes, July 22nd). Sabrina's statement indicated to me that there were difficulties in raising a child with a developmental disability that caused parents to avoid difficulty and do what is easiest. I wanted to explore dimensions of these difficulties and how they affected James' lived experience. As Sabrina and I discussed outdoor recreation activities that James already participated in, it became apparent that there was limited specialized recreation programming for James and she did not seem to consider regular, non-specialized programming as an option. During some of our outdoor activities James was the only person with a developmental disability participating and so at times when James' behaviour was atypical it would embarrass both Sabrina and I. The Line of Social Acceptability emerged as a discussion of the socially constructed boundaries that influenced James' access to outdoor recreation. While I still remain unsure of how aware James is of The Line of Social Acceptability, it did indirectly influence his lived experience

Relationships/Supports were a direct part of James' lived experience. James

actively and independently photographed his family (See Figure 5), myself (See Figures

6, 13, 14) and also a substantial amount of animals (See Figures 9, 10, 11, 12). What was

missing from James' pictures, interview transcripts and stories to his mother were

references to the many other people who were participating in the outdoor recreation

activities alongside James. I characterized this aspect of Relationships/Supports as The

Others and explored what James chose not to document during his outdoor experiences.

Therefore Relationships/Supports is an exploration of James relationships with animals,

the people in his life and their role within his lived experience of outdoor recreation.

As a horizon of meaning, Autonomy arose as a characteristic of James lived

experience of outdoor recreation in relation to his level of engagement. James had

indicated through his pictures, actions and words that some experiences were more

engaging for him than others. Autonomy was one horizon of meaning that could

partially explore an aspect of his lived experience that seemed to regulate his level of

engagement. Through my field notes, reflective journal and with input from Sabrina his

level of autonomy during outdoor recreation activities is explored to understand how it

influenced James lived experience of outdoor recreation.

During the formulation of this chapter it also became apparent that each

component of James' lived experience was so interrelated (van Manen, 1997) that often

I would compose a large piece of text under one heading only to repeat it under another heading. As I began to establish my themes in relationship to previous literature I found that despite conducting a literature review to inform the study, the data guided me to search out more literature related to outdoor adventure experiences, research methods with people who have limited verbal capacity and emerging social model research. Therefore, I present the horizons of meaning within James' lived experience in relation to both my literature review as well as additional literature that relates to James' experience of outdoor recreation. Finally, I present a critique of photo elicitation within the context of this study and related literature. In the following discussion, each horizon of meaning is explored as a forum in which detailed description of James' lived experience merges with academic theory to develop insight and understanding.

The Self

Writing about James' self, the experience of being in his body and experiencing his reality, was complicated. Van Manen's (1997) existential of lived body considers the physical body as a medium for experiencing reality: human senses process surroundings, emotions integrate with physical reactions. Moustakas (1994) suggests that descriptions of lived experience should be carnal and based in the flesh. Therefore, I refer to aspects of James' self, including his lived body, in an attempt to present the James I knew and learned about over the course of the research in an attempt to show the human and not simply the diagnosis (Ferguson, 1992, 2000; Goodley & Tregaskis, 2006). I have

structured this theme to present both how James is similar to others as well as how he is different. First I present James as *a teenager,* followed by the *physicality of emotions* that James experiences and lastly discuss some of his *atypical behaviours.*
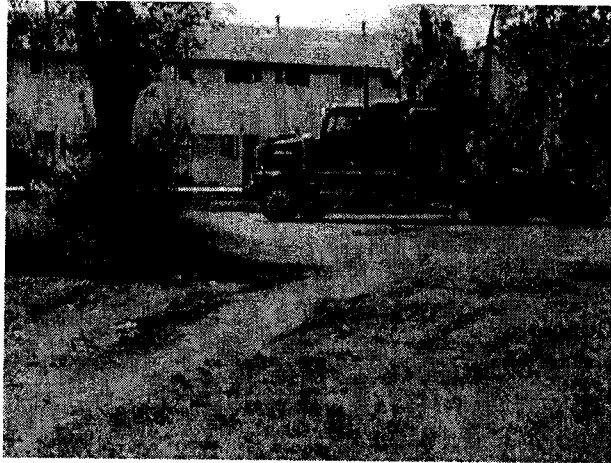
Figure 3. Picture of Transformers truck

James is a 19 year old young man of average height and build with short, dark hair. As I got to know him, it was apparent that James' main interests were movies, animals and "going fast".

Over the course of the summer some of James' favourite movies were *Transformers* (see Figure 3), *101 Dalmatians* and *Alaska.* According to his mother, Sabrina, James learned much of his vocabulary from movies, "James has always learned everything in his life, whether it was how to talk, how to interact with people, how to express his emotions has been through watching film...when he was learning language, it was film, he had to repeat movie language; when he was learning to express himself he had to repeat scenes from movies."

Movies were a venue for James to learn phrases that could help him communicate and express emotion. The first thing that James said upon arriving at the indoor rock climbing wall (see Figure 4) was, "Alaska," instantly connecting the ropes
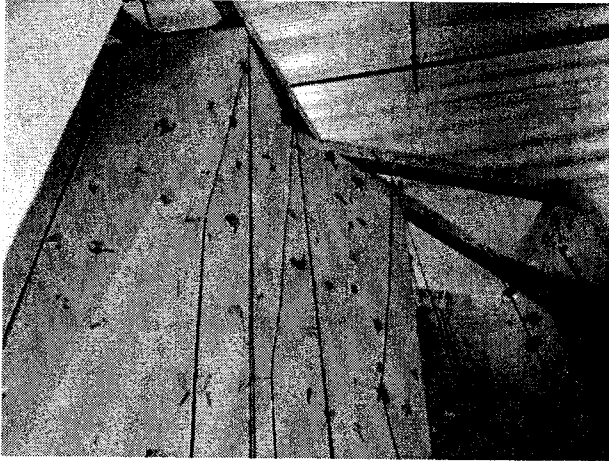
Figure 4. Picture of indoor climbing wall

and harnesses with what he had seen in the movie, *Alaska*. In retrospect, Sabrina noted that many of the activities James did over the course of the research were contained in that particular movie. "This summer he had the whole Alaska movie experience. If he had got to fly in a yellow little plane there, he would've been happy." While movies were a large part of James' life, he was also quite enthusiastic about encounters with various animals.

Over the course of the research James was quick to react to animals and took great pleasure in interacting with them. While James often seemed disinterested in getting introduced to people during activities, he did not hesitate to run up to animals and photograph them. On our first trial activity, a walk through James'

Figure 5. Picture of sister after winning kayak race

neighbourhood, James took 17 pictures of animals, both dogs and squirrels. Interacting

with various forms of wildlife emerged as one of the most enjoyable parts of outdoor recreation for James.

When he got the chance, James also seemed to enjoy the feeling of speed and risk. He was quite competitive when it came to any sort of race. While we were kayaking he would often ensure that his boat was ahead of mine. At one point, when James was distracted, I slipped my kayak past his and gained a few boat lengths on him. When he realized that I was ahead of him and grinning smugly back in his direction, he stuck his tongue out at me and quickly raced ahead. His sister joined in the race (see Figure 5) and after James won he exclaimed, "I'm the winner!" According to Sabrina's emails to me, he expressed to her that he had raced me and was proud to have won. In a previous summer, James became involved in off-road bicycle riding under the tutelage of a neighbour. Apparently upon learning to bike, he was so excited to show his mother that when she arrived home from work he sped towards her oncoming car and yelled, "BIKE RIDING," skidding to a halt in front of her as she hit the brakes. As with other teenagers, James expected his mother to buy him a new bicycle with appropriate equipment. Sabrina mentioned that James was disappointed when she did not purchase him a bike helmet with a full face mask similar to the one worn by the neighbour boy. In addition to enjoying risk inherent activities, James was apparently not immune to capitalist values and the marketing of "cool".

As a young man, James had a variety of interests which were unique to him but also noticeably normal: animals, bike riding and movies. I have presented him this way because, "individuality can be easily swallowed up by the scary stereotypes and diagnostic categories that lie behind the official labels." (Ferguson, 2000, p. 2). However, part of individuality for James was also a by-product of his personal attributes that led to his diagnosis.

Despite having an expressive verbal skill set and the ability to understand most of what is said to him, James was unable to engage in most verbal dialogue. Difficulty with verbal expression and dialogue is a diagnostic category for Pervasive Developmental Disorder (Bach, 2003) with which James is diagnosed. To give perspective, during the interviews, James was unable to answer questions such as, "Who was canoeing with us?", or "What made you feel happy?" He was able to understand that he was being asked a question; however, his cognitive and expressive capacity trapped his potential to answer and he was unable to respond. At times this meant that James could not communicate what he wanted to and this was frustrating for him. One example of this frustration was an instance when I asked James an interview question that he couldn't answer. He responded to the question with a quick burst of angry talk and a physical reaction.

A: Is there anything else you want to say about this picture?

J: FINE....apersonou (angry voice, unclear). I'm sorry (in pleading voice).

Happy, yeah.

A: Is there anything else at all?

J : (slapping sound of him hitting his own hand)

A: You're mad.

J : Sorry.

A: You hit your fist, that's okay, are you feeling mad?

J: No, happy.

In this situation James expressed his frustration both verbally and physically, by slapping his hand and angrily saying something unintelligible to me although he immediately claimed that he was still happy. Often I felt as though his bursts of unintelligible language, not limited to times when he was angry, were movie quotes. The affect in his voice would change, and it would seem as though he was quoting someone else in a different voice. One obvious instance of his movie quoting was when I made a mistake setting up the pictures for him to view on my computer. His voice changed from its general high pitched tone to a deep commanding tone, "Mission failed. Try Again. Mission failed." (August 4th).

Although James would get upset at times, he was generally a happy and agreeable person. According to Sabrina, James was diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) as opposed to autism, because he had more empathy towards other people's emotions than most people diagnosed with autism. She believes that when James received his diagnosis, people with autism were thought to be robots, incapable of sensing social emotion. With the rising prevalence of a spectrum approach to autism where individual autistic characteristics are highly individualized (Perry & Black, 2003) it is likely that James would now be diagnosed on the autism spectrum. While James often could not tell you how he was feeling, his physical reactions to emotive states often indicated what he was feeling.

Physicality of Emotions

During the initiation of this research project, Sabrina indicated that she was interested in finding out if James was capable of experiencing a range of emotions. It seemed that James was either happy or mad and she wondered if there was anything in between. These two affective states, indicated by Sabrina, were apparent in James over the course of the research. When he experienced emotions they were extreme. For example, when we were walking together towards a rock climbing area his anticipation and excitement was uncontainable and he ran ahead of all the other rock climbers, waving his arms in the air and talking excitedly to himself. My brief field note does not

capture his emotion, "James walked ahead of everyone, making noises" (Field Notes, Sept 9). Just before kayaking, an activity he greatly enjoyed, he would anticipate the activity by rocking back and forth on his feet waving his fists in the air, as though he were cheering for a sports team. This type of physical reaction is similar to a sports fan, jumping up out of a seat when his or her team scores a crucial point. The excitement is so powerful it cannot be contained and requires that a person jumps up and thrusts a fist in the air, perhaps cheering loudly. It seems as though for James the social buffer that typically prevents people from displaying extreme emotion in certain public settings is not as prevalent as it would be in a typical youth.

Some emotions seemed too strong to simply contain and would pour out of James both physically and verbally. Feelings of anxiety and anticipation seemed to be unregulated by cognitive awareness and would manifest themselves physically. At the end of the summer, when James started school again, we had to cancel one activity because he was so anxious about school that he was vomiting the day of the activity. I received an email from Sabrina stating, "he [James] is pretty grumpy and has thrown up once today, so he may be too excited about school and stuff and is getting worked into a state" (Sept. 2). Sabrina explained to me that because James is unable to internally identify and regulate his emotions, part of her role as James primary caregiver is to support James emotionally. According to Sabrina, a person without a PDD might

identify anxiety and take action to regulate it whereas James will let negative feelings of anxiety build up, bottled within him, until they reached a bursting point and he has a strong physical reaction.

The intensity of anxiety has been discussed by people with autism (Grandin, 2006; Humphrey & Lewis, 2008; Williams, 1992) and requires various creative coping techniques to manage. For example, Temple Grandin (2006), an author with autism, deals with anxiety by stepping into a padded machine, originally designed for cattle, that applies firm and consistent pressure to her body. Donna Williams (1992) who has also written about her experience of having autism discusses escaping strong feelings of anxiety with a range of techniques from rocking to rhythmically banging her head against a surface to block out overwhelming feelings and stimuli. I am unsure of how James internally copes with anxiety and can only speculate on what his mother and I observed.

Stereotypical Behaviours

In various situations James would retract into his own world and engage in behaviours such as rocking back and forth, waving his hands, running and quickly stopping, quietly talking or yelling to himself. At one point during the inclusive kayaking experience, when no boats were available, James was side by side on the beach with two other program participants who had developmental disabilities. All three of them were rocking back and forth on their feet while making various vocal noises with

their voices. They seemed to be almost unaware of each other seemingly content in their own separate places.

The repetitive motor movements I describe above have been referred to as stereotypic behaviour. Some researchers consider stereotypic behaviour to be self stimulatory, used purposefully by people with autism as a calming technique or method for dealing with competing sensory inputs (O'Neil, 2008; Perry & Black, 2003). Temple Grandin (2006) and Donna Williams (1992) both provide insight into their use of self stimulatory and/or stereotypic behaviours as a technique for dealing with strong emotions and anticipatory anxiety. Grandin (2006) found that, when she was younger, she could use spinning objects or falling grains of sand to completely consume her conscious thought so that she did not have to focus on competing stimuli. Donna Williams (1992) discusses her use of repetitive motions such as rocking from one foot to the other or rhythmically banging her head against the wall, to cope with strong feelings of fear and anxiety.

O'Neil (2008) suggests that to some extent all people engage in random repetitive motor movements, but that this behaviour in people with autism can stand out and result in negative social consequences. Stereotypic behaviour is not simply an aspect of disability or diagnostic criteria, but the manifestation of a physical need and/or an emotional process; the two are not mutually exclusive (Moustakas, 1994). During

outdoor recreation activities, James engaged in various types of stereotypic behaviour primarily when he was anticipating something exciting or when he was disengaged. His anticipation and disengagement fit well within the existential of lived time.

Phases of Outdoor Recreation

The phases of outdoor recreation were informed by the existential of lived time and refer to the subjective, lived experience of time within the "temporal dimensions of past, present and future" (van Manen, 1997, p. 104). With the exception of Schelly (2008), the experience of time passing for people with developmental disability has seen limited academic exploration. The wide range of subjective temporal experiences within outdoor recreation (Hull, Stewart & Yi, 1992; Lee et al., 1994; McIntyre, 1998) provide a good medium for exploring James' overall lived experience of outdoor recreation. Within James' lived experience, three cyclical categories of lived time emerged: anticipation leading up to and during activities, James' experience of time passing in a present tense and his recollection of the past.

Anticipation

Anticipation was a pervasive element of James' outdoor recreation experiences in that it occurred before, during and after activities. James looked forward to the outdoor recreation activities in the weeks, days and hours before the activity. I was flattered when Sabrina told me that over the course of the research James would ask, "'Is it an Andrew day? Is Andrew coming today?' Yes, we're doing something fun today,

wheeeee!" James considered our days together, "Andrew days." After completing

several interviews together, James and I excitedly talked about the next activity after we

had finished discussing his pictures. Even if the interview left both of us confused and a

bit frustrated by communicative barriers, James and I both experienced an immediate

change in affect when we started anticipating the next activity. Anticipation of outdoor

activities provided us both with a pleasant state of mind and something to look forward

to.

Aspects of anticipation as components of outdoor recreation experiences have

been explored in market research (Arnould & Price, 1993) with respect to experiential

expectations. Limited discussion of anticipation also exists in relation to outdoor

recreation (Hammitt, 1980; Tarrant, Manfredo & Driver, 1994).

Tarrant et al., (1994) focused more on recollection and lasting benefits as

opposed to how anticipation shapes experience. While simply recalling past outdoor

recreation experiences has been proven to have restorative effects (Tarrant et al., 1994),

James' affect when looking forward to future activities suggests that anticipation

provided pleasure as well. Hammitt (1980) studied changes in affect and mood over five

phases of an outdoor recreation experience: anticipation, travel to, on site, travel back

and recollection. He found that feelings of fulfillment, involvement, disengagement and

resentment changed over the course of the experience. Positive mood components

increased from anticipation to the onsite experience and then decreased afterwards. When positive mood increased it caused a decrease in disengagement. Of note, feelings of fulfillment and involvement were actually ranked higher by participants in the anticipatory phase than in the recollection phase.

Anticipating and looking forward to enjoyable experiences was a large part of James' overall lived experience. It also blended with his experience during the activities and served to create future recollection. Temporal aspects of outdoor recreation within the milieu of future, past and present are closely tied and I propose that future research into temporal aspects of outdoor recreation consider these aspects of time from an emic perspective as interrelated components.

Another aspect of anticipation explored within the literature is more closely related to the unfolding of experiences during outdoor recreation activities. It is the moment before committing to something that is considered risky or dangerous. One example is contained with McIntyre and Roggenbuck's (1998) examination of an outdoor adventure experience. They found that rafters entering an underground cavern by jumping off a waterfall experienced a growing state of anxiety, arousal and anticipation as they approached the waterfall, "I thought I would be gutsy and do the high jump...standing up there I was very nervous and scared" (McIntyre & Roggenbuck, 1998, p. 415). Post jump participants experienced relief, euphoria and achievement. Lee

et al. (1994) also found that apprehension and nervousness preceding a potentially risky

experience were part of their participants' experience during outdoor adventure

activities; "It's really apprehensive. I don't know what it's going to be like. My heart is

pounding, I'm having a little shortness of breath because I am excited but then on the

other hand it's apprehensive." (p. 203). After the experience, participants tended to

forget the tension and anxiety and shift their memories to focus on the positive aspects

of the activity, aspects they wanted to recollect. In summary, the experience of

anticipating and dealing with outdoor challenges leads to strong emotions that facilitate

vivid and meaningful memories for participants.

It was unclear at times whether James understood the risk inherent in some of the

activities and had the cognitive ability to make judgments accordingly. His mother

indicated that James generally has little fear of what others consider dangerous and this

was apparent on several occasions, such as when he approached the edge of a cliff

without hesitation or attempted to kayak across a lake on his own despite having never

done it before. During rock climbing both indoors and outdoors, there were moments

when James experienced fear and apprehension that occurs before committing to and

during a potentially risky action. Although James would start climbing with what

seemed like no apprehension, being lowered from the climb required relying on the rope

and his belayer to lower him (See Figure 7). James took a while to commit to being

lowered from the rope. When he committed he stumbled down the climb grabbing for holds. His recount of this situation occurred while we viewed the pictures together.

J: Surprise, scared....scared.

A: Rock climbing is scared?

J: It's scared.

A: Is James scared?

J: Yeah. Yeah.

A: What's scary?

J: I hate you. Allo! Scare down.

A: Scared to go down?

J: Yes.

Despite occasionally periods of fear and apprehension James seemed very proud of his rock climbing accomplishment, more so than in other activities; "Climbing rocks, big rocks. Climbing up, trees, yes, climbing up, yeah, oh, climbing up, I did it, yeah." Overcoming and succeeding in an activity despite his anxiety seemed to provide a powerful memory for James. Looking forward to outdoor recreation and overcoming

anticipatory anxiety was a component of James' outdoor recreation experiences that can

be further explored by examining his experiences as they unfolded during the "present"

of each activity.

The Present

The subjective experience of time unfolding in the present can be quite varied. In

a state of boredom, the seconds may slowly tick by while in a state of excitement hours

may pass without notice, especially within recreation experiences (Csikszentmihalyi,

1975; van Manen, 1997). I will discuss James' experience of the present with respect to

periods of activity where he seemed disengaged with his surroundings and periods of

time when he was engaged.

Engaged

The idea of engagement has been discussed in relation to outdoor adventure

activities for non- disabled people (Csikszentmihalyi, 1975; Lee et al., 1994; McIntyre,

1992; Priest, 1992) as well as for people with disabilities (Dattilo & Murphy, 1987;

Gibson, 2000; Rose & Massey, 1993). Inherent within descriptions of engagement for

people with disabilities is the idea that their everyday lives do not include opportunities

for engagement. The lingering of institutional mindsets and living arrangements

(Hayden et al., 1996; Hutchison & Potschaske, 1998; Pedlar et al., 1999) means that

there is basis for these assumptions, however I will attempt to move beyond them. By

placing James' lived experience in relation to both people with disabilities and the non-

disabled, both the texture and structure of his engagement can be explored within a humanistic context.

Within his outdoor recreation experiences, there were periods of time during which James seemed completely engaged in what was happening. Of all the activities, a descriptive account of kayaking provides the most vivid portrait of this thematic element. It was a hot, sunny morning when we arrived at the lake. I asked James for help while we were taking the kayaks off of the trailer and bringing them to the water. James was able to help me untie the boats, take them off the trailer and carry them down to the water with almost no verbal instructions. Although he had never unloaded kayaks from a trailer before, he immediately observed what he needed to do and did it. Once the task was done, James seemed to disengage, retracting back into his own mind, engaging in stereotypic behavior such as waving his hands and talking to himself, while the program leader and I organized the paddles and life jackets. One of my field notes refers to other individuals with developmental disabilities present who were engaged in stereotypic behaviour similar to what James was exhibiting: "Stood around with other participants yelling" (Field Notes, August 12th). I found the social dynamic within a group of developmentally disabled men, who seem very excited to be outside but appear to be unaware of each other, an interesting dynamic to observe. I found that their energy was

intoxicating. It made me excited to witness this energy, but I was too intimidated to think of participating with them in such a powerful public display of feeling.

Once James had his boat in the water and was sitting in it, he took off quickly, paddling out onto the lake. The change in affect was instantaneous. He went from being what appeared to be disengaged and stereotypic to completely engaged in kayaking. I got into my boat and floated, quickly trying to catch up my field notes so I could go paddle with James when he raced by me saying, "Hello....It's hot....Wait up!" The look on his face

Figure 6. Picture of Andrew in kayak

was one of sheer excitement. He seemed entirely present and living in the moment. He quickly shot a picture of me (Figure 6) and raced off to go see his sister, who was tentatively testing her boat out. She had decided to try kayaking after watching James participate without her two weeks earlier. I started paddling and James quickly turned around. He raced back to me and started paddling to the spot where he had seen three deer (which I discuss within the existential of lived relations), looking back to ensure I was following.

During kayaking, I did not prompt him once to take a picture. He was taking

multiple pictures on his own volition. He was present, engaged and documenting the

important elements of his experience. I received the following email from Sabrina after

the kayaking session. "I just wanted to let you know…that James hasn't stopped talking about Kayaking today!…boy did he have a good time!" After he returned from kayaking, he had been waiting by the window for his mother. When she arrived home from work, he rushed out to tell her about kayaking
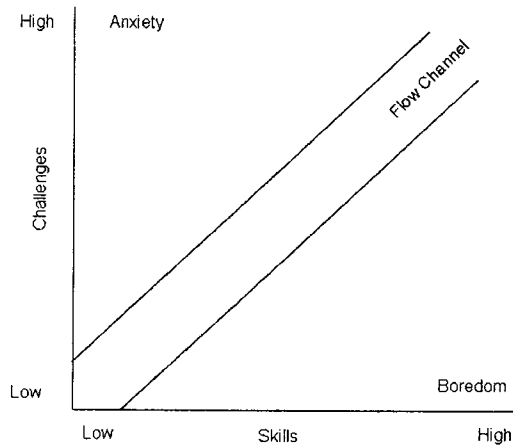
Figure 7. Model of flow (Csikszentmihalyi, 1975)

while mimicking the motion of paddling with his arms.

Of all the activities, kayaking and rock climbing seemed to be the most engaging

for James. Sabrina identified that James seemed to be most engaged in activities where

he was autonomous.

He wants to do activities where he's autonomous in it…that was clear between

kayaking and the canoeing, he loved kayaking cause he was in the boat with

himself, he got to direct where it went, how fast it went, what he did, wasn't so

keen about the canoeing, cause somebody else was picking and choosing where

he went.

Figure 8. Self prompted picture of rockclimbing

Being independent and autonomous during an outdoor experience was engaging for James. As a young man with an interest in going fast and taking risks, activities involving the element of challenge and novel situations seemed to be engaging for James as well. He seemed to celebrate his independence and ability to succeed at the activities as well. During kayaking, he took a picture of himself in the boat. During rock climbing, he prompted others to take pictures of him. James seemed to be indicating that what he was doing was worthy of being photographed. During outdoor rock climbing, his pride in getting to the top of the rock climb was palpable; he directed Sabrina to take pictures of him and shouted, "Wheeeeehooooo, I did it." (See Figure 7). The novelty and challenge of outdoor recreation experiences is one of its most engaging features (Davidson, 2001; Gibson, 2000; Patterson et al., 1998). Within an environment where James could be independent (Dattilo & Murphy, 1987; Dillenschnieder, 2007) he was able to experience overcoming the challenges present in outdoor environments and take pleasure in his success. This type of engagement in relation to outdoor recreation has been explored within a large number of theoretical constructs that are summarized in Loeffler (2004) and explored in more depth by Ewert (1989). The components of outdoor experiences and how they should be examined, especially with regards to adventure recreation, have been

extensively debated (e.g. Hull, Stewart & Yi, 1992; McIntyre, 1992; Priest, 1992). I

have limited my discussion to the theory of flow (Csikszentmihalyi, 1975). Flow is a

dominant model that provides a straightforward empirical framework which provides

room for phenomenological variation and multiple horizons of meaning (van Manen,

1997).

I was disappointed, at first, when James' lived experience fit so easily into a pre-

existing theory; I thought that perhaps I had failed at bracketing out my personal

theoretical knowledge. However, the fact that James' experience relates so strongly to

the concept of flow, which is so commonly experienced, highlights the shared essence of

experience within all humanity (Schmidt & Little, 2007; van Manen, 1997).

The concept of flow (see Figure 8) suggests that when an individual has the skills

and mastery to meet the intended goal of a challenging activity while maintaining a

sense of control, there is the potential to have an optimal or flow experience

(Csikszentmihalyi, 1975, 1990). Optimal experiences within the flow model are marked

by intense concentration, a transcendence of self awareness and a change in the

experience of time passing (Csikszentmihalyi, 1975). Csikszentmihalyi (1975) also

found that if the activity is too difficult to feel a sense of control and mastery it will

produce anxiety; if the activity to too easy to feel a sense of challenge then it will

produce boredom. In some cases, if an individual is not seeking a challenge, then they

might feel a state of pleasantness in easier activities as opposed to boredom (Vitterso, Vorkin & Vistad, 2001).

When James was able to exercise mastery and control, he seemed to experience a flow-like state which I refer to as engagement. During both of his preferred activities, rock climbing and kayaking, I could observe what seemed to be intense concentration and focus on the task. This relates to a study by Rose and Massey (1993) who examined the outcomes of a mountaineering expedition for several men with autism. The expedition created prolonged periods of engagement, facilitated trust building and deeper understanding between the men and their supports and would create role reversals where the men would sometimes support their staff in climbing the mountain. For James, outdoor activity provided long periods of engagement and facilitated trust building between him and myself which I will discuss within the existential of lived relations.

Another aspect of engagement, in accordance with the flow model (Csikszentmihalyi, 1975), was that being challenged beyond his ability caused anxiety for James. During outdoor rock climbing, the first climb that James tried was too challenging for him. As he attempted to get off the ground he yelled, "DAMN" in frustration. During kayaking, James became nervous when he paddled towards his sister who was standing on shore. I interpreted this nervousness to be associated with his

inability to keep the nose of boat facing directly towards his sister. James continually made over-compensating paddle strokes with increasing speed to reposition the tip of the boat and speak incoherently in an anxious-sounding voice. The anxiety James experienced when he was over challenged by an experience seems similar to the anxiety described by other non-disabled research participants placed in similar challenging outdoor situations (Lee et al., 1994; McIntyre & Roggenbuck, 1998; Patterson et al., 1998).

In relating James' experience of engagement to previous research, I found there was often a lack of detailed, textural description. This limited the connections with which I could relate James' experience of engagement to that of others. The accounts of participants (Lee et al., 1994; McIntyre & Roggenbuck, 1998; Patterson et al., 1998) in some studies provided some descriptive material to match James experience, both in his negotiation of anxiety as well as his excitement at fully participating in an activity. However, James could not tell me if he gained perspective, experienced self discovery or gained a spiritual connection with nature (Loeffler, 2004; Schmidt & Little, 2007). He could not describe the significance of overcoming challenges or whether he built confidence and mental strength (Davidson, 2001). While I observed indicators of mood that relates to the experience of engaging outdoor activities moving from anxiety to excitement (Lee et al., 1994; Patterson et al., 1998), it became apparent that the tendency

of academic outdoor literature to jump to abstraction without describing the textural components of an experience limits the connections that can be made between James' lived experience and that of others who do not dwell in the realm of abstraction. This is not to say that more cerebral reflections on the connection between humans and the outdoors are not warranted, but it may suggest that in reflecting on the abstract, the carnal reality of lived experience is overlooked.

What James indicated through his pictures, his behaviour and his accounts of engaging activities was that he enjoyed activities where he could be autonomous and independent. Through active engagement and passionate recounting of his experiences to his mother, James was able to create potential for being involved in these activities in the future. The fact that outdoor recreation was an engaging experience for James supports the notion that outdoor recreation activities containing an element of risk should be considered as a viable recreation option by people supporting individuals with developmental disabilities (Dattilo & Murphy, 1987; Hammitt, 1980; Rose & Massey, 1993). As the primary support for James, Sabrina reflected on her perceptions of James' engagement:

> You know I think he's gained a sense of confidence he never had before, he's
> also gained a sense of risk he never had before (laughing) which is good, you
> know, which is good because you know, as kids we all do that, we see Batman

movies and we think we can climb a tree, or swing like Tarzan and you fall and you break your arm and that's what happens. That's a normal part of human development right? Unfortunately children with developmental disabilities don't get that. Right? Because the parents can control their environment, they do keep them from those experiences, which inhibits their growth, right? So, this opportunity taking me outside my comfort zone and certainly putting him in situations which are risky or more adventurous etcetera allowed him to grow and challenge himself.

Disengaged

During many of the outdoor activities, James seemed disengaged from the activity for periods of time. While the term disengagement can have negative connotations, I am using disengagement to describe periods of time when James did not appear to be actively engaged in the activity and did not take pictures. It is possible that he was enjoying the activity despite appearing to be disengaged. I found that disengagement was often marked by James engaging in stereotypic behaviour while he was either waiting between periods of activity or during social interactions. He also seemed to be somewhat disengaged during more passive activities such as canoeing and horseback riding. James also seemed to disengage during periods of verbal decision making with other people participating in the activity. It was often uncertain whether

James had the capacity or interest to get involved in verbal decision making and social interactions with people with whom he was not familiar.

My field notes provide my initial interpretation of disengaged waiting for James. During our initial horseback riding session, I named this aspect of James experience, "Waiting while adults talk" (Field Notes, August 3rd). One of the owners of the stable engaged Sabrina and I in conversation while a previous group was out on the horses we were to use. James stood away from the conversation, completely disinterested in engaging in verbal dialogue and took one picture (See Figure 9). These types of

Figure 9. Picture of horse taken while adults were talking

situations, where individuals stood around talking and James disengaged, occurred before kayaking and several times during canoeing. James would often talk with himself at these times, perhaps thinking out loud. Although this seemed unusual at the time, possibly because he was speaking out loud, it is not unusual to think about things aside from the activity during an outdoor recreation experience. Participants in Lee et al. (1994) sometimes found themselves ruminating on other issues in their life during outdoor recreation experiences such thinking about a future luncheon or worrying about

an issue at work. When he was disengaged and talking to himself, James may have simply been ruminating. An example of rumination, although it may also be anticipation, occurred during horseback riding when James, while riding his horse, exclaimed, "Meatball sub" that I later learned from Sabrina was in reference to the submarine sandwich he was going to have after the activity. Most of my observations of James' disengagement during passive activities indicate that he was quiet and distant seemingly absorbed in thought. This was a marked difference from his demeanour during engaging activities.

Several studies have documented feelings of disengagement and boredom occurring within outdoor recreation experiences (Hammitt, 1980; Hull, Stewart & Yi, 1992; Hull, Michael, Walker & Roggenbuck, 1996). Within the multiple phases of the recreation experience, situations occur where there is inadequate stimulation leading to boredom (Csikszentmihalyi, 1975). Participants in Hammitt (1980) found the drive home from an outdoor activity to be a period of disengagement. Hikers in Hull et al., (1992) experienced boredom when hiking through areas of dense vegetation that lacked a view. In another study Hull et al. (1996) found that people who were walking and sitting within a natural setting experienced boredom, and were more likely to experience boredom when they were sitting or had a bad view of the surroundings. In relation to the literature, it is natural that James may have been somewhat bored with passive activities

such as paddling in the front of a canoe or trail riding on horseback. He is a person who is interested in excitement and speed as well as autonomy. His disengagement with social situations, however, differs from what is found within related studies. Surprisingly, with the exception of McIntyre and Roggenbuck (1998), social regulators of mood have generally been excluded from research examining the temporal phases of a recreation experience.

With respect to disengagement with social situations, I will return to my statement "waiting while adults talk". Upon reflection, I realized that I had inadvertently infantilized James (Schelly, 2008; Tregaskis, 2002). My statement assumes that despite being 19 years old, James is still a child, unable to make his own decisions and that the non-disabled people in his life, the adults, organize things to best suit James, the child. Similar to Schelly (2008), I felt that the most disturbing aspect of being disinterested in communicating or lacking the capacity to communicate with people aside from his family and myself was the fact that James could not advocate for himself in planning situations. During group decision making he would often have to wait for the person advocating for him to direct and manage negotiations. During our second time horseback riding, the leader immediately put James on a lead line that attached his horse to the leader's horse without even testing to see whether he could use the reins. It was assumed

that James could not control his own horse and so James had a passive role in the activity based on the perceptions of the activity leader.

During canoeing, the activity leader and I chose what boat James would paddle, who he would paddle with, where we were paddling to and when we stopped without any input from James. There were a couple of times when James gave me a confused look or smacked his hand with his fist, especially when we had to stop paddling repeatedly to discuss changing plans based on the weather and an unfortunate cell phone call informing the leader of the activity that her dog had run away. James seemed to have an opinion on the situation but was unable to voice it, and I was not comfortable enough as an advocate to speak for James. These examples highlight the amount to which James' supports influenced his level of autonomy and potential engagement.

Disengagement caused by social interactions seemed to be marked by inaccessible situations and/or disinterest. James' behavior seems to inversely support the direct relationship that Hammitt (1980) found between involvement and disengagement in an outdoor recreation activity, when people were more involved in the activity, feelings of disengagement decreased. In James' case, his level of disengagement increased in communications where he could not be involved. Based on his personalized style of communication, which required interpretations from his supports, many of the social interactions occurring during outdoor recreation activities may have been

inaccessible to him. Therefore, disengagement would be natural. Sabrina suggests that if people use complex language when speaking with James it is similar to using a foreign language. ``He [James] has limited vocabulary, um, it's not his comprehension that's limited, but if you're not getting the verbage to go with the actions, it doesn't all make sense all the time so it's like somebody giving you instructions in Chinese." After a life time of being surrounded by conversations that he cannot engage in, it is feasible that James would become disinterested in them and disengage.

When James and I were driving home from canoeing, I was already well aware of his disinterest in small talk, so we drove in silence listening to the radio. Generally I rely on small talk and conversation to pass the time in a vehicle. At one point James turned up the volume when an opera song came on and I mimicked the opera singer, just out of habit. I looked over and found that James was intensely staring at my face. He quickly turned away and copied my opera imitation. For the next 15 minutes we sang opera together and then fell back into silence. As I reflected on our car ride, I came to the conclusion that James is a man of action. Any successful conversation that we had was centered on a shared interest (Spitzer, 2003) and led to some form of action.

Although disengagement has been referred to as a negative mood characteristic (Hammitt, 1980), it is more likely to be a natural component of an outdoor recreation experience. While the concept of disengagement highlighted components of James'

lived experience that were inaccessible, it also raises the questions; does James want to be included in all social interactions? Should casual conversations stop because they are inaccessible? More to the point, should the supports of people with developmental disabilities attempt to manage their recreation so that the entire experience is an engaging as possible? As a result of this research, I think that recognizing James behavior, actions and personality as input into the group dynamics of an outdoor experience is a more likely solution. During canoeing, when James hit his fist with his hand, I recognized that he was probably indicating the desire to keep paddling and stop talking. If I had voiced this for James within the group, and all group members were aware of this action, then he could have affected the situation with his input. The importance of having supports that understand the communication style of the person or people they are supporting and a willingness to act on this communication is paramount.

Recollection

The life enriching story provided by outdoor recreation is created and interpreted by the participant (Patterson et al., 1998). It also changes over time. The recollection of the outdoor story and the meanings that are ascribed to it provide pleasure both in personal reminiscing as well as recounting the story to others. This story is also what researchers seek out in their examinations of the outdoor recreation experience. They seek recollections and the meanings that are associated with the experience after it happens (e.g. Loeffler, 2004; Patterson et al., 1998). In a unique study, Tarrant,

Manfredo and Driver (1994) measured physiological attributes of people while they recollected past outdoor recreation experiences. Recalling active recreation experiences caused a positive physiological and psychological response indicating that recalling outdoor recreation experiences has beneficial effects beyond the actual experience. To summarize past research, part of the outdoor recreation experience involves creating personal meaning, internally reminiscing about the experience as well as sharing the experience with others.

James was enthusiastic about sharing his story. After an exciting activity, he would wait for his mother to come home so he could regale her with the story of his adventure. According to Sabrina, "The moment I got out of the car to come home, he opened the window and started yelling at me across the walkway about, "Mommy, Mommy, I was on a boat and a paddle and then the deer" and he just wouldn't, couldn't get enough words out fast enough to tell me all about it." When James and I would review his photographs together, once I was finished asking him questions, James would repeatedly look through all his photographs with an intense look on his face, quietly whispering to himself. My audio recordings of the interviews contain long silent periods between discussions where the only sound is James repeatedly clicking the mouse as he goes through the slideshow of his images. It was almost as though he was reliving the experiences in his mind through the photographs (Grandin, 2006). Part of the pleasure of

being involved in these activities was sharing the story with the people for whom he cared.

Theoretical Reflection

The temporal aspects of James experience are cyclical in nature. For activities James enjoyed, anticipation leads to being engaged in activities that provide memories for recollection and start the process of anticipating the future. For many people with developmental disabilities who require the support of an agency, it is possible that process of anticipating and hoping as well as the pleasure of recollecting and reminiscing is obstructed by their supports. In Pedlar et al.'s (1999) book, people with developmental disabilities found that they had little continuity with their relationships, recreation and housing. It was difficult to build memories and relationships because service providers would move people to different locations and shift their programming around. The logistical component of supporting people with developmental disabilities has influenced access to temporal continuity, looking forward to preferred activities and interactions with friends.

In examining James' temporal experience, the implications of not participating in outdoor recreation and other types of adventurous activities becomes apparent. Being denied access to adventure, in this case outdoor adventure, is not simply a missed opportunity to play outside, but an avoidance of challenging circumstances inherent in outdoor recreation as well as the chance to overcome them, build memories and create

future possibilities. From Sabrina's perspective, James experienced growth through exposure to challenging, risk inherent outdoor activities that had an effect on her.

> We have to find him a way to get him into kayaking even if it is just at boulevard and you know, like, just going back and forth across the lake and that kinda stuff, cause he really enjoyed it, um, but then, you know, for me that means seeking out those opportunities…I have to find more opportunities for him to do things, and I also have to be aware of, not looking for specialized programs, unless it's offered for people with developmental disabilities, families are less likely to get their child involved but James proved himself to be very capable, to keep up with anybody.

Over the course of the research, James seems to have demonstrated to Sabrina that he is able to participate not only in specialized programming but also in regular community recreation programming. This indicates the separation between specialized programming from regular non-disabled programming. In this case, with the support of his family and I, we were able to begin drawing together this separation.

The Line of Social Acceptability

A structural component social relationships is the presence of various socially constructed rules referred to as social norms by which people evaluate each other's behaviour and appearance. I use the idea of *the line* to refer to the point at which

abnormal behaviour will be socially recognized and create consequence. Goffman's (1963) classic work on the stigmatization of people who fall outside the social norm states that to be different from what is considered socially acceptable is to be judged and outcast by society. Goffman refers to the non-stigmatized as 'normals' and suggests that, "in social situations with an individual known or perceived to have a stigma, we [the normals] are likely, then, to employ categorizations that do not fit, and we and he are likely to experience uneasiness" (p. 19). When an individual is perceived or observed to be appearing or behaving outside the social limits of acceptable behavior, Goffman (1963) feels that they would be classified as different and stigmatized within the social context causing uneasiness. During the various outdoor activities when James was either behaving or appearing outside of the normal, he crossed this invisible social line and caused uneasiness.

While I read some studies either discussing or based on Goffman's work (Gray, 2002; Wendell, 1996; Winance, 2008) to further explore the concept, I felt that the complexity and pervasiveness of *the line* is almost beyond description. In certain social contexts crossing *the line* may be as simple as an inappropriately timed facial expression. For example, rolling one's eyes at an employer in the wrong context may result in severe social consequences. People with autism have identified *the line*. Grandin and Barron (2005) have written a book aptly titled, *The Unwritten Rules of Social Relationships* that

documents their struggles with social norms and having autism. In some cases, people

with autism have criticized people with typical neurological function for being overly

obsessed with social norms and behaviors (O'Neil, 2008). Researchers have taken a

keen interest in documenting the negotiation of social norms for people with autism as

well. Some recent examples include Humphrey & Lewis' (2008) research on the

experience of secondary school students with autism as well as Devine and Parr's (2008)

discussion of social capital in an inclusive camp context.

I was aware of my own personal feelings and thoughts as related to what later

emerged as *the line of social acceptability* during the course of this research. What I was

unsure of, and remain unsure of is, whether James was aware of or sensitive to *the line*

in social situations. I am also unsure of the inner dialogue going on within the people

who were present during instances where James crossed the line. I am able, however, to

provide a description of how James crossed the line during one of our activities as well

as my reaction.

During outdoor climbing, when we arrived at the top of the cliff where we were

to climb, James immediately walked over to the edge of the cliff to have a look down. I

yelled to James to stop and be careful and directed him away from the cliff edge, not

knowing whether he understood the risk. James may have been unsure of why I spoke to

him so harshly, and as I got a harness and helmet for him he seemed upset and started

expressing this verbally by telling me to, "Shut up". Sabrina then told him to behave

and he responded in a loud voice to both of us, "Shut up, I hate you." All the other rock

climbers seemed to be getting on their equipment and looking the other way. I could see

Sabrina's face flush red; I was embarrassed by James' behaviour as well. The blood

rushed to my cheeks and I felt them burning, I focused intensely on tightening the straps

of James' harness, pretending that there was no one else there, just the harness and I. I

know logically that James is in a new place, surrounded by new people putting on

equipment he does not quite understand the use for and perhaps expressing confusion

and frustration at being spoken to harshly by someone [myself] who has never spoken to

him that way. The fact that he has crossed *the line* of socially acceptable behaviour in

front of a public audience caused an intense physiological in me and an emotional

response to which James seems oblivious. Once James had his harness on, he happily

walked to the base of the climb with Sabrina and I.

The sense of embarrassment that Sabrina and I experienced closely mirrors other

parent's accounts of embarrassment that occurs when their autistic children act out in

social situations (Grey, 2002; Woodgate, Ateah & Secco, 2008). Grey (2002) found that

the experience of parenting a child with autism involves parents enduring stigmatization

and exclusion because their children publically cross *the line* of socially acceptable

behaviour in a given environment. One of the parents in his study describes her

experience of being embarrassed by her autistic child; "he called me an idiot in front of all these people, and swearing started to come out, and everybody just freezes. Everybody is just embarrassed" (p. 740).

My primary focus, however, is James' experience. While James is unable to verbally explain to me what caused his verbal outburst during rock climbing, by considering his behavior as human rather than autistic, I can begin to interpret the behavior within the context (Cocks, 2008; Ferguson, 2000). James is a 19 year old male who had been scolded by both his mother and I. He has limited expressive verbal skills, with a small vocabulary of words to express a wide range of emotion. Directing him away from the cliff edge with a harsh commanding voice and putting strange equipment on him may have been confusing, annoying and perhaps embarrassing for James. The only words he could use to express these feelings this were, "I hate you." A contextual, humanizing look at James' behaviour within the circumstances provides insight into what may have caused the behaviour. In this scenario, it seemed as though James did not much care what the other rock climbers thought of him. He was interested in rock climbing. While crossing *the line* was embarrassing for Sabrina and I, it seemed inconsequential for James. I quickly forgot my embarrassment in anticipation of climbing and Sabrina seemed more concerned with the implications of her son climbing a vertical rock face than with the social implications of James' behaviour.

McAvoy et al. (2006) suggest that sometimes people with cognitive disabilities will use socially unacceptable behaviors to gain a sense of control. If their input is ignored, they will cross *the line* to ensure people take notice. However, there are many accounts of both aggressive and verbal behavior in people with autism for which the purpose is unknown or remains unexplored (Benderix et al., 2007; Cole, 2001; Gray, 2002). James did not seem to use *the line* intentionally but simply used a behaviour that worked to get his point across. Using angry words to stop me from asking interview questions had the same desired effect.

As a structural component of James' lived experience of outdoor recreation, *the line* is a fundamental concept in how he integrated with all the people involved in his experiences. It is also an essential component in negotiating inclusion in social contexts. People with developmental disabilities, along with their parents, services providers and supports, have to deal with social consequence and thus it is an essential component of lived experience.

Relationships/Support

The theme of Relationships/Support was informed by the existential of lived relations, characterized by van Manen (1997) as the experience of living in relation to others. For this research I have included animals within the theme of relationships because James indicated through his photographs that animals were a primary

component of his experiences (see Figure 11). With respect to relations among people,

social model disability research often focuses on the insights of people with disability

into living in relation with non disabled people (examples include Tregaskis, 2002;

Wendell, 1996) providing an opportunity for many to either relate to or understand

essential elements of the disabled life world. Although some social model researchers

warn against assuming that non disabled people will be able to understand the

experience of the disabled (Kitchin, 2000), Susan Wendell (1996) provides a

counterpoint stating that both disability and death are essential parts of life, shared

between the disabled and the non disabled. If the purpose of social model research is to

remove socially constructed barriers that impair people with disabilities (examples

include Hodge, 2008; Walmsley, 2001), then understanding essential elements of social

relationships between the disabled and non disabled is necessary to examine and affect

the social structures which inhibit people with disabilities to participate in society.

Within the context of outdoor recreation, James' relationships are discussed with

respect to animals, his family, myself and the others.

Animals

Within all the pictures James took, there was a prevalence of animals among

them. I initially felt that James may have been taught to take pictures of animals through

social conditioning (Cederholm, 2004). As the research progressed and I bracketed my

theoretical presumptions, it was apparent that James was very interested in animals. He

was excited when animals were present during activities. He actively documented them

with his camera (See Figure 11), had things to say about them during the interviews and

would talk to his mother about them. Of all the animals, two stood out as being the most

important for James. The first was an encounter with three deer while kayaking (See

Figure 10). James and I were both paddling across the lake when I spotted three deer

grazing in a small bay, a mother and two younger deer. Knowing that James was very

interested in animals, I mentioned the deer and pointed to where they were. With his

limited paddling skills he started paddling towards them quickly and erratically. He was

visibly excited, and fumbled with his camera making sure it was on. As he approached

the deer, he yelled, "Wait deers." I told James that being loud would scare the deer and

he continued paddling but said quietly, "Wait deers." When he got close enough to the deer for his liking, he took a picture of the deer. After a moment, the three deer walked into
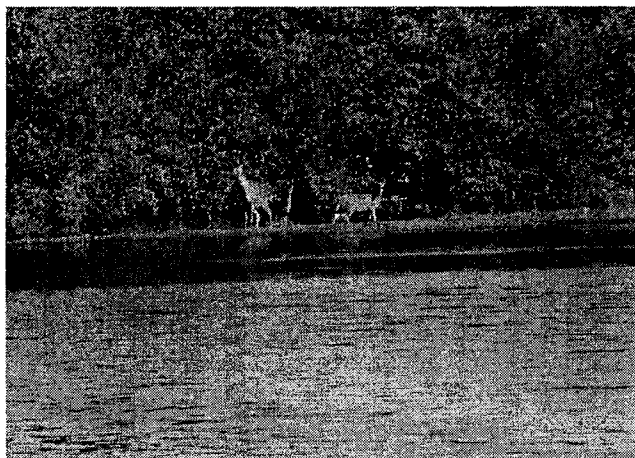
Figure 10. Picture of three deer

the woods and left. Later James and I had to return to the shore twice to let other people

use our kayaks. Each time James and I went back out on the lake that day, as well as

during our second day kayaking, the first place James paddled to was the bay where we
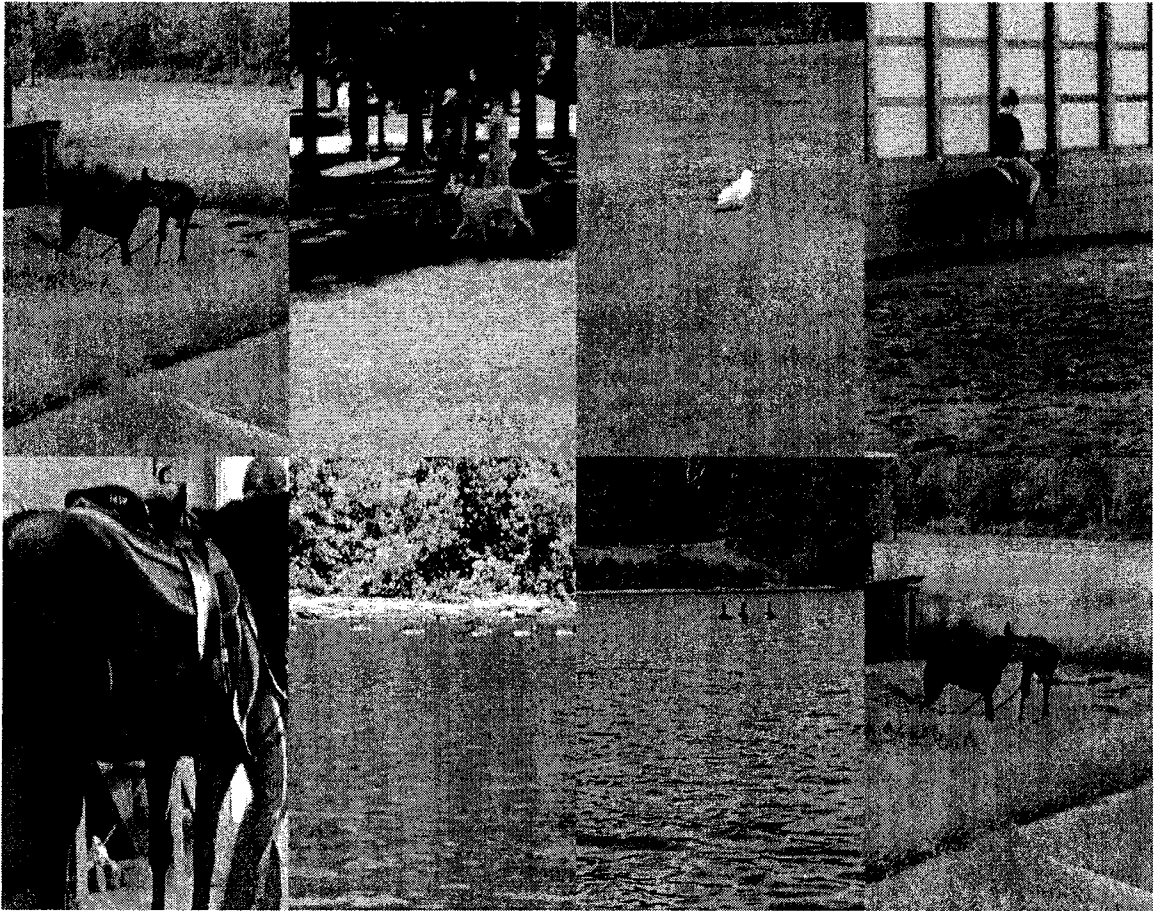
Figure 11. Collage of select animal pictures

first found the deer. During our interview the day after our second kayaking experience,

James discussed the picture he took:

J: Deer.

A: You really like that one. Okay so let's stop now, tell me about this picture.

J: One two three, three deers.

A: There are 3 deers, right on. How does seeing the deers make you feel?

J: Secret, secret deers.

A: They're secret deers?

J: Yes

A: What's secret?

J: There's a trees, run away.

James had thought about the deer and could recount what had happened during

that moment. Within the continuum of lived time, the animals provided both a memory

to enjoy as well as something to anticipate during future kayaking adventures in the

same area.

The second animal encounter that stood out was when James found a frog on the beach. He put the frog in his hat and then laugh and jump when the frog escaped as though he was both excited and fearful at the same time. At this point in the activity James had returned the camera to me so I could download his pictures, but his sister came over and told me that James had requested the camera to photograph the frog (See Figure 12). He took two close-up pictures of the frog and returned the camera to me. Although James had little to say about his encounter during the interview, ("Frog, ribbit, ribbit. Ribbet. Good stuff."), the animal within its natural setting provided the opportunity for a dynamic interaction (Winkle & Goode, 2008).

According to Sabrina, animals are one of James primary interests. He enjoys the zoo and is also requesting that she buy him a dog. She also indicated that, when James gets to interact with animals, it provides a more powerful memory for James. ``Five minutes alone or five minutes engaged or engaging an animal is gonna have a greater impact in him and you're going to hear about it more and more and more...(laughing) all the time.``
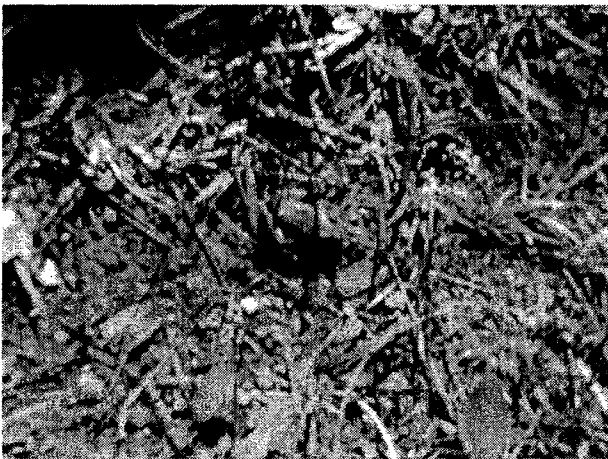
Figure 12. Picture of a frog

One question that arose in mind during the activities was the fact that

James would attempt to document nearly every animal he came close to, but would not document many of the people he interacted with. Literature concerning the relationship between people with autism and animals centres around the practice of animal-assisted therapy (e.g. Conner & Miller, 2000; Niska, 2007; Winkle & Goode, 2008). While the focus of this research is not on providing therapy, there are some insights to be gained by those who have watched people with developmental disabilities interacting with animals. Niska (2007) suggests that both dogs and people who are non verbal often communicate through behaviour and therefore this is a strong basis for understanding each other and having a relationship. She goes on to say that her therapy dog is disabled simply because it is not human. I thought that this was a profound yet simple manifestation of the social nature of disability. If a certain collectively understood standard is not met then someone is considered disabled (Winance, 2007) from a socio-cultural perspective. Grandin (2006) has produced excellent literature on the similarities between people with and without autism and animals with respect to behaviour, non verbal communication and brain functioning. She states that her autism and unique neural processing allow her to understand the behaviour and needs of animals much more than people with typical neural functioning.

Another example that supports the idea of a special bond between people with autism and animals is Barol-Lucero's (2008) research involving a therapy dog and a

child with autism. It is apparent when watching the online videos that the relationship between dog and child forms quickly and results in positive interactions. For the child, it seems as though it was easier to have a dialectic relationship with a dog than with his therapists and other people.

While the literature I reviewed seems to point to the idea that people with autism may find it easier to develop relationships with animals than with people, I am unsure whether this is true for James. It is one possible line of reasoning that would explain why James was interested in animals but not in casual relationships with other people present during the outdoor activities within this research. A dialectical interaction with a frog is simple when compared with the complexity of social interactions among humans (Niska, 2007). Through behaviour, pictures and discussion, James has indicated that viewing and interacting with wildlife was a large part of his outdoor lived experience. Aspects of lived relations among people were more complicated.

Family

Similar to other families that include a child with autism (Seltzer et al., 2001), James' mother Sabrina is his primary support. For any activity occurring outside of school, Sabrina's roles included organizing James' activities and interpreting his emotions and behavior to provide appropriate support during activities. Since Sabrina's role directly affects James, I discuss the relationship between James and Sabrina

primarily from Sabrina's perspective to explore the meaning of their relationship and how it affects James' lived experience.

Sabrina's characterization of supporting James logistically to participate in recreation is similar to other parents of people with developmental disabilities in that it requires extended parental effort and initiative to facilitate recreation (Mactavish et al., 2007; Mactavish & Schleien, 2004).

> Well, it's any activity right?....if I wanted to get him involved in that, I 'd have to go find those things and that's a given in any family, when the child initiates it and they're independent and they can do it on their own, that's a whole different thing, but when the child is not independent, then it becomes the responsibility of the parent to find the opportunities, schedule it within time, you know, make all those arrangements, so that is the biggest challenge for any family, but certainly for any family with a child with developmental disabilities. The onus falls on the primary person, whether that's the caregiver or you know, support worker, whatever to then seek out opportunities for them to continue their interests, right? It's a matter of my initiative.

During the activities, James required someone to make and pack his food, facilitate transportation, ensure that he was wearing appropriate clothing and had necessary

supplies packed. James' sister shared in the responsibility; however Sabrina was the primary support.

Sabrina also participated in several of the outdoor recreation activities, to support James during the activity. This support took the form of translating James' cues both back to himself as well as to other people. One example of Sabrina translating James behavior to support him occurred when James and Sabrina showed up for indoor rock climbing. Upon arriving, Sabrina mentioned that James had only slept four hours the previous night. Sabrina's experiences of James being unable to sleep at night is similar to other parents of children with autism who often mention difficulty with their children's sleeping patterns (Benderix et al., 2007; Seltzer et al., 2001). Despite being overtired, James was still determined to come climbing and once climbing he was determined to make it to the top of the wall. After making it to the top of the climb once, James went to the running track near the climbing area to tell runners that he had climbed the wall. James became frustrated on subsequent climbs and began to loudly argue with Sabrina yelling things like, "Mom, you hate me" and "Go to jail". Sabrina would continually try to ask James if he was tired or if he needed help and James would continue to respond to her angrily. James was tired. He did not have the endurance or strength to continue climbing to the top. He even expressed, "No fun today, no try

again." However he would not stop trying to climb until Sabrina made James quit. She described later in our interview.

> Like at that point, with the rock climbing, he was either going to throw up or he was going to cry. That's how upset he was. At that point he was ready to cry and I've seen him cry when he's frustrated at different things and most of the time it's because he's tired, he's not feeling well, whatever. And when he gets like that, he will never quit on his own. He will never stop on his own, he will keep going. You have to interject and say, 'Okay, you're done.'"

In this case, James' determination overrode his physical and emotional state to the point that, even though he seemed to know he was done, he was unable to stop. It was necessary for Sabrina to read his behaviour, interpret its meaning and act to support James when appropriate. Sabrina is careful to point out that providing support for a person with a developmental disability during recreation requires:

> An objective person, that's focused solely on them [the person that requires support], you know, that helps them and keeps their eye on what they need and doesn't necessarily need to be, you know, hand over hand, for them, just being able to stand back and go, 'Okay, no I can let that go, or this is where I need to step in or this is where I need to back off' because it's important that they

[people with developmental disabilities] do as much as they can on their own

otherwise it's just, you know, a useless experience, for them.

While having one-to-one support is not always an option, Sabrina has indicated that if

too much support is offered during an activity, the activity becomes worthless. The idea

that people facilitating recreation for people with developmental disabilities can over-

control a leisure opportunity is mirrored by Tregaskis (2004). Independent leisure

providers, in Tregaskis' research, who took a policing approach to supervising leisure in

a community leisure setting created an environment where leisure participants were

hesitant to even talk or enjoy themselves. Pedlar et al. (1999) discuss the lack of

challenging vocational and recreation opportunities for people with developmental

disabilities and indicates that in some cases their supports can also be hindrances.

The experience of parenting a child who has autism has been extensively

documented (e.g., Seltzer et al., 2001; Gray 2002; Woodgate et al., 2008). Often the

autistic child's inability to control emotional reactions and therefore crossing *the line* in

public settings is cited as a major disruptor of family life (Benderix et al., 2007; Gray,

2002; Woodgate et al., 2008). Aggressive physical or verbal reactions in autistic children

seem unpredictable for their non disabled caregivers (Benderix, Nordstrom & Sivberg,

2007; Ferguson, 1992; Gray, 2002). In some instances the behaviour is so difficult to

interpret and manage that parents are unable to cope with it in their own home and

require alternative living accommodations for their child (Benderix et al., 2007).

Conversely, with the exception of Williams (1992), there is little insight into the

experience of being parented from the perspective of people with autism.

What is profound about the relationship between Sabrina and James is that she is

able to negotiate instances of James crossing *the line* in public, maintain a positive

attitude and continue to support James in public settings. This ability to negotiate *the*

line may be one of the factors responsible for the group of families indicated in Burns

and Graefe (2007) who found that having a family member with a disability was not a

significant barrier to outdoor recreation. According to a study on hardiness in parents of

children with autism (Gill and Harris, 1991), Sabrina's state of mind may be the most

important factor in her negotiation of stressful instances when supporting James. In

their study, Gill and Harris (1991) found that when parents of autistic children had a

strong belief system, felt effective in their parenting skills and viewed stressful events as

opportunities for growth, they were less likely to experience stress related symptoms.

For James, having a person to support him who was hardy enough to endure the social

consequences of his sometimes *line* crossing behaviour, yet still retain the emotional and

mental capacity to support James in these environments, was an essential component of

his lived experience.

Sabrina has a strong belief system and also views stressful events as opportunities for growth. This is exemplified in her thoughts on protecting James from the possibility of social stigmatization that often governs what experiences parents allow their children with developmental disabilities to be involved in.

> I think parents [of children with developmental disabilities] are all focused on different things, right? And you know, them having an athletic experience isn't high on the priority list, and we also spend a lot of time protecting our children. We're protecting them from bullies and we're protecting them from being humiliated and made fun of. You don't want to hear the, "That's the, you know, 'tard kid." You know, you don't want to hear that, so we isolate our children from that. Unnecessarily so, you know, because they're not going to build resilience unless you present them with that, and that is a failing for us [parents of children with developmental disabilities] on a number of levels.

Part of being a parent for Sabrina means providing the opportunity for James to have experiences both negative and positive that can lead to personal and emotional development. An entry in my reflective journal writing just after going rock climbing refers to my impression of Sabrina and James' hardiness, developed over a lifetime of living together: "Overcoming social anxiety is not just a process for them [Sabrina and James] but for us [society] as well, [for example] Sabrina and James standing below the

cliff together, battle hardened warriors, out of their element, but sticking together."

Sabrina has taken James to an unknown environment with an unknown group of people

with unknown social norms. Within this context, James has had some verbal outbursts

and potentially embarrassing behaviours, but both James and Sabrina stand side by side

the entire time and do not get separated from each other. While the journal entry is brief

and disjointed, it provides a brief window into the apparent underlying assumption that

my version of society is one where Sabrina and James are singled out due to James'

disability and that both mother and son must become hardened or hardy to endure living

in a world where she and her son are considered as different from the norm.

To contrast this perspective, I present one aspect of Sabrina's hardiness which

includes the caring perspective she takes in relation to her son. "I look at James as a

person, he's my kid and everything, the law makes me love him (joking chuckle), but

over and above that I think he's just a really cool person and I don't mind hanging out

with him. And there's a lot of parents [with children who have developmental

disabilities] who don't [think this way], and it's sad." For James, Sabrina's flexible

approach to supporting him and her desire to embrace risk and provide opportunities for

growth, mean that James has the potential to experience and develop. One of Sabrina's

personal findings during this research is as follows.

[The outdoor recreation activities] had a greater risk to them, than I would ever be comfortable with which was good because then it challenged him to do things that he wouldn't normally do obviously and it challenged me to recognize that he is capable of doing those things with those risks...as a parent, you overprotect your child, therefore you keep them cloistered from those activities.

Part of the experience for both James and Sabrina was a dialectical exploration of James' abilities. James would demonstrate his proficiency and ability to perform in the recreation setting and Sabrina would alter her perception of his ability to participate in risk inherent activities. She also came to the realization that James could be involved in regular community programming as opposed to specialized disability focused programming.

This negotiation of constraints closely relates to the findings of a study on inclusive outdoor recreation experiences for families that include a member with a disability (Scholl et al., 2003). First of all, James is 19 years old, which is when he "ages out" of his community offered recreation programming, an issue of importance to the parents interviewed (Scholl et al., 2004). For the families, outdoor recreation provided an opportunity for the entire family to participate in "normal", age appropriate recreation and to overcome perceived constraints to recreation, an issue of importance in other related studies (Lassetter et al., 2007; Mactavish & Schlein, 2004). This study provides a

textural account of findings similar to Scholl et al. (2004). Family members could participate in the programs along with James and the family overcame perceived constraints to recreation. In some cases, James would inspire family members to participate in activities they were initially hesitant about.

During the first kayaking experience, James' sister sat on the shore and watched because she was afraid she would roll the boat. When James took off in the boat and raced across the lake, she was so excited she used her cell phone to call her mother. The next time we went kayaking, his sister decided she would participate as well. James' participation inspired her to overcome her fear and join in. Sabrina had a similar experience. After watching James rock climb outside, she decided to climb up a steep path to the top of the cliff that she had initially avoided. She proudly posted her accomplishment in a humorous statement on a social networking website. "Andrew tried to kill me with the rock climbing."

In conclusion, James experiences are regulated by the support of his family. Having a strong relationship guided by Sabrina's hardiness, values and care for James created the opportunity for situations where James enjoyed himself in social recreation settings (Mactavish & Schlein, 2004). Having a close person to share the experience provided a venue for James to share his stories and communicate his preferences, therefore leading to more experiences. Originally I had intended to do each outdoor

recreation activity once, however, since James enjoyed kayaking so much, Sabrina

encouraged us to go again. Since the activities ended, Sabrina and James have attended a

kayak show and also are looking for paddling partners within their community of friends.

Through his relationship with Sabrina, James has access to many possibilities.

Myself

My relationship with James evolved over the course of the research. This

evolution was influenced by several experiences that greatly shaped the experience of

research. After our first meeting, Sabrina mentioned that James had taken to me simply

because I spoke directly to him instead of looking to Sabrina to answer for him (Rabiee,

Sloper & Beresford, 2005). I thought Sabrina was simply being polite, however she

stated the fact that he did not simply leave the room after a couple of minutes was proof

of his approval. As the social model of disability suggests, I wanted to hear James' story

and have him guide the research process (Knox et al., 2001; Rodgers, 1999). I wanted

James' voice to be the voice of authority (Hutchison & Samdahl, 2000). When I

presented him with an assent form and he slowly read it out loud, one word at a time, I

realized that, even though I had tried to simplify the language, it was not an effective

form of gaining consent (Knox et al., 2001). I also realized that while my scripted

experiential activity and Photovoice training were effective in showing me that James

would be able to photograph things that were important to him, they were not effective

in informing James as to what he was agreeing to participate in. Therefore, using a

flexible approach to circumstance (Patton, 2002) Sabrina, James and I all agreed to go for a 'practice' hike followed by a 'practice' interview.

Sparked by the realization that informed assent for James was indeed continuous process that occurred throughout the course of the research by monitoring his unique style of communication (Cocks, 2006; Knox et al., 2001; Rodgers, 1999), I was beginning to understand that the application of theory that has been read in an office does not directly translate into competence in the field. I found it distressing to balance what I thought was expected of me in terms of methodological rigor with the relationship that James needed to tell his story. In essence, I felt, "disempowered by uncertainty, unfamiliarity [and my own] feelings of inadequacy" (Morris, 2003, p. 343) at both the process of participant observation and interviewing James. Initially, he did not give me the information that I wanted or expected and it was not until I gave up my attempt at objectivity and decided to, "be with" James (Morris, 2003, p. 345) that I was able to hear James' true story. The following paragraph recounts a pivotal experience where I finally was able to "be with" James in the way that was required of me.

During our first kayaking experience, I facilitated introductions between James and a group of kayakers. I let James introduce me and he referred to me as "teacher" which surprised me initially. I thought that James perceived me as the fun person who facilitated exciting experiences for him. Upon telling Sabrina that James considered me

a "teacher" she felt that he had recognized me as an authority figure. My persona as an

authority figure and teacher was apparent during the interview process. Despite reading

Wyngaarden's (1981) suggestion to avoid creating a testing environment during

interviews with people who have developmental disabilities, that is precisely what I had

done. I refrained from becoming fully involved in the activities, talking into my voice

recorder or making field notes and then later questioning James about each picture that

he took. He would respond to me as he would to a teacher during the interviews. He

named the subject of each picture and, if pressed, would count animals or trees, tell me

what colour they were and would make the appropriate noise for each animal. I did not

have the required credentials to gain any more than superficial access to James' world

(Knox et al., 2001).

I was also denying the fact that I was a part of his story from the beginning. As

Sabrina stated, "James is a very physical and active person so, he liked getting out and

doing all sorts of physical activity... but the other part too was the activities that he was

involved in were not activities I ever would have picked even if I wanted to take him on,

um, a recreational thing." I had recruited James and his family to do outdoor recreation

activities they would not have otherwise accessed, however I still wanted to keep myself

separate from James during the activities. I was hoping that others would facilitate the

activities so that I could document his story from a distance, however I could not

ethically remain separated from James experiences and still affirm and document his story (Cottle, 2002).

The moment at which I assumed my role was during our first day kayaking together. I sat with James' sister at a picnic table waiting for the kayaking facilitator to come over so that I could observe and take notes. It became apparent that we would be waiting a long time for someone to recognize that James was waiting and that in the interim we would have to sit at the table waiting. At this moment I distinctly remembered being questioned during my proposal defence about my role during the activities. My impression was that leading the activity would have a negative influence on the research. However in this situation it was apparent that if I did not lead, then James would not have a full experience. To me, sitting back and observing him miss out on an experience was not ethical behaviour for a researcher. If I sat back and waited while James walked around on the beach, I would be denying James the chance to create a story while I told what would then be the story of others denying him access to the experience. Since many of the people leading the activities knew who I was they may have been confused about my role and expected me to take the lead, therefore writing that they had denied James a chance to participate would not have been an entirely accurate observation. In making a decision whether or not to support James, I quickly decided that the experience had more value than my objectivity and separation from the

research. I then fitted James up in kayaking equipment. Since each of the other kayakers

was travelling along the shore with a support worker sitting on the back of the boat with

their feet on the ground directing the boat, I did the same with James. James, however,

had ideas of his own and was quickly trying to race across the lake. I redirected his boat

back into the line but after he broke away two or three times, I told his sister to hold his

boat. I got a boat for myself (see Figure 13) and off we went across the lake to paddle

and explore. While we were paddling, James' sister phoned Sabrina from the shore and

Sabrina recounted, "his sister told me, you know was exactly that. You know they were

supposed to be going parallel to the shore line, and he was just having none of that and it's just like, 'I've seen this on TV once' and that's the way he is, I've seen it done once, I'm a genius, I can do it, I'm gone."
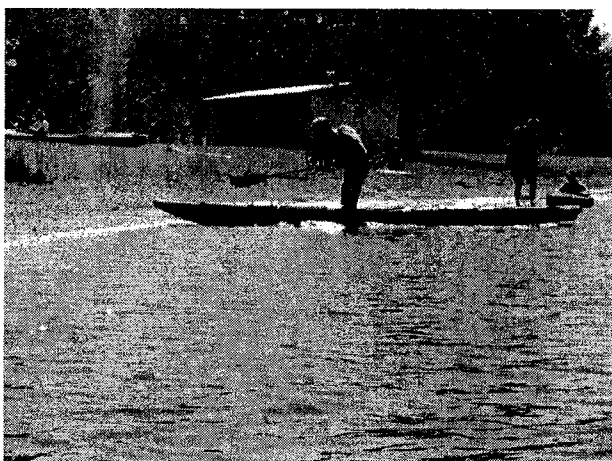
Figure 13. Picture of Andrew getting in his boat

While I was able to maintain my research role in taking notes from time to time,

we were sharing the experience together co-participants. During all activities after the

aforementioned kayaking experience I became a support and companion for James as

well as a fully active participant during each activity (Spitzer, 2003). By affirming my

part in his story, as a full participant, I accepted that, to participate in these activities, he

required my support and therefore I seemed to also affirm his story (Cottle, 2002). As

Sabrina stated, "You're his side kick, you're [the] Robin to his Batman." In her eyes, he

was the leader and the ultimate creator of the narrative, but I was his necessary

subordinate, facilitating adventures in my role as a sidekick. I felt it was significant that

after kayaking together, James always referred to me as, "Andrew" instead of "teacher";

I had gained the credentials I needed to become a genuine person with my own name in

James' world (Knox et al., 2000). Despite having program leaders during each activity, I

became the primary support for James during each activity. Horseback riding, in which I

had no experience, was the exception. I

ensured that James had the appropriate

equipment and was both safe and

comfortable within the outdoor settings.

My observations became more than

documentation but also caring and
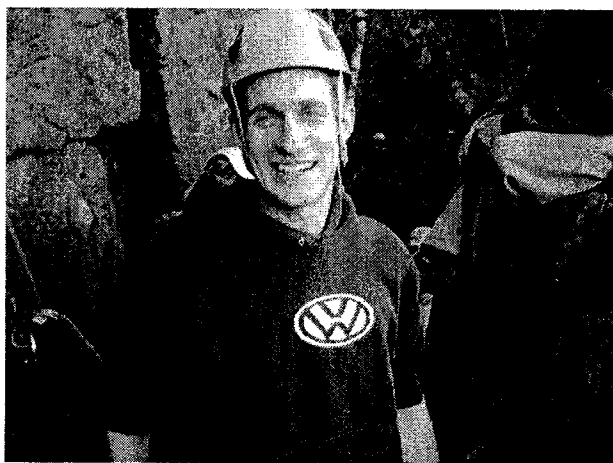
Figure 14. Picture of Andrew taken during rock climbing.

accommodating when possible (Cottle, 2002). I felt as though I was introducing James

to these experiences and that it was partly my responsibility to ensure that he was having

a good time. I was surprised during the last activity when James came running across a

parking lot and gave me a big hug. I did not expect this display of affection. Up until this

point I had not observed any physical public or private display of affection from James. This led me to question what rapport and having a trusting relationship are within the social model disability research, especially with people who do not primarily communicate through speech.

In her research observing children with autism, Spitzer (2003) states that, "Researchers need to suspend judgment and operate under assumptions that recognize all of a child's actions as being potentially communicative....Highly individualized communication systems can be built on the shared experience of participating in daily [occupations]" (p. 72). While James never verbally communicated that we had developed a strong relationship, we developed a communication system both during field work and interviews. During field work, James and I would communicate through action and brief verbal prompts. During both canoeing and kayaking, James would help me load, unload and tie boats with little to no words exchanged between us. He communicated that he wanted me to follow him during kayaking by always stopping a certain distance away from me, looking back and waiting for me to follow. Increasingly, I noticed that James would disengage during small talk, so I slowly stopped trying to engage in conversations with him. For me this meant becoming comfortable with remaining silent during periods of inactivity and verbally communicating when necessary. We seemed to understand each other most when we engaged in what Spitzer

(2003) would call "shared occupations" (p. 72) and simply got to know one another through our behaviours during these periods of occupation.

While there were still definite communication barriers between us, especially during the interview process, I found that within our relationship, James and I developed individualized communication techniques efficiently. I think that one of the key elements of my relationship with James which influenced both our communication and engagement with each other was that I was not a paid friend. I mentioned this idea to Sabrina and she believed that James was aware that I was not an employee and that it had positive implications to our relationship. What Sabrina and I defined together as "paid friends" are support workers or personal assistants who facilitate experiences for people with developmental disabilities. Schelly (2008) refers to paid support relationships as being created by the socially constructed concept of disability where people with disabilities require paid staff to function normally within society. The prevalence of paid friends is uncovered by examining sources of knowledge that inform disability research. Some recreation related examples include McAvoy et al., (2006) who relied heavily on several support workers for input into the effectiveness of outdoor recreation on people with disabilities. Schelly (2008), who reflected on his role as a paid personal assistant for his research participant; Cole (2001) who observed support workers while they delivered programming and reported on their experiences, as well as

Forster and Iacono (2008) who interviewed Developmental Support Workers to understand their interaction with a person who was profoundly disabled. Although Sabrina was not paid, I relied heavily on her to inform this study.

Outside of the university, I also work as a paid friend, supporting people with disabilities in leisure and recreation activities. I found the experience of being with James freeing. There were no time lines or hourly restrictions. In essence, my shift never ended so we could participate in each experience as long as we wanted. There were no agency guidelines, policies or therapeutic objectives to follow. We were just free to be ourselves. I was not trying to 'normalize' James but simply shared lived experience with him (Winance, 2007).

Within the phenomenological paradigm, there were no right or wrong behaviours or reactions during the activities, because James' story simply emerged through whatever behaviour and language he decided to use and whatever pictures he decided to take (van Manen, 1997). I was free to support James and experience the activities along with him and he was free to be himself. Cocks (2006) seems to have had some experiences similar to my own during her participant observations within a setting that contained special education staff. One of her initial interactions with Tim, a student with autism, involved passing a piece of fluff back and forth between each other. This was something that Tim would only do with people he trusted. He seemed to sense that

Cocks had no agenda aside from sharing an activity (occupation) with him and so she gained his trust and a relationship much more quickly than staff working with Tim thought was likely. Spitzer (2003), in her attempt to both experience and observe autistic communication and perception, took an empathetic approach to observation, listening to audio recordings of ambient noise during observations as well as mimicking body position of children to see what they saw from their perspective. Spitzer (2003) concluded that perception and language for people with and without autism operates on a continuum as opposed to being a dichotomy. What we share is being human.

The relationship between James and I inadvertently became an attempt at living what Schelly (2008) and Winance (2007) discuss as a shift in paradigms from normalization to reconstructing our social view of ability and difference. I began the research attempting inherently to personify a 'researcher' role hoping that James would somehow miraculously provide 'normal' data during the interviews. As the data collection proceeded, I began to realize that his mode of perception and communication did not fit within that paradigm. I could not be the typical researcher nor could he provide the typical data.

The Others

Although James was quick to photograph and point out his family members and I, there were many other people involved in the study of which James seemed to take no notice. In his interviews and in recollecting experiences to his mother, James made no

mention of several people he had interacted or spent part of his outdoor experiences with. In three instances, James had photographed an activity leader, two of whom he referred to as 'teacher' and one of whom he referred to as 'man'.

While the experience of social relations between the disabled and non disabled within a recreation context has been explored (Devine & O'Brien, 2007; Devine & Parr, 2008; Tregaskis, 2004), this study is unique in that it attempts to capture the experience of a person who was unable to reveal complex social phenomena in a formal interview through participant observations (Cocks, 2008) and self-directed photography. James' experience differed from those documented in previous research (Devine & O'Brien, 2007; Devine & Parr, 2008) in that he did not seem concerned with social acceptance and involvement. While difficulty with social interactions is a defining criteria with respect to autism and PDD, (Brown, 2003), Orsmond et al. (2004) suggest that it is unknown whether people with autism are not as interested in social relationships or simply have difficulty with social behaviors such as eye contact and empathizing. By exploring James' experience of interacting with others, a deeper understanding of James' social relations outside of his family can be gained.

In several social situations involving people that James did not explicitly know, James would tune out and make indiscernible vocalizations, quoting movie lines, rocking back and forth and talking to himself about his favourite things, such as the

movie *101 Dalmations* and *Transformers*. The experience of a canoeing day trip in small group of five provides an example. When our group stopped for lunch in a small bay, James made excited exclamations about eating, and all of the other paddlers could relate to this. We sat down to eat and one of the paddlers attempted to engage James' in a conversation.

P: How old are you?

J: How old are you.

P: Yes, how old are you?

J: Yes, James....Happy?

James was unable to understand the context of the question or provide an answer. Thus the social interaction ended with awkward silence until I finally cracked and shared James' age with everyone. For the remainder of lunch we all sat on the hard, Canadian Shield granite, making small talk and at times I would look to James for any sort of input, as if eye contact would somehow include him in the conversation. After a short while, James finished his lunch and he began talking to himself, alternating loud noises with whispering to himself about the movie *101 Dalmations*. In this case, James was unable to be involved in further conversation and retracted into his own mind.

Often the social aspects of an outdoor experience are considered to be some of

Figure 15. Sole picture taken during canoeing

the most important. Loeffler's (2004) participants describe the experience of shared decision-making and reliance on others as a major component of the outdoor experience. Participants in an outdoor psychosocial rehabilitation program found meaning and enjoyment

in sharing time with others, both eating and performing simple tasks, like washing dishes

together (Wilding, 2000). Dillenschneider (2007) felt it was awkward when a physically

disabled individual was excluded from the social milieu of a shared lunch spot on a

canoe trip because this site was inaccessible for this individual. The experience of

watching someone be excluded from a social context because of a disability gave rise to

Dillenschneider (2007) publishing a set of guidelines on how outdoor leaders could

avoid this situation in the future. While James enjoyed sharing engaging experiences

with Sabrina, his sister and I, he was not as interested in interacting with people he did

not know. Despite spending an entire day canoeing with several people who shared a

boat with him, ate lunch together, talked and endured paddling against a strong

headwind, not one of these people were included in the sole picture he took that day.

The only things James recollected of this event during the interview was what he had for

lunch, "it's a lunch cake...it's a cake, hotdogs, the coke, pepsi, 2 pepsi." That there was a spider in the boat, "there's a spider, in the canoe spider" and also that he went slowly and quickly in the yellow canoe, "canoe in water, fast. Slowly. Slow down."

There were several instances where he seemed to place little or no significance on social interactions and people other than with Sabrina, his sister and I. Some people seemed not exist to him or simply did not warrant interaction.

Conversely, James often appeared to be disregarded by many people present in the activities as well. During the rock climbing activity, several people climbed in close proximity to James, his mother and I. With the exception of one young lady, many people simply ignored James. He would have been difficult to ignore, considering that he talked to himself while on the ground and made loud exclamations while climbing. For some people, unsure of how to deal with this novel situation, it may just have been easier to ignore James' presence than to engage in social interaction.

After James' aforementioned brief verbal outburst at the top of the cliff during rock climbing, an instance of mutual avoidance occurred. While organizing my rope at the base of the climb, I thanked one of the activity leaders for doing all of the top rope set ups. He said, "Well, you have your hands full", which I would assume was a reference to my responsibility of managing the loud, disabled fellow since I had not done anything else. For most of the activity, none of the activity leaders or participants

paid any attention to James and it was apparent that they considered his experience to be

my responsibility. To the activity leader and some of the other climbers, James was the

other (Wendell, 1994). The idea of the *other* relates to the non disabled experience being

the subject of greater importance for society, and therefore, disabled experience is the

other or of lesser importance (Wendell, 1994).

During rock climbing, James was different than the general participant. This

communication style and behaviour immediately separated him from the rest of the

group. James is not the typical person expected to show up at the cliffs. He is sometimes

loud, he does not wear typical outdoor clothing, he does not engage in small talk and

therefore he is perhaps unknowingly perceived as the *other*. While rock climbing

participants probably did not intentionally and consciously ignore James, the pervasive

social structures inherent in society which I consider *the line* seemed to make it difficult

for people to recognize James' presence during the activity.

Conversely, the activity leader was the *other* to James. While the activity leader

did a brief instructional session, which we all gathered around to observe, James

completely ignored the leader while talking to himself and moving his hands. This

duality of being unable to relate to each other is similar to Tregaskis' (2004) statement

that the experience of a disabled person's oppression is shared by the oppressed and the

oppressor; and that neither may be aware its presence. During rock climbing, neither

James nor any of the non disabled participants were probably aware of the social context

and variables that led to a normative system where James' behaviour and style of

communication was considered *line crossing* (Winance, 2007). What is real is the

otherness that existed for both the non disabled and disabled people during this activity

and the need for someone to translate and bridge the gap that exists in the interface

between the non disabled and the disabled in this setting (Tregaskis, 2004).

Some researchers have provided suggestions on how to negotiate *the line*.

Ferguson (2001) suggests that humanizing atypical behavior or translating the behavior

so that people in the context can understand its purpose from a human perspective is one

technique to cross *the line* with respect to social "otherness".

Grandin (2006) and O'Neill (2008) discuss the autism

spectrum as part of a continuum of human functioning

where differences in cognitive functioning come with

unique sets of strengths and weaknesses. Winance (2007)

has suggested that the renegotiation of social norms is
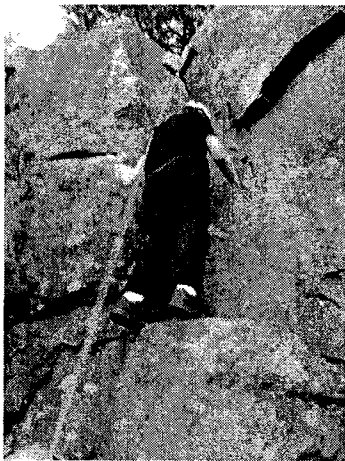
Figure 16. Picture of James outdoor rock climbing

necessary to include people who are considered different

from normal; normal needs to be redefined.

During rock climbing (see Figure 16), I recognized that there was a gap between

James and non disabled participants that was bridged when people could relate to James

behaviours. The loud and angry reaction that James had when getting his equipment on, while socially unacceptable at that time, was completely acceptable while climbing. When James cursed at the rock as he struggled with his first climb, many climbers looked over with a knowing smile on their faces, having experienced a similar thing. Some people even cheered for James, especially on his second climb. As James reached the top of the rock, he let out a loud, "YEEEEAAAHHH HOOOOOOOO!" and others looked over towards Sabrina and I smiling. I interpreted this as the group humanizing James' behaviour and relating to it. His excitement and frustration, while expressed louder than most, was easy to relate to for many climbers and therefore acceptable.

During the interview, James indicated that what was most exciting about his accomplishment during rock climbing was reaching the top of the cliff. While I was aware of the social context and interactions, it seems as though being involved in the social milieu was not very important for James. The idea that James is more interested in doing the activities than in socializing is mirrored by Schelly (2008) in his account of providing personal assistance for a person with autism, "we played basketball; he spoke little and shot a lot, seemingly oblivious that my only role was that of a rebounder." (p. 721) While James seems more empathetic than Schelly's (2008) research participant, James' enjoyment of outdoor recreation was not as focused on the social aspects as what is contained within other research (Loeffler, 2004; Wilding, 2000). Our relationship as it

unfolded could perhaps be an example of me starting as one of the 'others' and then slowly gaining access to his trusted circle. By paying attention to his behaviour as a valid form of communication (Spitzer 2007; Cocks, 2008), humanizing various stereotypical behaviours (Ferguson, 2000) to understand them and acting as a full participant and support during activities, I was able to bridge the gap.

Autonomy

Aspects of Autonomy were largely informed by James' negotiation of outdoor environments. I observed that within James' lived experience of outdoor recreation James was able to either independently negotiate an environment or his interaction with the environment was dependent on others.

Independence

In a kayak, James seemed comfortable and integrated with the water, as though his body was an extension of the boat. He moved where he wanted to, he was fully engaged with the entire area of the lake, looking for the deer, aware of a plane flying over, he would spin his boat around and move around sometimes slowly and at times with frantic speed, or as he puts it, "Kayak, kayak fast! AH!...James fast." Contained within this statement is James' excitement at going fast as well as reference to the fact that he is fast. James is the one making the kayak go fast by controlling the boat and making it move according to his desire.

For James, being independent in his environment enhanced the experience for him. He was able to integrate with his surroundings and engage in a self-directed journey. During kayaking, James seemed to be aware of everything within a visible range, as though the whole area was an environment that he could explore. The water was a new medium for him to travel on. The only sense of constraint that I observed was his need to be close to someone he knew. It was almost as though an invisible string was tied between us. When he got a certain distance away, he would stop and wait for me to follow. The entire space of the lake was open to him, as long as somebody was nearby to experience it with him. Sabrina characterized James awareness of a trusted person within his experience as, "he's putting you into that parental role or that authoritative role…so he's aware of the safety consciousness… he's correlating that, like I'm going to wait now."

Both the indoor and outdoor rock climbing walls were also spaces where his movement on the rock was independent. When he was climbing, my observations indicate that it seemed to take up his entire being; he was engaged. He seemed to be entirely focused on figuring out how to get to the top, thus that his spatial awareness must have been limited to the immediate area (Csikszentmihalyi, 1975). Both his body and his mind seemed completely engaged in the task of climbing. He was also focused between attempts at climbing the rock wall indoors. He would sit on some nearby crash

pads and stare at the wall intensely; Sabrina said he was trying to figure out the puzzle of

getting to the top. He was also proud of his accomplishments. Upon getting to the top of

the indoor wall he yelled, "Weehoo, Yeeehaw, I did it." and, upon returning to the

ground, attempted to tell some runners jogging on a nearby track that he had climbed the

wall. This was the only time during the research that I saw James intentionally initiate an

interaction with bystanders. Another example of his self recognition occurred during

outdoor climbing. Upon arriving at a ledge, close to the top of the cliff where he could

stand and relax, he looked down and said, "Cheese", directing Sabrina to photograph his

achievement (Figure 16). In fact, of all the outdoor recreation activities, James seemed

very proud of his rock climbing accomplishment more so than in other activities

according to his response to pictures during the interview, "Climbing rocks, big rocks.

Climbing up, trees, yes, climbing up, yeah, oh, climbing up, I did it, yeah." In regards to

James' independence, Sabrina said,

> And that was the other thing that came out of the summer, is to recognize…he
>
> wants to do activities where he's autonomous in it? Like he likes the group
>
> activities and he likes doing things with other people, but that was clear between
>
> the kayaking and the canoeing, he loved the kayaking cause he was in the boat
>
> with himself, and got to direct where it went, how fast it went, what he did,
>
> wasn't so keen about the canoeing, cause somebody else was picking and

choosing where he went, you know? So, finding activities like that where he's autonomous and in control,…that's why he liked the rock climbing, cause it was all him, just him doing it, him giving 'er, you know?

In relating James' lived experience of independence in outdoor recreation to theory, I found that studies considering outdoor experiences as transactions with a natural setting provided insight into how the space of a natural setting is experienced (Patterson et al., 1998; McIntyre & Roggenbuck, 1998). The concept of situated freedom that guided Patterson et al. (1998) suggests that an environment naturally restricts what types of activities are possible within it, but people have the freedom to have unique and variable experiences within those confines.

I found that James' experience within outdoor recreation activities was more regulated by the people supporting him than by what the environment afforded. This is perhaps because Sabrina and I would not put James in a situation where he had no chance of being independent. Within both the kayaking and rock climbing settings, it was ensured that James had a good chance of being independent within his space so he could control his interaction with the environment. In reading Rose and Massey (2003) I realize that, within an extended outdoor trip, there is the potential for people with developmental disabilities to redefine their role and support non-disabled people within the context of a challenging experience. Since this research focused on short term

experiences, there is the potential that through longer term interactions James may have demonstrated that he required less support than Sabrina and I provided.

In this case, however, Devine's (2004) important differentiation between being a 'doer' and a 'viewer' in inclusive leisure contexts demonstrates how the social context and the behaviour of recreation facilitators moderate access to independent leisure environments and activities. During activities where James was independent to experience the challenges offered by a particular environment, he was a 'doer'. In other situations however, James was a 'viewer'.

Dependence

During both the horseback riding and canoeing experiences, James seemed more like a passenger or a viewer within the context. During canoeing James was unable to steer the canoe, he remained in the front of the boat paddling and was not in charge of which direction we went. On horseback, James was tied to a lead line attached to the horse ahead of him and thus he had little to no control over his own horse. During both of the activities where James was dependent, he seemed subdued. It seemed as though, instead of integrating and interacting with the outdoor environments and people, he was more of a passenger travelling through them. On horseback, the horses travelled along their path at a consistent speed and pace. While participants in Wilding (2000) found this type of passive travel exhilarating, one spoke to the lack of control over their mode of travel, "[the horses] would do it their own way and when they got behind they would

trot and you could pull on the reins as much as you liked, but it didn't matter, they didn't

stop" (p. 5). James did not have the opportunity to direct the horse. It merely followed

the lead horse.

While canoeing, despite being an active paddler, James was in the bow of the

boat and could not steer or contribute to the direct of travel. I wondered if the experience

for James was almost like travelling on a tram ride, passing through an environment and

watching. Perhaps he was experiencing a state of pleasantness (Vitterso et al., 2001). His

mother indicated that he enjoyed riding the horses and talked about a miniature horse

that was neighing to him during one horseback ride. Despite this feedback, James

seemed much more animated and excited during our initial walk through his

neighbourhood than he did during both canoeing and horseback riding activities.

Returning to the idea that James' experience of outdoor environments is highly

regulated by non disabled people, Sabrina's perception, of what James was capable of,

regulated which experiences he would be exposed to. As James demonstrated his

competence in certain activities, Sabrina became more receptive to activities deemed

higher risk, as for example, rock climbing. At the beginning of the study, Sabrina

emailed me, "James would love horseback riding...kayaking sounds fun...Rock

climbing at the bluffs is a bit too much! He would be freaked out by heights" (July 19th).

On August 19th, after participating in some of the activities, I received an email from

Sabrina which ended, "Rock climbing sounds fun, we'll see if he likes it." And by

September 2nd, Sabrina seemed excited at the prospect of James outdoor rock climbing,

"let's cross our fingers [that it doesn't rain] for next Tuesday... so he can be Spiderman

again..." Her perceptions shifted as James successfully participated in the various

activities.

What I learned from James was that he most enjoyed being in situations where

he was independent within the environment. Understanding that James' access to

recreation contexts is highly regulated by his social supports, it is apparent that his social

supports need to create an environment both socially and physically where James can be

independent to the maximum extent. Within the broader social context it is apparent that

some people with developmental disabilities are involved in passive, sedentary

recreation designed to pass the time that is regulated and supervised by staff (Hayden et

al., 1998; Hutchison & Potschaske, 1998; Tregaskis, 2004). In situations where people

with developmental disabilities are unable to communicate or make choices within the

mode selected by their caregiver they become passive viewers in decisions about their

preferred spatial surroundings both from a recreational point of view as well as in a

broader societal context (Devine, 2004; Pedlar et al., 1999; Schelly, 2008; Tregaskis,

2002).

By examining James' autonomy within outdoor recreation activities, I began to listen to his story of what space he would prefer to be in during his recreation time. I had the luxury of no other agenda or responsibilities in planning and participating in his recreation and so I could gain a unique perspective. Through his pictures, behaviours and discussion, James actively communicated a substantial amount of information about his preferences. With respect to lived space, James' control and autonomy in an environment changed his experience of it.

While not all individuals require risk and challenge, autonomy and control is one horizon of meaning that is shared within various related research. For one recreation group with disabilities in Tregaskis (2004), the staff simply watched and policed participants while smoking and exchanging inappropriate jokes, there was no autonomy or control for participants. In both Wiersma (2003) and Wilding (2000), people who had been institutionalized were put in an outdoor environment where they had control and autonomy. Moving from a setting that had automatically locking doors and policed entrance ways to a cabin which had unlocked sliding doors and a sunny deck to sit on was very freeing for all participants (Wiersma, 2003). Within a strong supportive family structure, with a parent who was actively seeking out positive opportunities for James, having a chance to experience challenge and risk in new activities was a chance to exercise autonomy and explore aspects of his personality as he becomes a young man.

Methodological Results

The secondary objective of this research was to pilot photo elicitation as a technique for accessing the lived experience of a person with a developmental disability. Since James had minimal verbal skills, this research presented a unique challenge, both for James in communicating his point of view and for me in attempting to understand what he was communicating. Upon completing my fieldwork, I came across a recent Photovoice study done with people who have intellectual disabilities (Jurkowski, 2008). James and I directly experienced several of the challenges that Jurkowski included in her conclusions:

- The ethical challenge of ensuring that James was informed and assented to participating in the research.

- The fact that I could not communicate with James regarding appropriate times and places to take pictures

- Difficulties in engaging in a critical discussion of the photographs that James took which aside from Jurcowski (2008) was also experienced by Dyches et al. (2004)

In light of these challenges as well as other unique challenges that James, Sabrina and I faced over the course of the research, the guiding framework, philosophy and ethical discussion contained within Photovoice methodology (Wang & Burris, 1997; Wang & Redwood-Jones, 2001) allowed Sabrina and I to gain a substantial amount of

knowledge about James' lived experience. To explore the benefits and challenges of photo elicitation as it evolved over the course of this research, I will discuss the processes of informed consent, taking the photographs, using alternative data sources and formal interviews.

Informed consent

Although I have discussed the experience of my initial meeting with James within the theme of Relationships/Support, it is necessary to discuss what worked and did not work with respect to informed consent. Despite developing what I thought to be an appropriate assent form (Wang & Burris, 1997) designed for my perception of James' ability, when presented with assent form, James could read the words but could not comprehend the implications. Initially, I had developed an experiential activity (Dyches et al., 2004) to conduct the training suggested by Wang and Burris (1997) and this activity served a function in informing assent. To ensure that James understood what he was committing to, I created a training activity that allowed his behaviour during the training to be the source of assent to participate as opposed to his signature on an assent form. I also realized that his assent would be an ongoing process throughout the research and I would have to pay attention to his behaviour and ensure I was acting in accordance with his expressed choices. While the idea of using an experiential, ongoing approach to assent were initially informed by Dyches et al., (2004), Knox et al. (2000) and Rogers

(1999), after collecting my data I found strong support for using an ongoing, sensitive

approach to assent (Cocks, 2006; Morris, 2003; Spitzer, 2003).

During our first meeting, I asked James to photograph something important to

him. He went up to his room and collected some of his favorite movies, placed them on

the table in front of me and photographed them. It was obvious that he knew how to use

a camera and was able to understand what I had asked of him, but actually explaining

the research process seemed too abstract to be effective. Therefore, Sabrina, James and I

agreed to go for a walk down some outdoor paths near his house. During the activity,

James photographed things that interested him. When we returned to his house, I

recorded an interview of him discussing the pictures with me and played a section of the

interview back to him so that he knew I was recording him. He seemed intrigued with

hearing his own voice and I considered this to be assent. Sabrina was also present for

this walk and the interview to advocate for James.

As the person who legally consented for James to participate in the research,

Sabrina was a strong advocate for James, translating his communication and managing

the research when required based on James' interests. Often requiring the consent of a

third party creates difficulty within the research process (Lennox et al., 2004), however

having Sabrina as an active part of the research was very helpful. She sat with us during

the first interview to advocate for James, she cancelled activities if James was not up for

them and acted with James' best interests in mind. When I could not interpret what James was feeling, I could consult Sabrina and get her expert advice. During this research, having active third party consent was a valuable part of the research process. There were times however when both Sabrina and I influenced the research in ways I hoped to avoid. I will discuss these in respect to James' photographs.

Photographs

The influence of authority figures on the subjects of pictures within photo-based research has been discussed (Dyches et al., 2004; Rampton et al., 2007) and I was able to witness this influence first-hand during my fieldwork. During our initial walk activity, Sabrina would point out things that she knew James was interested in for him to photograph. Since I was concerned that James might photograph things that we wanted, instead of what he was truly interested in, I mentioned that we should not tell James what to photograph. Later on I was confused when James did not seem to take any pictures during horseback riding. Therefore, at certain points during the activity, I would ask James if there was anything he wanted to take a picture of. At one point during horseback riding I saw Sabrina look over at James and mimic taking a photograph as if to remind him to take pictures. I think she could sense that I was concerned about the lack of pictures James was taking. I thought that if he did not have many pictures, it would be difficult to interview him and I would have limited data.

While reflecting on whether I should completely halt any sort of prompting during the activities, I considered Loeffler's (2004) ethical stance. She decided not to direct students to document their outdoor experience with respect to her research study because she felt making photography and documentation a large focus of the activity potentially detracted from the overall experience. I thought that perhaps I should just let James experience the activities without reminding him to take pictures and see what happened. After making the decision to limit prompting, I witnessed James racing across the lake during our first kayaking activity and scrambling for his camera to photograph the three deer he saw. It was apparent that, if something was vivid and worth documenting, James would photograph it independently. Consequently, I made note of both prompted and unprompted pictures in my field notes during activities, and separated them during my analysis.

During our last activity together, James reversed the roles and prompted Sabrina and I to take his picture. While he was rock climbing, he looked at both of us and said, "Cheese" directing us to photograph him. Towards the end of the data collection period, James would also manage his pictures. As he became more adept at using the digital camera, he would review some of his pictures after taking them to ensure their quality. In some cases, if a picture was too blurry, he would retake the picture.

The process of taking photographs was an evolution. Where initially Sabrina and I were tentative about James' ability to independently document his interests through photography, through negotiation and critical reflection we were able to let James guide himself. As James became used to the photo elicitation process, he was increasingly autonomous with his photographs and in some cases actually directed Sabrina and I to take pictures.

Another issue regarding participant photography is that I was unable to communicate to James issues around photographing people without their written consent (Jurcowski, 2008). During our initial training walk, James took several pictures of dogs that included people who had not consented to be photographed. He also took pictures of vehicles that included license plate numbers. These pictures were removed from the research. I addressed the issue of consenting to be photographed by discussing the research and handing out consent forms at the start of each activity to all of the participants. James only photographed people who had consented to be in the research. However in two photographs people who had not consented to be photographed were in the background. I compensated for this by reviewing the pictures and removing the two pictures that accidently contained identifiable subjects (Wang & Redwood-Jones, 2001) who had not consented to be photographed.

Interviews

A substantial component of most photograph based methodologies is a critical discussion of participant photographs. Health researchers using photo elicitation have used either individual interviews (Dyches et al., 2004; Rampton et al., 2007; Thompson et al., 2008), focus groups or both (Jurcowski, 2008). For this research, the interviews provided limited insight into James' lived experience. The interview process emerged similar to Dyches et al. (2004) in that although James, "could label the major content in [his] snapshots, [he] could not verbally provide detailed meanings about the images." (p. 179). One effective component of the interview process was being able to see James' affective reaction to the photographs. When he saw a picture he liked, he would sound excited. During analysis I relied more on listening to the interviews to hear his tone of voice than on written transcripts. Another informative occurrence during the interviews was that James would go through all the pictures he had taken up to that point in the summer during every interview. James would get silent and focused and he would often stop on the same pictures each time he went through them and make a whispered comment. I interpreted this behaviour to be interest. Of all the pictures he took, James seemed most interested in the picture of the three deer, followed by pictures of his family members and unique animals such as a miniature horse he called "Minimi", several ducks and a frog.

The limiting aspect of the interviews was the reliance on verbal questioning. Most questions that began with the words, "What, why or how," would be met with frustration by James. At times I would ask him if he was angry or suggest that perhaps he was mad. However he would often deny it. During one interview James seemed particularly upset, but I was unsure if he wanted to stop the interview,

J: Get out! Canadothisrightnow (angry talk) why? Surprise! Happy!....

A: Is there something in the pictures that makes you feel mad?

J: No, no

A: There's nothing that makes you feel mad?

J: No, I hate you. Happy! Youfity (continues mumbly talk)

During the interview I was confused. James seemed upset with me but he would finish his angry expressions with a "Happy!" or some sort of exclamation. I considered his behaviour as revoking assent initially and tried to stop the interview, but when I informed James that I was stopping, he expressed wanting to continue. I began to realize that James did not want to stop looking at the pictures with me. He simply wanted me to stop asking specific questions.

Wyngaarden (1981) suggests avoiding a "testing atmosphere during the interview" (p. 108) and "avoiding questions which might encourage the respondent to

please the interviewer by trying to give the "right" or expected answer" (p.109). In my interviews, despite having read Wyngaarden's advice beforehand, I seemed to have set up a testing environment. He would name the subject of each picture, and if I did not seem satisfied, then he would count how many subjects there were or name the colours. At the end of each of our interviews together, he would finish by asking me, "Happy?" to see if I was satisfied with his performance.

The assumption that James would somehow be able to provide a coherent interview transcript, despite observing his expressive capacity in the recruitment process, points to my error in assuming that photo elicitation, based on a methodology designed for people who can talk about their experiences (Jurcowski, 2008), would somehow cause James to deliver a coherent narrative simply because he could use the photographs as an aid (Eckhardt & Anastas, 2007).

In talking to Sabrina, I learned that Jackie Rodgers' (1999) statement, "successful interviews [with people who have learning difficulties] could take place with very little input from the researcher and much self-directed reflection by the interviewee" (p. 426) would prove correct. James would often provide his mother with a detailed, emotion filled, self-directed story, without any input from me, after he returned home from his outdoor recreation activities. When I learned this, Sabrina and I started exchanging emails and having discussions to record James reactions and comments

regarding his experience of outdoor recreation and so, to some extent, James' true account of his experiences are included, regardless of the interview process.

In future studies, formally consulting family members or trusted supports as co-researchers on both the methodology and research process in the initial phases of the research would be very beneficial (Robison & Wyngaarden, 2003). With Sabrina's help as a formal co-researcher, we may have developed a more effective interview strategy as a team. It is apparent that Sabrina was indirectly conducting an effective interview process despite me formally conducting the interviews.

CHAPTER 5

Conclusions

During the analysis and writing phases of this research I continually pondered the idea that aspects or structures of human experience are shared by all humanity (van Manen, 1997); we all experience time passing, we live in relation to other people, we exist within a space and all of these are experienced through the human body and mind. Yet, within those structures each individual's experience is infinitely variable. There is a balance between the subjective experience of the individual and its relation to shared aspects of human experience, essentially order and chaos. Social model disability research has been negotiating this balance between valuing the individual's subjective experience and collectivizing individual accounts to paint a societal portrait (Walmsley, 2001). I believe that this research presents an individual account of James' lived experience that many people will be able to relate to and learn from in some way. Within the readers' subjective individual experience I hope that there is some component of this research that is grounded within the collective reality of humanity.

One of the most influential writing that influenced my research process was the work of Susan Wendell (1996). She believes that the sharing the perspectives and input of people with disabilities at a societal level will improve quality of life for both people with and without disabilities. I see the truth in her statement when my children are able

to open a previously inaccessible door by pressing a button designed to make the doorway wheelchair accessible. This adaptation benefits many people, not just people who use wheelchairs.

Another realization I made during this research is that the human body and its variations are infinite and nuanced; every person requires some form of physical and social support to account for their inherent strengths and weaknesses. The inevitability of disability and difference is an essential part of being human, and through this work I believe it should be embraced, examined and shared, not feared and avoided.

Guided by James' lived experience, the social model of disability and the overarching phenomenological framework, the implications of this research are explored in order of methodological implications, theoretical implications and practical implications.

Implications for Methodology

One of the primary objectives of this research was to examine whether photo elicitation would be an effective methodology for eliciting the perspective of a person with a developmental disability. In this research, the process of photography was an effective technique for James, a person with a developmental disability and limited verbal communication skills, to document things of importance to him during outdoor

recreation activities. Using a digital camera James was able to independently photograph aspects of the outdoor recreation experience.

As indicated by Jurkowski (2008), the process of verbally interviewing a person with limited verbal capacity was not ideal for eliciting James' perspective. Through the methods used during this research I will present several strategies that may assist in including a person with limited verbal capacity in a photo elicitation study.

- Having the research participant experience every aspect of the study by simulating each aspect of the research process is one technique that may assist in both informing potential research participants who are unable to read consent forms and information letters about the study.

- Research participants who may not be able to understand issues of privacy concerning taking photographs of others can be supported by the researcher or caregiver in the provision of consent forms for potential subjects and removing pictures of identifiable people who were accidently contained within the photographs

- Interview data with people who do not have the ability to fully express themselves within the interview framework may require supplementary data. Participant observations allowed for unique behavioural communication and affect to be included in the study. Being present during the photography to

document context and affect had benefits that needed to be balanced with the amount to which I affected what was being photographed.

- Family members and people known to a person with a developmental disability can provide assistance in translating research participant's unique communication as well as supplement data. In this study, James' mother was able to email me and recount stories that her son had told her when I was not present as well as help me understand certain behaviours that I could not interpret during the fieldwork. Future studies may seek to include the research participant and their family or supports in developing research methods as co researchers.

As an aside to the initial research objective, I found that the varied and context specific aspects of James' lived experience support the idea that outdoor recreation experiences are multi-phased, complex and emergent (e.g., McIntyre & Roggenbuck, 1998; Patterson et al., 1998; Watkins & Bond, 2007). The use of multiple qualitative methods including photo elicitation, interviews, email and participant observations provided numerous pieces of the overall puzzle that is the outdoor recreation experience. In searching for literature that may have related to James' lived experience it became apparent that the lived experience of many outdoor activities remains undocumented from perspectives of the both the disabled and non disabled. Future research into the human experience of

outdoor recreation would benefit from the use of creative, multiple qualitative data collection techniques such as photo elicitation (Loeffler, 2004) and video elicitation (Gibson, 2000). Using a variety of qualitative methodologies not only serves to include people who could not be included in typical research, but also assists non-disabled people in sharing their perspectives in a unique format that may potentially provide rich, unique data (Wendell, 1996). Anderson et al. (2001) wondered, "what is it about the integrated wilderness experience, specifically, that is growth-producing for people?" (p. 228). By better understanding how outdoor recreation is experienced and what people find meaningful in its pursuit, future research can continue to expand its knowledge base.

Implications for Theory

One of the primary theoretical tenets guiding the initiation of this research was that recreation experiences are a part of and provide insight into the social construction of disability on a societal level (Devine, 2004; Devine & Dattilo, 2001; Devine & O'Brien, 2007; Hutchison & McGill, 1992; McGill, 1996; Tregaskis, 2004). In developing and proposing this research I found that research concerning outdoor recreation and people with disabilities is focused on the effects of outdoor recreation on people with disabilities (Anderson et al., 2001; Dattilo & Murphy, 1987; Gibson, 2000; McAvoy, 2001; McAvoy et al., 2006; Rose & Massey, 1993) as opposed to lived experience.

Inherent within the effects based approach are tenets of normalization theory (see

Walmsley, 2001), which assumes that 'us' the non disabled are trying to help 'them', the

people with disabilities, or the stigmatized (Goffman, 1963), become or appear 'normal'

like 'us' (Walmsley, 2001; Winance, 2007). The development of disability related

discourse has evolved from institutionalization to normalization and now the social

model is being encouraged as the next paradigm shift (Schelly, 2008; Walmsley, 2001;

Winance, 2007). The current shift from normalization to the social model is

complicated as the vestiges of normalization theory are difficult to shed. Social model

researchers are struggling with how to restructure research relationships so that people

with disabilities are considered as equals to their non disabled counterparts (Kitchin,

2000; Rogers, 1999; Walmsley, 2001).

I think that outdoor research is engaged in this struggle. One example is Rose

and Massey (1993) who state that outdoor recreation should not be considered therapy

for people with disabilities, a statement in line with the social model, but continue to

document the effects of outdoor recreation as though it is a treatment, a practice in line

with normalization theory.

I accounted for the tenets of normalization theory within my thesis by discussing

my personal reflexivity with the results of this research in an attempt to be as explicit

and transparent as possible. I relied on critically reflexive accounts of social model

research practice (Rogers, 1999; Schelly, 2008; Tregaskis, 2004) to assist me in this process. As opposed to being objective, this research supports the idea that an authentic, interpretive approach to research with people who have disabilities (Ferguson, 2000; Rogers, 1999) is desirable and valuable. Future research into outdoor recreation experiences for people with disabilities would benefit from a clear statement of the researcher's assumptions and agenda. Embracing and adhering to the social model of disability and its related discourse can provide assistance in revealing inherent assumptions that guide traditional research practice so that they can be exposed and accounted for.

For this research phenomenology was an ideal theoretical paradigm, in that through epoche and bracketing it allowed me to shed my personal and political intentions and remain open to all possibilities. Instead of examining James' experience with a specific framework I could adapt the methodology and analysis to attempt to hear James true story as he told it. Using this approach I found an overarching theoretical principle that contributes to both the advancement of the social model within the recreation field. This principle is to view the unique attributes of people with developmental disabilities on a spectrum of shared human experience (Grandin, 2006) by using a humanizing lens (Ferguson, 1992; 2000). By viewing James' communication and behaviour using a humanizing approach, James' lived experience can be

incorporated into the structures and textures that are experienced by all of humanity. The benefit of this theoretical approach is to extend the idea of normal human functioning to include James, who is unique in his differences but similar in his humanity (Wendell, 1996; Winance, 2007).

Implications for Practice

The idea that people with developmental disabilities are segregated from regular community programming is apparent in the literature (e.g Hutchison & McGill, 1992; Jones 2003/2004; Tregaskis, 2004) and stated by James' mother. Within the research setting it was apparent that there were two streams of community recreation programming, one for the disabled and one for the non-disabled. This research demonstrated that James enjoyed and was able to participate in both a specialized program (kayaking) as well as community based programming primarily offered to non-disabled participants (rock climbing, horseback riding).

The main barrier that inhibited community involvement was the line of social acceptability. Although Sabrina did not seem to have as great a fear of social consequences with respect to James' sometimes atypical behaviour as do other parents (Gray 2002; Woodgate et al., 2008), it is apparent that within the research setting, societal structure guides parents of children with developmental disabilities to primarily seek specialized disability based recreation programming. This cultural phenomenon

prevented Sabrina from considering the wide range of opportunities available within everyday community programming. It was also apparent during my fieldwork that the people within community based outdoor recreation programming were not used to seeing people with developmental disabilities sign up for their programs. Based on the results of this research I will present some strategies that can assist in negotiating the line of social acceptability in the practice of seeking and providing unique recreation opportunities, including outdoor recreation.

Within James' lived experience he seemed most engaged when he could participate independently in an autonomous self guided activity with people that he knew, such as his family or myself. Offering recreational activities that allow for autonomy and independence does not just benefit people with disabilities but also benefits anyone who wants to participate in the activity (Wendell, 1996). I was recently shopping for pontoons that can be used to stabilize longer, narrower kayaks so people having difficulty balancing can paddle in a more efficient boat. While I was hoping that James would able to use a better, faster boat by using the pontoons, I witnessed someone testing out kayaks with his wife and he rolled the boat twice trying to get in it. The pontoons would have helped this non disabled person as well. Creating independence and autonomy in outdoor recreation does not simply involve adapting regular activities

so the disabled can be involved but more in creating an accessible setting for a wide range of human ability.

What I learned about socially supporting James in outdoor recreation activities in that it involved interpreting James' unique behavioural and verbal communication with a humanizing state of mind (Ferguson, 2000). What that meant during the research was that I interpreted and related to James' expressed emotions and thoughts by considering his unique communication style as a form of human expression. Interpreting and translating James behaviour communication sometimes required the assistance from people who knew him and were familiar with his communication style. When James had a verbal outburst or behaved atypically crossing the line of what was socially acceptable behaviour within the setting, supporting him required hardiness (Gill & Harris, 1991) to endure the embarrassment of crossing the line of social acceptability and move past the issue to continue supporting him.

In revealing the complex, context specific aspects of the line, it seems apparent that the concept of disability is in a constant state of social renegotiation. Since participating in kayaking, James has attended a kayaking festival and is interested in buying a boat and establishing what McGill (1996) would call a leisure identity as a kayaker. Sabrina is focused on finding kayaking opportunities for James and in mentioning it to her friends has found that people are interested in going kayaking with

James. Through this research James, his sister, Sabrina and I have all renegotiated the implications of his diagnosis and ability level with respect to his recreational opportunities. In sharing James' interests and abilities with others the socially constructed concept of James abilities are being renegotiated on a more public scale. To conclude I will present some suggestions, based on this research, into how outdoor recreation practitioners can begin to extend the idea of normal within their practice:

- Understand and be aware of social norms and assumptions within the delivery of outdoor recreation programming. Creating the opportunity for people with developmental disabilities to participate in outdoor recreation activities may involve some anxiety for everyone involved related to crossing the line of social acceptability established over a long period of time. Incorporating the tenets of hardiness (Gill & Harris, 1991) can assist in negotiating social tension:

  o Adhere to a philosophy of practice that relates to the human aspects of people with developmental disabilities as opposed to diagnostic criteria

  o View stressful events as opportunities for learning, growth and positive change

- Outdoor recreation facilitators, participants with developmental disabilities and their supports may be required to negotiate the line of social acceptability during activities. My results indicate that recognizing and relating to the communication

expressed by a person with a developmental disability, including forms of non-verbal and behavioural communication, is one negotiation technique. For outdoor recreation facilitators and the supports of people with developmental disabilities, this may involve assisting other program participants in understanding what a person with communicative difficulties is expressing through behaviour is so that they can relate to the human aspects of this person.

- Develop outdoor recreation programming that can be marketed simultaneously to both the disabled and non-disabled. This involves:

  o Creating a physical environment where people within a large spectrum of ability can participate autonomously and experience engagement.

  o Creating a social environment where people with developmental disabilities and their supports can feel comfortable and welcomed.

Recommendations for Future Research

There is much to be learned from the lived experience of people with developmental disabilities by creating a research context where they are the primary informants (Dyches et al., 2004; Wendell, 1996). Outdoor environments provide a setting that facilitates a variety of potentially life enriching experiences and serves as excellent research data (Patterson et al., 1998). I think that conducting future research studies during longer and more extended outdoor experiences would create the

opportunity for an evolving group dynamic that could be related to larger societal structures and provide some profound insights. Therefore, I recommend that future research into the outdoor recreation experiences of people could include:

- An examination of outdoor experiences from the perspective of people with developmental disabilities as they unfold over a longer, wilderness based experience.

- An in depth exploration of the communication styles of people with developmental disabilities using participant generated multimedia and participant observation.

- The experience of negotiating social norms for both people with disabilities and non-disabled participants within an extended wilderness based trip.

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APPENDIX A

Verbal Recruitment Script

Hello. My name is Andrew Heppner. I am a Masters student at Lakehead University in the Outdoor Recreation, Parks and Tourism program. I am looking for a volunteer to participate in a research project that is looking at the experience of outdoor recreation for people who have developmental disabilities.

At first we would sit together and look at some different outdoor recreation experiences that you could choose to participate in this summer as part of the research study as well as looking at some experiences that you may already participate in which could be included in the study.

I am using a method called Photovoice. This is a new method that is used to share people's perspectives with authority figures and the rest of society. For this study, Photovoice means that I will be loaning you a digital camera so that you can take pictures of important parts of the selected outdoor recreation experiences. These pictures could focus on parts of the experiences that are enjoyable for you as well as parts that are challenging for you. A day or two after each experience, I will sit down with you, and we will look through your pictures and you can show me what is in your pictures and what they mean to you.

These discussions will be audio taped so that I can have an accurate record of our conversations.

I am doing this project to learn about your outdoor recreation vacation experiences and to share your stories with people who provide funding and support for outdoor vacations. I also would like to see how Photovoice might work with people like you and if we can use it in the future for other groups of people. I think that Photovoice has the potential to help share your stories, experiences and thoughts with a wide audience in a meaningful way.

If you are interested in this study or have any questions, please ask me. I have some forms here that contain my contact information. If you would like some time to think about this study feel free to contact me with questions or comments.

APPENDIX B
Information Letter for Participants

Spring 2008

Dear Potential Participant,

I want to invite you to participate in a study that I am doing through Lakehead University. I am doing this research to better understand the experience of outdoor recreation for people with developmental disabilities using a methodology called Photovoice.

Your participation in this research project would include a number of activities: (1) Meeting with me to choose some outdoor recreation activities you would like to participate in this summer; (2) participating in the selected outdoor with me (3) taking pictures during your outdoor experiences; (4) participating in 30 minute to 1 hour interviews a day or two after each outdoor experience to discuss the pictures you have taken, the interview will be digitally recorded on audio. First you will meet with me to pick outdoor activities you would like to do this summer and talk about what you need to do for the study. You will be provided with a digital camera and instructed on its use. During the outdoor activities you will take pictures of your experiences, focusing on things that are important to you. This may include pictures of activities you participate in, places you go and people on the trip. After each experience, I will take the camera and put the pictures on a computer, and you will be asked to talk about the photographs. I will record this talk on an audio recording device. If you want to keep some or all of your pictures, I will give them to you.

Since we will be participating in these outdoor experiences together, some people may learn that you are participating in this study and know who you are. This means that I cannot promise that nobody will know who you are or that you are doing this study with me.

Our talks will happen at a time and place that works for you. Ideally, I would like to digitally record audio of our conversations so I do not forget anything that you say. Nobody will look at any of your pictures or listen/read anything from our talks except me, unless you and your caregiver give me permission. All of the information you give

me will be kept in a locked filing cabinet at Lakehead University for five years after the study because those are the rules of Lakehead University.

If you would like to take part in this study, I will be asking you to sign a letter, called a letter of assent, saying that you agree to participate. Your participation is completely voluntary and you may choose not to participate. During the interview, you do not have to answer all the questions, just tell me you do not want to answer and I will ask the next question. You may also choose to quit being in this study at any time. If you choose to quit you can still do the selected activities without the researcher and nobody will be upset with you.

You or your caregiver can call the Office of Research of Lakehead University if you have any questions. They can be reached at this number (807) 766-7289. Should you have any questions about my study, please feel free to contact me at (807) 629-5296.

Thank you for your interest and potential participation in this project. I look forward to working with you.

Sincerely,

Andrew Heppner
Masters Student, Masters of Environmental Studies
Lakehead University

APPENDIX C
Information Letter for Parent/Third Party Caregiver

Spring 2008

Dear Caregiver of Potential Participant,

I want to invite your family member to participate in a study that I am doing through Lakehead University. I am doing this research to better understand the experience of outdoor recreation experiences for people with developmental disabilities using a methodology called Photovoice.

Your family member's participation in this research project would include a number of activities: (1) Meeting with me to choose some outdoor activities you would like to participate in this summer; (2) participating in the selected outdoor experiences with me (3) taking pictures during your outdoor experiences; (4) participating in 30 minute to 1 hour interviews a day or two after each outdoor experience to discuss the pictures you have taken, the interview will be digitally recorded on audio.

First your family member and the other research participants will meet with the researcher. Your family member will be provided with a digital camera and instructed on its use. During your family member's selected outdoor recreation activities he/she will take pictures of his/her experiences, focusing on things that are important to your family member. This may include pictures of activities, places and people participating in the experience. After the activity, the camera will be collected from your family member, the photographs will be uploaded to a computer, and your family member will be asked to participate in an interview regarding the photographs that will be audio taped. Your family member will be given duplicates of the pictures he/she has taken, if your family member wishes.

Since your family member and I will be participating in these outdoor recreation activities together, I cannot guarantee anonymity of your family member as they may be identified as being a participant in this research study.

The interview will be conducted at a time and place to suit your family member's preference and convenience. Ideally, I would like to digitally audio record our conversations so I can better understand experiences and have an accurate record of our

conversation. All information gathered throughout this study, including pictures and the audio files of the interviews will be kept strictly confidential and will only be accessed by me. I will provide you and your family member with the chance to provide explicit consent for the use of pictures in any form of dissemination before using them.

All information pertaining to the study will be kept in a locked filing cabinet at Lakehead University for five years.

If you decide to consent to your family member taking part in this study, I will be asking you to sign a letter formally stating your consent for your family member to participate. Participation is completely voluntary and you and your family member may choose not to participate. During the interview, your family member may decline to answer particular questions. You or your family member may also choose to withdraw from this study at any time. Any decision not to participate will have no impact on your family member's services received from any of the organizations involved in this study.

The Office of Research of Lakehead University is available for any concerns and comments pertaining to this study and can be reached by contacting (807) 766-7289. Should you or your family member have any questions about my study, please feel free to contact me at (807) 629-5296.

Thank you for your interest and potential participation in this project. I look forward to working with you and your family member.

Sincerely,

Andrew Heppner
Masters Student, Masters of Environmental Studies
Lakehead University

APPENDIX D
Informed Assent Letter for Participant

I have read and discussed the information letter provided by Andrew Heppner, Masters Student, Master of Environmental Studies Program at Lakehead University, describing the purpose of his study. I understand that our talks will be audio taped and that some of the things I say in the audio taped interview may be written in the final report of the research, but that my name will be changed to a different one so that the people reading it will not know exactly who I am.

My consent for participation in this research project is made under the following conditions:

- That I have read and understood the information in the study cover letter.

- I have been asked to participate in and take pictures of my experiences of outdoor recreation activities this summer and then participate in individual interviews lasting about 30 minutes to 1 hour after each activity.

- Participation is completely voluntary and all of my pictures and comments will only be used for the research.

- I understand that some people might know who I am and that I am participating in this study.

- All information will be kept strictly confidential, that means only Andrew and I will have access to anything used in this study. My name will be changed in anything Andrew writes or talks about for this study so nobody knows my name, and what I said to Andrew.

- I will be provided with copies of all the pictures that I have taken throughout the data collection period, if I want them.

- I do not have to answer all the questions in the interview and the focus group if I do not want to. I can tell Andrew not to use any of my photographs if I do not want him to, I can tell Andrew this at any time.

- I can stop being in the study by simply telling Andrew. If I do not participate or withdraw from the study this will not change my chances to participate in community based recreation activities.

- I do not think I will experience physical or psychological harm from being in this study.

- The researcher will write and talk about this study to share the findings with people who are interested

- All the pictures and comments in this study will be joined together, so that nobody can tell who I am, unless I specifically tell Andrew and sign a form saying I agree to be identified
- All the pictures and comments will be locked in a filing cabinet at Lakehead University for five years.
- I can ask Andrew what he found out from the research after it is over. These will be available through Lakehead University after Fall 2009.

This study has been approved by the Research Ethics Board at Lakehead University.

I assent to providing Andrew Heppner with photographs I have taken of my experiences during the data collection period

___ **Yes** ___ **No**

I assent to participating in an interview with Andrew Heppner after each activity at a time and place convenient for me

___ **Yes** ___ **No**

I assent to having my interview discussion audio taped

___ **Yes** ___ **No**

Name of Participant

Signature of Participant

Date

Signature of Researcher

Date

APPENDIX E
Informed Consent Letter for Parent/Caregiver

I have read the information letter provided by Andrew Heppner, Masters Student, Master of Environmental Studies Program at Lakehead University, describing the purpose of his study. I understand that interview discussions will be audio taped and that excerpts from the audio taped interviews may be included in the final report and/or publications to come from this, but that pseudonyms will be used to identify all quotations.

My consent for my family member to participate in this research project is made under the following conditions:

- That I have read and understood the information in the study cover letter.

- My family member has been asked participate in and take pictures of his or her experiences of outdoor recreation during the summer and then participate in individual interviews lasting about 30 minutes to 1 hour, after each activity

- Participation is completely voluntary and all data will be collected and used solely for research purposes

- I understand that the Andrew cannot guarantee the anonymity of my family member, due to the nature of the study

- All information will be kept strictly confidential, accessed only by Andrew. Pseudonyms for all participants involved will be used on all documents pertaining to the study and in all oral and written reports of the project. My family member's name will never be used unless explicit consent/assent is provided

- My family member will be provided with copies of all the pictures that he/she has taken throughout the data collection period, if he/she wishes

- My family member may decline to answer any questions at any time during the interview and the focus group. My family member may request to have any of his or her photographs eliminated from the research data at any time.

- My family member may withdraw from the study at any time by simply notifying Andrew. Any decision not to participate or to withdraw from the study will have no impact on the support services for my family member, provided by the agency.

- It is not anticipated that my family member will experience physical or psychological harm.

- The finding of the research will be prepared for publication at professional conferences and journals

- The data will be published in aggregate form, and no individual participants will be identified in published results without their explicit consent.

- All data will be securely stored in a locked filing cabinet at Lakehead University for five years.

- I or my family member may request an executive summary of the finding upon completion of the study. These will be available through Lakehead University after Fall 2009.

This study has been approved by the Research Ethics Board at Lakehead University

I consent to providing Andrew Heppner with photographs my family member has taken of his/her experiences during the data collection period

___ **Yes** ___ **No**

I consent to my family member participating in interviews with Andrew Heppner after each outdoor recreation activity at a time and place convenient for my family member

___ **Yes** ___ **No**

I consent to having my family member's interviews audio taped

___ **Yes** ___ **No** .

Name of Participant

Signature of Participant

Date

Name of Caregiver

Signature of Caregiver

Date

Signature of Researcher

Date

APPENDIX F
Informed Consent Letter for Parental Interview

I have read the information letter provided by Andrew Heppner, Masters Candidate in the Master of Environmental Studies Program at Lakehead University, describing the purpose of his study. I understand that this interview discussion will be audio taped and that excerpts from this audio taped interview may be included in the final report and/or publications to come from this, but that pseudonyms will be used to identify all quotations.

My consent to participate in this research project related interview is made under the following conditions:

- That I have read and understood the information in the study cover letter.

- I have been asked to participate in an interview lasting between 1 and 2 hours in a place convenient for me.

- I have been asked to permit Andrew Heppner with use of our personal communications between myself and him as research data. These personal communications include in-person conversations, phone conversations and email messages that occurred during the data collection period.

- Participation is completely voluntary and all data will be collected and used solely for research purposes

- I understand that the Andrew cannot guarantee my anonymity, due to the nature of the study

- All information will be kept strictly confidential, accessed only by Andrew. Pseudonyms for all participants involved will be used on all documents pertaining to the study and in all oral and written reports of the project. My name will never be used.

- I will be provided with a copy of the research report that may include quotations from this interview before it is published or presented to review and ensure my views are accurately represented.

- I may decline to answer any questions at any time during the interview. I may request to have parts of the interview eliminated from the research data.

- I may withdraw from the interview at any time by simply notifying Andrew. Any decision not to participate or to withdraw from the study will have no impact on support services for my family member or my relationship with Lakehead University.

- It is not anticipated that I will experience physical or psychological harm during the interview.
- The findings of this research will be prepared for publication at professional conferences and journals
- The data will be published in aggregate form, and no individual participants will be identified in published results without their explicit consent.
- All data will be securely stored in a locked filing cabinet at Lakehead University for five years.
- I may request an executive summary of the finding upon completion of the study. These will be available through Lakehead University after Fall 2009.

This study has been approved by the Research Ethics Board at Lakehead University.

I consent to providing Andrew Heppner with information from personal communications, emails and phone conversations with myself pertaining to my family member's recreation experiences during the data collection period

___ **Yes** ___ **No**

I consent to participating in an interview with Andrew Heppner at a time and place convenient for me

___ **Yes** ___ **No**

I consent to having my interview audio taped

___ **Yes** ___ **No**

Name of Participant

Signature of Participant

Date

Signature of Researcher

Date

APPENDIX G
Interview Guide

Since I will have already met with the research participants and their family as well as participated in an outdoor activity with them, they will know who I am. However in the initial interview with each participant I will review these points

- Your participation is voluntary

- I will be audio-taping this interview but this tape will only be accessed by me.

- If you choose at any time not to answer a question or withdraw from the study, this will have no impact on your chances to participate in outdoor recreation activities offered within the community.

Interview questions varied at times, I followed this general framework to guide the interviews

1. Show me a picture that you like.

2. Tell me about this picture

3. What do you like about (this picture)

4. This picture make you feel...

5. Is there any pictures you don't like?

6. Is there anything else you want to tell me?

APPENDIX H
Informed Consent Letter for Photographs

I consent to have my picture take by _____

<div align="center">(name of participant)</div>

I understand that my picture will be used for a research project studying the experience of outdoor recreation. I understand that my picture may be used in presentations that may come from this research. I understand that my consent to have my picture taken and used for the research is completely voluntary and will only be used for research purposes and for presentations that may come out of the research.

I consent to having my picture taken: _____ Yes _____ No

Name of Individual: _____

Signature of Individual: _____

Date: _____

Signature of Participant: _____

Date: _____

APPENDIX I
Sensitizing Framework for Participant Observations

- Environment (Time, Location, Partners, Weather)
- Social Interactions (verbal and physical interactions between all people)
- Emotion/Affect
- Physical, verbal and behavioural communication and actions
- Level of involvement
- Activities and occurrences
- How was it experienced in terms of conditions, events, social context, situations

Textural aspects of experience – For further explanation during interviews

Direct quotes

APPENDIX J

Pictures of Emotions

Happy   Sad   Mad

Scared   Surprised