"It's hard when people try and get their kids away from Cole": Stories of (in)dignity from a family experiencing autism

by

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Abstract

Dignity encompasses feelings of self-respect and worth (Nordenfelt, 2004). These feelings can be shattered by the cruel acts of others, resulting in humiliation or embarrassment (Johnston, Goodwin, & Leo, 2015). It has been argued that children with autism experience increased rates of indignity over other children through physical, verbal, and relational forms of bullying, often in public settings (Goodwin, Johnston, & Causgrove Dunn, 2014; Ryan, 2005; Schroeder, Cappadocia, Bebko, Pepler, & Weiss, 2014). Feelings of being 'lesser than' also extend to family members, particularly in public settings (Ryan, 2005).This study was conducted to gain an understanding of how a family with a child with autism experienced dignity during community-based family leisure. The experiences of three generations from one family were captured; Mom, Dad, Grandma, and Great-Grandma. An interpretative phenomenological analysis case study was completed (Smith, Flowers, & Larkin, 2009; Stake, 2005). Data were collected through two semi-structured, audio-recorded interviews, conversational interviews, and researcher field notes. Interviews were transcribed verbatim and all data were subjected to thematic analysis (Smith et al., 2009). The conceptual framework of relational ethics (Bergum & Dossetor, 2005) facilitated the interpretation of the findings. The results are organized to reflect the experiences of the four family members. The themes were: (a) living under a microscope, (b) screw your microscope; we're going anyway, (c) stories of belonging, and (d) feeling overlooked; lamenting the future. The family members experienced dignity on different levels during community-based family leisure. Dignity was cyclically maintained, temporarily lost, and regained through interactions with community environments. Through their refusal to acquiesce to exclusionary actions and stranger imposed indignity, Mom and Dad reclaimed the self-respect needed to maintain engagement in community-based family leisure. In doing so, they also experienced dignity through engaged interactions with others in the community. By following examples set by the parents, Grandma and Great-Grandma also learned the strategies necessary for maintaining self-respect and making leisure outings enjoyable. The Grandmothers felt as though engaged interactions between their family and members of the community ensured their sense of dignity. The stories of the family members may provide leisure and recreation practitioners, researchers, families, and the general public with insights into cultivating practices that ensure dignified experiences of family leisure.

Keywords: dignity, parents, grandparents, autism, family leisure, qualitative

PREFACE

This thesis is an original work by Kassi A. Boyd. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name “Dignity in Leisure: The Story of a Family Experiencing Autism”, No. Pro00059506, February 1, 2016.

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Chapter One: Introduction

Choosing a thesis topic was not a simple or quick task. In fact, it proved to be one of the most difficult decision-making processes of my Master's degree. Although discussions with my supervisor, colleagues, and other professors in the faculty brought about many exciting ideas, most left me feeling hesitant and unsettled. With each new topic I stumbled upon, I would ask myself, "Who will this research serve? Will this research assist in creating kinder, more self-aware individuals in society? Will this research help give voice to those whose voices have been predominantly absent in research?"

In September of 2014, coincidentally the same time I began my Master's program, I began journaling for pleasure. Following a long meeting with my supervisor about various unsettling ethical dilemmas, she encouraged me to begin writing out my thoughts. After one year of (somewhat inconsistent) journaling, I started to realize a topic trend in my writing: the concept of dignity had become very important and fascinating to me. I began to notice the word 'dignity' in several entries. On October 9, 2015, after reflecting on an interaction with another human, I wrote: *Dignity is such a tough concept to grapple with; is it something we possess or something we experience? More importantly, what can I do to support a complete stranger to feel dignified?*

After reading further about stories of (in)dignity, and reflecting on some of my own experiences interacting with individuals experiencing disability, I gained an acute awareness of the importance of dignity in people's lives. I decided that dignity should not remain a taken-for-granted state of being for some and consistently violated for others (Shannon, 2007). The field of adapted physical activity (APA) has been largely silent on the importance of dignity until recently, and its relevance within the field of APA is arguably worthy of further study (Goodwin, Johnston, & Causgrove Dunn, 2014). In their study about the importance of dignity in exercise participation, Johnston, Goodwin, and Leo (2015) pondered: "Could dignity be among the social influences mediating participation in community exercise settings for people experiencing disability?" (p. 108). As I reflected on this question deeply, I began to wonder how the experience of dignity impacts families with children with autism[1] as they engage in community-based family leisure.

Fenton and Mitchell (2002) summarized dignity as "a state of physical, emotional and spiritual comfort, with each individual valued for his or her uniqueness and his or her individuality celebrated" (p. 21). The authors suggested that dignity is maintained "when individuals are enabled to do the best within their capabilities, exercise control, make choices and feel involved" (p. 21). Connors and Stalker (2007) reported that children with impairments are made to feel of lesser value by the hostile words and actions of others, be they strangers or friends. Based on the description provided by Fenton and Mitchell (2002), this type of devaluation would result in feelings of lost dignity. It has been argued that children on the autism spectrum experience lost dignity more frequently than their non-disabled counterparts through physical, verbal, and relational forms of bullying (Fisher, Corr, Morin, 2016; Schroeder, Cappadocia, Bebko, Pepler, & Weiss, 2014). Feelings of being 'lesser than' also extend to family members of children with impairment particularly in public settings (Ryan, 2005). Engagement in family leisure, an important component of family life (Mactavish & Schleien, 1998; Poff, Zabriskie, & Townsend, 2010), is challenging for families with children with impairments due to the effortful preparation necessary for each outing (Meirsschaut, Roeyers, & Warreyn , 2010) and can result in stranger imposed indignities (Goodwin et al., 2014). Shannon (2007) argued

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[1] I am using this label to describe the child in the family experiencing autism. I recognize that the experience of the child and the family is tied to social influences involved in labelling and interaction with service providers.

that although there has been much work done to promote inclusion, people experiencing disability are still being denied dignity and face chronic exclusion from various opportunities in mainstream society. Gaining insight into how (in)dignity is experienced and negotiated by families has the potential to open dialogue among families with children with autism, service providers, and researchers about the importance of dignity and its impact on participation in community-based family leisure. Study findings may be of use in helping make leisure more accessible for families experiencing disability.

As humans, we have the ability to support one another to flourish in our shared world. Barclay (2016) said it well when he wrote, “it is a uniquely human capacity to be able to shape a life in accordance with principles or standards, and thereby fill out each life with its own meaning and purpose” (p. 137). My hope is that this project will bring an awareness of the importance of dignity in people’s lives and be a catalyst for reflexive professional practice on the promotion of dignity for all humans.

Chapter Two: Literature Review

Dignity

Dignity is a fundamentally human state of being and is often “given little consideration unless one becomes vulnerable or can anticipate its loss” (Mains, 1994, p. 952). Dignity refers to the “quality or state of being honoured or esteemed” and is related to a person’s autonomy and integrity (Hoffman, 2002, p. 89). It is a state of being that can be considered internally stable, meaning the person maintains self-respect and a positive self-image until outside forces disrupt these feelings (Johnston et al., 2015). Adding to the notion that dignity is internally stable until disrupted, Shotton and Seedhouse (1998) explained that “anyone who has ever been in a degrading situation knows what dignity is: it is exactly what was lacking when it was most needed” (p. 246).

Nordenfelt (2004) suggested that dignity is characterized as a position on a value scale and is influenced “through its relations to the notions of right, respect, and self-respect” (p. 69). In other words, dignity is experienced along a continuum from the dignified self to the undignified self (Gallagher, 2004; Nordenfelt, 2004). A person is said to experience the dignified self when she or he is “capable of exerting control or choice over his or her behaviour, surroundings and the way in which he or she is treated by others” (Mains, 1994, p. 952). The undignified self is experienced when feelings of self-respect and worth are shattered by the cruel acts of others that result in humiliation, embarrassment, or removal of autonomy (Johnston et al., 2015). When the ability to realize one’s values and standards are jeopardized by the behaviors of others, the physical setting, or one’s own actions, dignity is threatened (Barclay, 2016). The undignified self is also present in situations where one feels foolish, incompetent, inadequate or unusually vulnerable (Shotton & Seedhouse, 1998).

Types of dignity. Nordenfelt (2004) outlined four types of dignity that are experienced by humans (a) dignity of merit, (b) dignity of moral stature, (c) dignity of identity, and (d) dignity of Menschenwürde. See Table 1 for a summary of Nordenfelt's (2004) types of dignity.

Dignity of merit is associated with the notions of rights and respect. This type of dignity depends on "social rank and formal positions in life" and includes many subtypes as it is unevenly distributed among people depending on the position they hold within a given society (p. 80). Dignity of merit can be earned formally through bestowal or appointment (e.g., a doctor), or informally through deeds (e.g., an athlete). Nordenfelt (2004) claimed that dignity of merit can come and go; people can be promoted, resulting in feelings of dignity, but they can also be demoted and consequently feel as though their dignity of merit has been removed. For example, a doctor may be promoted to a particular position in a hospital (i.e., Chief of Surgery) that earns him/her specific rights and respect. Upon retirement, that individual will no longer hold the rights and respect that accompany such a position.

Dignity as moral stature is "dependent upon the thoughts and deeds of the subject" (Nordenfelt, 2004, p. 72). This concept of dignity, like dignity of merit, is positional and "depending upon the moral value of one's actions the degree of dignity is high or low" (p. 72). The notion of respect is linked strongly to dignity of moral stature as the moral agent respects the right of others and experiences self-respect. For example, as an onlooker witnessing the mistreatment of one human by another, demonstrating passivity would lessen the onlooker's dignity of moral stature. On the contrary, stepping forward with the intent to stop the mistreatment and support the person's dignity would in effect preserve the onlooker's dignity of moral stature. Unlike dignity of merit, dignity of moral stature does not assign any specific rights to the moral subject, for if it did, the value of any moral action would be diminished.

Table 1

Types of Dignity (Nordenfelt, 2004)

Type	Description
Dignity as merit	• Rights and respects that come with a particular position, rank, or office • May be born with dignity as merit (e.g., hereditary monarchy) • Merit bestowed on an individual by an appointment (e.g., doctor) • Merit may be earned through deeds (e.g., scientists, athletes) • Can come and go (e.g., promoted, but can be demoted)
Dignity as moral stature	• Tied to actions of exceptional moral value • It does not provide rights • The moral value of an action lost if it results in privileges for the agent • The agent respects others and experiences self-respect
Dignity of identity	• Dignity we attach to ourselves as autonomous persons • Attached to the person’s integrity and identity as a human being, including his or her social relations • It can be easily shattered by the cruel acts of others as well as injury, illness, and old age • Can also be restored
Dignity of *Menschenwürde*	• Dignity that we all have as humans • All humans experience this dignity to the same degree • No one deserves less respect than others with regard to human rights

The third type of dignity, as outlined by Nordenfelt (2004) is dignity of identity. This dignity is that which "we attach to ourselves as integrated and autonomous persons, persons with a history and persons with a future with all our relationships to other human beings" (p. 75). Dignity of identity can be influenced by acts of others, injury, illness, impairment, and old age. A person's dignity of identity can be ensured by others through respectful interactions but also taken away by others through cruel actions such physical abuse, humiliation, or removal of autonomy. Much like dignity of merit and moral stature, dignity of identity can come and go; one's identity can be broken and restored.

Dignity of *Menschenwürde* is the final type of dignity described by Nordenfelt (2004). This is the dignity all humans hold equally just because we are human. Dignity of *Menschenwürde*, unlike dignity of merit, moral stature, and identity, does not change or fluctuate. All human beings are assigned this type of dignity because of their ability to think and "reflect upon themselves" (Nordenfelt, 2004, p. 78). Nordenfelt (2004) maintains that all humans should be treated with the same respect regardless of position in society. Humans also live with dignity of *Menschenwürde* because they are free to create their own ways of life, unlike other creatures in the world. Nordenfelt (2004) explained that dignity of *Menschenwürde* is a "dignity belonging to every human being to the same degree all through his or her life" (p. 79).

Levels of dignity. Consistent with the notion that dignity is experienced along a continuum, Shotton and Seedhouse (1998) explained that in addition to Nordenfelt's four forms of dignity, there are different levels of dignity. The authors presented four levels of dignity but explain that these levels are not mutually exclusive. The four levels of dignity are (a) dignity is maintained, (b) dignity is lost in a trivial way and easily restored, (c) significant loss of dignity that requires a considerable effort to restore, and (d) devastating loss of dignity that is only restored through support and help from others. The level of dignity experienced shifts as the individual interacts with her or his environment.

The levels of dignity can be understood as experienced through leisure activity such as a baseball game. If an individual goes to play baseball, and does not commit any errors in the game, that individual would feel competent and dignity would be maintained. Should that same player be charged errors in the game, or strike out while at bat, the player might feel as though her or his expectations of competency were not met and dignity may be lost in a trivial way, but easily restored. A more significant loss of dignity may occur if the baseball player strikes out in the last at bat, ultimately feeling at fault for the team's loss. After taking some time to reflect on the experience, and realize that it was just a baseball game, the individual may begin to regain a sense of dignity. If the coach yelled at the player in front of the rest of team for not getting on base during the last at bat of the game, that individual might experience a devastating loss of dignity. In that moment, the player would feel singled out and may need considerable support from others to restore a sense of dignity.

In a study by Meirsschaut and colleagues (2010) parents of children with autism reported that it is difficult to do "normal family activities such as going to the playground with children, going on vacation, visiting friends, etc." (p. 11). More specifically, it has been discovered that engaging in leisure can be challenging for families with a child with autism as parents anticipate unforgiving reactions of others in the community (Martins, Walker, & Fouché, 2013). According to Nordenfelt (2004), identity as a typical family engaging in typical activities is decreased, subsequently decreasing dignity of identity. Similarly, the dignity of moral stature of the offending others is decreased in the eyes of the family because of their hurtful deeds.

Understanding the levels at which dignity may be experienced will create a deeper appreciation for the role that dignity plays in family leisure.

Violations of dignity. Mann (1998) brought attention to the ways that dignity can be violated, leading to negative feelings of the self. They include “not being seen, being subsumed into a group identity, invasion of personal space, and humiliation” (p. 33). The first violation, not being seen, occurs when a person feels she or he has not been recognized or acknowledged by others. This violation results in a person’s dignity of identity feeling threatened. Mann (1998) offers an example of people feeling unheard or even ignored in a doctor’s office or health care setting and suggests that this type of dignity violation is a common one. Shotton and Seedhouse (1998) may have interpreted this to be a serious loss of dignity or a devastating loss of dignity, depending upon the person’s need to be heard (seriousness of illness). For example, if a person is chronically ignored, her or his loss of dignity will likely be greater than a person who is ignored once. As a population that has endured a history of discrimination and exclusion (Shannon, 2007), people experiencing disability may be more susceptible to serious or even devastating losses of dignity.

The second violation, being subsumed into a group identity, involves “being seen, but only as a member of a group” (p. 33). When a person is subsumed into a group identity, her or his individual character is denied and there is a real threat to dignity. Mann (1998) explained that when someone is told that she should not do something because she is, for example, a woman, it “ignores individuality in favor of a group categorization” (p. 33). When a person makes an assumption about an individual experiencing disability based on her or his impairment, it ignores the individual’s lived experiences in favor of their ‘impairment group’ and threatens the individual’s dignity through stigmatization (Goffman, 1963). It could be said that those who assign the category are lowering their dignity of morale stature. In doing so, their actions are harmful as it is effortful to recover from chronic stigmatization.

Violations of personal space, is the third violation of dignity outlined by Mann (1998). The author suggested that this type of violation is culturally defined and therefore different for many societies across the world. When a person's culturally defined 'space' is breached without permission, she or he may experience a loss of dignity. For example, pushing someone in a wheelchair without permission to do so could be interpreted as a violation of personal space. In a study by Goodwin (2001), a participant (who used a wheelchair) recalled a time when he experienced a violation of personal space. During a floor hockey match in general physical education class, the student was forcefully removed from the play by a classmate. The participant explained that as he was attempting to block another player, that player grabbed the handlebars of his wheelchair to remove him from the play. In this interaction, there was an interference with participation, removal of autonomy, and violation of personal space which likely resulted in feelings of lost dignity.

The last violation of dignity as explained by Mann (1998) is that of humiliation. This violation occurs when a person is "being distinguished and separated from the group or from a social norm" (p. 34). If a person is singled out in front of others, criticized and made to feel lesser than the group, they will undoubtedly feel as though her or his dignity has been stolen. For example, mothers of children with impairments have reported feeling singled out when they are stared at and questioned about their competence as a parent when out in public with their child (Ryan, 2005).

Even in spite of the categorization of dignity in numerous forms, Haddock (1996) maintained that dignity is difficult to quantify as the concept is extremely "abstract and interpersonal in nature" (p. 930). Enes (2003) added to the notion that dignity is complex and explained, "dignity requires freedom to `be' yet there must also be control; it reflects a shared humanity and relationship but needs individuality and preservation of the self" (p. 268). Despite its complexity, understanding people's' experiences of dignity is crucial to reversing the processes of exclusion in Canadian society (Shannon, 2007). Dignity is important because it is a basic human right (Nordenfelt, 2004). However, due to various socio-economic and historical circumstances, people experiencing disability are marginalized by a society that "regularly neglects to recognize their needs, capacities, and merits as individuals" (Shannon, 2007, p. 12). As Shannon (2007) explained that although this marginalization may be occurring unknowingly, the actions of ableism[2] that are imposed on individuals experiencing disability need to be revealed. In doing so, the actions and contexts that remove dignity from individuals experiencing disability will create awareness of the processes of marginalization of the disability community.

Subjective Experiences of Dignity

The experiences of those accessing services. The definition and different facets of dignity have been discussed for many years, but it appears that the study of subjective experiences of dignity is relatively recent. For example, studies have been conducted with the aim of exploring the experiences of dignity of people living with different medical conditions. Söderberg, Lundman, and Norberg (1999) interviewed women living with fibromyalgia, an invisible illness. The participants felt a threat to their dignity when they perceived they were not being taken seriously by healthcare professionals and social insurance personnel.

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[2] Ableism: "a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability is cast as a diminished state of being human" (Campbell, 2001, p.44).

In a study by Lohne, Aasgaard, Caspari, Slettebø, and Nåden (2010) on the experiences of multiple sclerosis in the context of a rehabilitation ward, participants reported experiencing both dignity preservation and dignity loss. Participants preferred healthcare personnel who spent the time to engage in thoughtful and caring conversations with them about their illnesses. This was understood as being treated with dignity. In contrast, some participants described times when they had not been met with respect and not been taken seriously, resulting in feelings of lost dignity. Much like the findings reported by Lohne and colleagues, (2010), individuals living with head injuries felt dignity was maintained when they were taken seriously and encountered knowledgeable healthcare professionals, but lost when they were left unnoticed, others were skeptical of the truth of their stories, or when they encountered healthcare professionals that lacked knowledge about their conditions (Slettebø, Caspari, Lohne, Aasgaard, & Nåden, 2009).

Dignity and being treated with dignity have been found to be of particular importance to older adults (Calnan, Badcott, & Woolhead, 2006). Calnan and colleagues (2006) discovered that the dominant concern expressed by participants in their study was the negative treatment and care of older adults that threatened personal autonomy and identity. Autonomy and identity are embedded in our Western understanding of dignity (Shannon, 2007). Similarly, Heggestad, Nortvedt, and Slettebø (2013) found that individuals with dementia residing in two nursing homes, also reported that their autonomy as individuals was not taken seriously (Heggestad, Nortvedt, and Slettebø, 2013). The participants did not feel respected as individuals by nursing home staff and resulted in loss of dignity. Being perceived as an object, rather than an autonomous person was also reported by individuals living with Ehlers-Danlos syndrome and multiple sclerosis (Berglund, Mattiasson, & Randers, 2010; Lohne et al., 2010). Bridges and Nugus (2010) also explored the urgent care experiences of older adults. Through an interview process, the authors revealed that older adults experienced a “diminished sense of individual significance” and felt as though their presence was perceived as insignificant compared to other patients (p. 43). After conducting a qualitative study of ageing and long-term care planning perceptions of Hispanics living in the United States, Cruz-Saco and López-Anuarbe (2016) concluded that providing the proper supports for Hispanic older adults that are both culturally sensitive and promote the dignified self, remains a work in progress. Dignity is culturally and contextually experienced, and worthy of further study.

Authors have also explored the experiences of dignity for marginalized groups such as individuals experiencing homelessness. From a database of more than 500 interviews with individuals experiencing homelessness, Hoffman and Coffey (2008) found that interactions with service providers were characterized in mostly negative terms. Although there were instances where participants reported feeling positive toward service providers, feelings of being objectified and infantilized were more powerfully and frequently cited, resulting in many opting out of social service programs to preserve personal dignity (Hoffman & Coffey, 2008).

The experiences of service providers. Scholars interested in the phenomenon of dignity have begun to explore its meaning as perceived by healthcare providers. Khademi, Mohammadi, and Vanaki (2012) found that although there has been much attention dedicated to patients’ experiences of dignity while under the care of health care professionals, nurses also experience indignities imposed by others in the healthcare setting. Nurses reported various forms of negative interactions, such as humiliation and physical attacks, from nursing managers, physicians and patients’ relatives (Khademi et al., 2012). Further, nursing managers were perceived to control decision making and violate personal privacy, resulting in lost professional autonomy (Khademi et al., 2012).

Nurses were also made to feel undignified when they saw other healthcare professionals behave rudely toward a patient, ignore a patient, or humiliate the patient at the end of life (Lindwall & von Post, 2014). Notably, nurses described feeling a sense of indignity when they could not provide adequate care for patients, often due to a lack of resources and managerial focus on profit over care (Dwyer, Andersehd, Nordenfelt, Ternestedt, 2009). A sense of preserved dignity was experienced by nurses when they perceived true engagement of healthcare professionals with their patients and received their trust (Lindwall & von Post, 2014) and received feedback from patients and other staff that their work was meaningful, valued, and perceived as ‘doing good’ (Dwyer et al., 2009). In their study, Dwyer and colleagues (2009) made links to the types of dignity as outlined by Nordenfelt (2004) and found that the meaning of dignity for the participants was closely related to self-image and identity (dignity of identity). Other authors were not explicit in terms of the type of dignity in which they examined (Khadmi et. al, 2012; Lindwall & von Post, 2014).

As I am interested in how families experience dignity, it was important that I acknowledge dignity as experienced by a person accessing services, and dignity as experienced by those providing services. Although I will not be engaging directly with service providers, I felt it was important to review the experience of dignity from multiple perspectives to demonstrate the relational nature and associated complexity of dignity.

Dignity in the Community

Goodwin and colleagues (2014) explored the meaning of dignity in professional practice by reflecting on a narrative of lost dignity. In the story, Jack, a man living with autism, and his support worker, Keith, were approached by a stranger in a community recreation setting. They were treated with undue verbal cruelty, resulting in an extreme loss of dignity. Jack and Keith’s story is an example of how dignity can be supported by the actions of service providers (such as through respect from the sport complex staff), but also removed due to the (in)actions and reactions of others (verbal abuse from a stranger). Given the severity of the cruelty, dignity may be difficult to regain – for both Jack and Keith (Goodwin et al., 2014). In this interaction, Jack was not provided with the necessary relational space to express his individuality, thereby violating his dignity of identity (Goodwin et al., 2014). Public spaces can be heavily regulated and hierarchically arranged, imposing restrictive social expectations that lead to the mistreatment and exclusion of some people (Ryan, 2005). Through the lens of relational ethics (Bergum & Dossetor, 2005), this story reveals the need for further reflection on the (in)dignity that is experienced by people in recreation and leisure settings.

In a further study by Johnston, Goodwin, and Leo (2015) around the meaning of dignity and its importance in exercise participation, participants expressed a similar sentiment that "dignity was and could be bestowed on them through the actions of others and could be just as quickly removed" (p. 120). In this study, adults with impairments felt comfortable in the specialized exercise environment and perceived the environment to be a socially supportive community that contributed to their feelings of dignity. In contrast, participants felt as though they were perceived negatively by other community members that they encountered on their way to and from the specialized setting, consequently placing the participants' dignity at undue risk. Further emphasis was placed on the loss of dignity that occurred outside of home. "Public gaze, being judged, or being overlooked" contributed to feelings of lost dignity for the participants (Johnston et al., 2015, p. 115). "Autonomy, control, and self-esteem—tenets of dignity—were damaged when the public spaces surrounding the exercise gym needed to be negotiated" (Johnston et al., 2015, p. 120).

Dignity, Leisure, and Families Experiencing Disability

Under a deficit or medical model of disability[3], children with autism spectrum disorder (autism) experience *limitations* in social functioning, impaired communication, and repetitive behaviors or interests (Altiere & von Kluge, 2009; Areheart, 2008). It is most often during interaction with institutions and networks outside of the family environment that the difficulties associated with autism become evident (Martins, Walker, Fouché, 2013). In some settings, due to the level of sensory stimulus, children with autism may find it difficult to regulate emotions and behaviour (Bromley, Hare, Davidson, & Emerson, 2004) and may be less effective at asserting themselves socially (Szatmari et al., 2009). Consequently, children with autism may find it difficult to participate fully within rule-governed and socially complex public settings (Martins et al., 2013).

Parents of children with autism may experience financial strains, the need to leave employment as supports services particularly in small centres are not available, challenges related to engagement in leisure and recreation, and various other psychological challenges associated with the perception that they would never achieve a societally imposed 'normal' family life (Altiere & von Kluge, 2009). As a result, families with a child with autism may demonstrate elevated stress and isolation in comparison with other families (Baker-Ericzn, Brookman-Frazee, & Stahmer, 2005; Davis & Carter, 2008; Martins et al., 2013). Fathers of children with autism claimed that the fear of potential negative reactions and lack of understanding from others toward their children limited the extent to which they felt comfortable going out in public (Martins et al., 2013). Similarly, when partaking in recreation and leisure in

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[3] "Under this framework, disability is based in the body, normal is constructed as ideal, disabled people are dependent" and disabled identities are tragedies in need of intervention (Withers, 2012, p. 31)

public settings, mothers of children with autism experienced challenges related to ignorance and insensitivity toward their children (Woodgate, Ateah, & Secco, 2008).

Parents of children experiencing impairment have found it necessary to challenge the actions of others, make difficult decisions, and face conflict in order to ensure their child's dignity (Marshall & Long, 2010). For example, parents of children with autism claimed to make decisions regarding who they will befriend and spend leisure time with based on how people reacted to their children (Marshall & Long, 2010). Parents in Marshall and Long's (2010) study were identified as "active combatants", constantly at odds with educational staff that repeatedly underestimated their children's abilities (p. 110). One parent, in particular, experienced distress when she perceived that her daughter was not being afforded the school related opportunities she deserved and therefore was not being valued and treated with respect. Participants expressed having to 'let go' of prior expectations of what their experience as a parent would be like, and derived a new sense of purpose and meaning in ensuring their child's dignity (Marshall & Long, 2010). Recently, researchers have reported that many families displayed factors of resilience, reporting that they became stronger as a result of experiencing disability within the family unit and the potential associated challenges (Bayat, 2007; Bekhet, Johnson, & Zauszniewski, 2012).

In a study by Pearce (2010), a mother refused an opportunity for her son to be part of his school's "garbage duty" and instead negotiated him a spot on the basketball team as a manager. This mother demanded an "extracurricular activity with 'dignity' for her son" (Pearce, 2010, p. 136). As she was responsible for negotiating recreation activities for her son, this mother felt that negative assumptions might ensue if she allowed her son to participate in garbage duty. That same parent commented on how unstructured leisure, such as dances or bowling nights, may be avoided altogether because she was not comfortable sending her son alone, and she may be too tired to attend (Pearce, 2010). It appears that ensuring that everyone feels dignified during family leisure can be effortful as it involves careful planning, decision making, negotiation, and obtainment of resources (Woodgate, Edwards, & Ripat, 2012).

It is important to consider the role of the grandparent and the relationships to the grandparents within the family unit when aiming to understand how a family unit experiences dignity. Hillman (2007) noted that generally, grandparents' expectations of their role include assumptions that interactions with one's grandchild will occur during pleasurable, occasional visits. However, the experiences of grandparents of children with autism, and their perceived role as a grandparent, are not well understood (Margetts, Le Couteur, & Croom, 2006). Researchers have reported that positive parent-child relationships (i.e., between the parents of children with autism and their own mothers and fathers) are associated with decreased parental stress (Harris, Handleman, Palmer, 1985; Trute, 2003) as grandparents often provide practical, informational, and social support to their children (D'Astous, Wright, Wright, & Diener, 2013). In contrast, researchers have also noted perceptions of burden related to grandparental involvement with children with autism such as disagreement over management of child's behaviors (Hastings, 1997). Margetts and colleagues (2006) argued that "grandparents should be regarded as potential major supports to parents at the crucial time of assessment and intervention" which can be a stressful event (p. 572). As such, understanding how grandparents of children with autism experience dignity during family leisure is worthy of further study and may provide further insights into their perceived roles as grandparents.

Family Leisure

Involvement in family leisure is an important component of family life (Orthner & Mancini, 1990; Poff, Zabriskie, & Townsend, 2010; Smith, Freeman, & Zabriskie, 2009;

Zabriskie & McCormick, 2003) and all families deserve to feel dignified while accessing family leisure in their communities (Shannon, 2007). Repeated and enduring loss of dignity may enhance feelings of depression and hopelessness (Chochinov, Hack, McClement, Kristjanson, Harlos, 2002). As such, it is important to gain an understanding of how dignity is experienced during family leisure by families with children with autism and learn about the measures they employ to address the dignity of each family member.

In the field of leisure studies, an ongoing challenge has been the conceptualization of the term 'leisure' (Shaw, 1985). For a description of leisure, I turned to Stevens and colleagues (2004); "[l]eisure includes discretionary activities that occur during time that is free from obligations such as jobs, chores and daily routines" (p. 450). For this project, I have focused specifically on family leisure. The term 'family leisure' has been used to refer to the time that "parents and children spend together in free time or recreational activities" (Shaw, 1997, p. 98). Shaw and Dawson (2001) offered a reconceptualised definition of family leisure; one that downplays certain characteristics of previous definitions such as free choice, intrinsic motivation, and enjoyment. Family leisure is "a form of purposive leisure, which is planned, facilitated, and executed by parents in order to achieve particular short- and long-term goals" (Shaw & Dawson, 2001, p. 228). Parenthood brings a decrease in self-determined leisure and an increase in role-determined leisure (Kelly, 1993). Researchers suggest family leisure is related to increases in perceptions of family functioning, family cohesion, family bonding, family adaptability, family life satisfaction, and family communication (Orthner & Mancini, 1990; Poff et al., 2010; Smith, K. M. et al., 2009; Zabriskie & McCormick, 2003). Hodge and colleagues' (2015) called for an examination of the costs and constraints of family leisure in order to promote family well-being. I am deeply interested in the experiences of dignity of families with children with autism.

Statement of Purpose and Research Question

The aim of this research was to capture the stories of how a family with a child with autism negotiated their and their child's dignity during family leisure. More specifically, my study was driven by one interpretive question: How is dignity experienced by a family with a child with autism as they engage in community-based family leisure?

Conceptual Framework

Relational Ethics

As a qualitative researcher with an interest in the experiences of others, I am inspired, as is Ellis (2007) to act from my heart and mind, acknowledge my interpersonal bonds to others, and take responsibility for actions and their relational consequences. I am deeply interested in the ways people relate to and affect one another as understood through the phenomenon of dignity. Many people live with a taken-for-granted view of dignity. Relational ethics was a useful lens to frame this study. Relational ethics offers the capacity to transform our ethical understanding by encouraging us to become conscious of our habitual points of view, in order to see from another perspective.

Relational ethics encompasses four major tenets (Bergum & Dossetor, 2005): (a) mutual respect - an acknowledgment of the circular and reciprocal nature of giving and receiving; includes respecting oneself and respecting others, (b) engaged interactions - personal responsiveness, true presence, and empathy are required for authentic connections and engaged interactions with others; relational engagement is established when there is a shared moment in which people look at something together, (c) embodiment - relationship requires knowledge of both the thinking mind and the feeling body, and (d) environment - an appreciation of the relational space of the individual being tied to community, social, and political contexts.

Bergum and Dossetor (2005) argued that mutual respect is realized when agents maintain self- respect and respect for others. “Mutual respect occurs in an atmosphere of interdependence, where I acknowledge that what I do affects you, and what you do affects me” (p. 69). Mutual respect not only fosters respect for persons, but also respect for different kinds of knowledge and differing values. Mutual respect can also mitigate power relations between people or groups of people by encouraging appropriate use of power and recognition of how it can be shared.

Relational engagement, the second tenet outlined by Bergum and Dossetor (2005), is “found in the moment in which people have found a way to look at something together” (p. 103). The authors proposed that engagement involves both giving and receiving. Further, when relational engagement is achieved between persons, replenishment is experienced through involvement with others. Engagement requires dialogic conversation that is rooted in authenticity, trust, accountability, and intentionality.

A commitment to embodiment, Bergum and Dossetor (2005) explained, shifts our thinking to that which honors the integration of mind, body, and spirit. The authors argued that “relationship cannot happen without embodiment” as relationship requires knowledge of both the thinking mind and the feeling body (p. 137). It is within the tenet of embodiment that we come to focus on healing the split between objective and subjective, self and other, to create a relational space characterized by “interdependence and interconnection” (p. 139).

The last tenet of relational ethics, environment, helps us understand how relationships affect decisions and in turn, decisions affect relationships. Within a relational ethic, autonomy and freedom become inescapably tied with responsibility to our larger community. Bergum and Dossetor (2005) offered:

> When a stone is thrown into a pond, the ripples touch the whole pond. Although the impact of a decision is greater for those who make the decision, the ripples created by the decision made will extend to those who may not even recognize what it means to them (p. 173).

This conceptual framework enabled an interpretation of the way people are with one another in their various roles (Bergum & Dossetor, 2005) which speaks directly to the types of dignity as explained by Nordenfelt (2004). According to Shaw (2011) "relational ethics encompasses the territory in which people come to reflect on, think about and decide on their obligations and responsibilities to self and other" (p. 2). Dignity can indeed be influenced by the actions of self and fellow humans and so through an understanding of the tenets of relational ethics, an in-depth understanding of beliefs and behaviours can contribute to others' dignity as well as their own (Nordenfeldt, 2004).

Within a relational ethic, "commitment, agency, and responsibility for self and to the other arises out of concrete situations that invariably involve relationships between two or more people and affect two or more people" (Bergum & Dossetor, 2005, p. 10). A relational approach to ethics does not undermine the importance of autonomy, but rather reframes it as interdependence (Wright & Brajtman, 2011). Furthermore Goodwin and colleagues (2014) explain that "autonomy, or being free from interference, is reconceptualized to reflect the deeply interdependent existence of humans" (p. 18). Fundamental to relational ethics is the notion that the nature of a relational ethic lies within ethical commitment and responsible agency (Bergum & Dossetor, 2005). Rather than placing emphasis on universal ethical principles, a relational ethic places its focus on relationships and knowledge that are shared between people as the grounding for our ethical action (Bergum & Dossetor, 2005; Evans, Bergum, Bamforth, & MacPhail, 2004). Through an understanding and commitment to a relational ethic the experiences of dignity, and the social factors that influence those experiences, may be captured.

In addition to providing a lens through which to understand and interpret people's experiences of dignity, relational ethics also assisted me with my role as a researcher. For Brooks

(2006), qualitative researchers should "strive to foster connections between researchers, participants, and the communities in which they live—an endeavor that recognizes the proposition that all knowing is relational" (p. 197). Therefore, a relation ethic has enabled me to deal with the complexity and practice of changing relationships between myself and the research participants (Ellis, 2007). This framework has supported me to be mindful and reflexive in my role as a researcher.

For Sandelowski (1993), "[t]heory in qualitative research may be employed in the service of accurately interpreting, and evocatively and imaginatively representing the data" (p. 217). According to Sandelowski (1993), phenomenologists often rely on theory as a guide in hermeneutical reflection. For me, relational ethics was used to facilitate the interpretation of the findings, and in the representation of the data. Relational ethics provided me with a useful framework as it 'fit' the data well; comparisons from the data to the major components of relational ethics were easily drawn (Sandelowski, 1993).

Chapter Three: Method

Paying Homage to My Participants

In my proposal, I had originally decided to frame the project as a qualitative descriptive case study (Sandelowski, 2000). Little research has examined people's lived experiences of dignity, and so producing a descriptive summary of experiences seemed appropriate. However, early on in the data collection process, I realized that a descriptive summary would not pay homage to the participants' experiences and the deeply riveting stories they shared. I knew I needed an approach that would enable me to bring a deeper level of interpretation to the data to produce rich and detailed findings. Ironically, I ended up coming back to the approach I considered before qualitative description: interpretative phenomenological analysis (IPA) (Smith, Flowers, & Larkin, 2009).

Although my research approach has changed since completing my thesis proposal, I feel as though the change has made my study more rigorous, which will be discussed in the section regarding trustworthiness of the qualitative findings. I feel confident about this change in approach as it demonstrates the high level of reflexivity I maintained throughout the research process.

Paradigmatic Stance

A paradigm is an overarching set of beliefs and assumptions that guide "how researchers understand reality and the nature of the truth, how they understand what is knowledge, how they act and the role they undertake, how they understand participants and how they disseminate knowledge" (Markula & Silk, 2011, p. 25). A research paradigm captures what is possible to know about our world, and how it is possible to know it (Mayan, 2009). The interpretive paradigm is "founded upon the premise that the social world is complex and that people, including researchers and the participants, define their own meanings" (Markula & Silk, 2011, p. 31). Within the interpretive paradigm, the focus is on individual meaning-making as it assumes that there is one reality with multiple openings to that reality (Markula & Silk, 2011). Therefore, ontologically, I approached the study with an understanding that individuals construct multiple meanings of reality. In addition, I assumed a subjective epistemology meaning that I view the knowledge-making process as a collaboration between myself and the participants.

Research Approach

A qualitative inquiry approach was used to conduct this research. This means that information was gathered by asking people directly about a particular phenomenon (i.e., dignity) and interpreting texts that I have written (Markula & Silk, 2011). As a qualitative researcher, I am interested in understanding people's lived experiences. Therefore, my aim was not to limit the phenomenon, but rather to "break it open, unfasten, or interrupt it so that a description of the phenomenon, in all of its contradictions, messiness, and depth, is (re)presented" (Mayan, 2009, p. 11). In addition, I have come to understand myself as a situated observer as I acknowledge that my background and current situation has influenced the research process and shaped the results (Markula & Silk, 2011). As a researcher situated in the interpretive paradigm, my research question, data collection strategies, and data analysis technique were grounded in my epistemological position (Smith, J. A. et al., 2009). For J. A. Smith and colleagues (2009) the researcher is always seeing the participants' experiences through their own "experientially-informed lens" (p. 36). As an individual who identifies as 'able-bodied', I acknowledge that I do not experience disability, nor do I have children who experience disability. I also have a degreed background in adapted physical activity and have a pre-existing relationship with the participants in this study. Therefore, I wish to acknowledge the results have been interpreted from my specific position.

Qualitative researchers study a naturally occurring phenomenon and attempt to interpret the meaning people attach to that particular phenomenon (Mayan, 2009). Working inductively, qualitative researchers attend to individual cases rather than from pre-existing frameworks or theories (Mayan, 2009). Qualitative research is sensitive to multiple practices for collecting empirical material to gain an understanding of the phenomenon of interest (Markula & Silk, 2011). Erickson (2016) contended that qualitative social research "advances human rights and affirms human dignity by seeking and telling the truth about what particular people do in their everyday lives and what their actions mean to them" (p. 113), making a qualitative approach suitable for this project.

Interpretative phenomenological analysis was used to conduct this study (Smith, J. A. et al., 2009). This research approach enables the researcher to understand how people make sense of an experience (Larkin & Thompson, 2012). The focus of researchers conducting IPA studies is to understand "how people perceive an experience, or rather what any particular experience means for them: a focus on the lifeworld" (Langdridge, 2007, p. 107). Throughout the duration of this research process, I was required to balance placing the importance on the participants' experience, and making my own personal interpretations of the accounts (Safe, Joosten, Molineux, 2012, p. 296).

This research approach was chosen because IPA is said to be "appropriate in areas with limited previous research, where the lived experience of participants is of primary interest" (Munroe, Hammond, & Cole, 2016, p. 6). In addition, IPA continues to be used by other authors as a way to examine the experiences of parents of children with autism (Ilias, Liaw, Cornish, Park, Golden, 2016; Munroe et al., 2016).

Theoretical foundations of IPA. IPA is informed by three key tenets: phenomenology, hermeneutics, and idiography.

Phenomenology. IPA can be considered phenomenological because researchers are concerned with detailed investigations of lived experiences. Researchers using this approach aim to conduct their investigations in ways that allows experiences to be expressed in their own terms (Smith J. A. et al., 2009). The study of human experiences through the approach of IPA is interpretative and therefore is seen as operating alongside phenomenological description. In other words, IPA is a method for "undertaking a phenomenological interpretative strategy" (Martins, Walker, Fouché, 2013, p. 6).

Hermeneutics. Researchers using IPA understand that analysis always involves interpretation. More specifically, researchers using IPA employ a 'double hermeneutic', meaning that the researcher is trying to make sense of the participant making sense of his or her experiences (Smith, J. A. et al., 2009). The researcher must facilitate the "coming forth" of the phenomenon, and then "make sense of it once that has happened" (p. 35).

Idiography. Idiography refers to a concern for the particular (Smith J. A. et al., 2009). IPA's commitment to idiography is apparent in two ways. First, attention to detail and depth of analysis for each participant in the study is required. Therefore, J. A. Smith and colleagues (2009) encourage a thorough and systematic analysis of interview transcripts. Secondly, researchers adopting IPA maintain a commitment to idiography by focusing on understanding how a particular phenomenon has been understood by particular people in a particular context (Smith, J. A. et al., 2009). In other words, researchers taking on IPA aim to understand what an experience is like for a certain person and how that person makes sense of what has happened to him or her; to provide an in depth analysis of the understandings of a selected group, rather than making generalisations about larger populations (Huws & Jones, 2008).

Case study. Single case studies enable researchers to gain an understanding of the “holistic and meaningful characteristics of real-life-events” (Yin, 2009, p. 4). Furthermore, a single case study provides the opportunity for “in-depth analysis and thus provide individual or unique perspectives on participants’ experiences and intrapersonal processes” (Martins et al., 2013, p. 6). In other words, I have chosen to study one family, as a single case, to help me better “understand complex social phenomena” (Yin, 2014, p. 4). As experiences of dignity are complex, and under-researched, I decided to focus on one case in order to best understand its complexities in-depth (Stake, 2000). Case study is an appropriate complement to IPA because, according to Stake (2005), case study is a choice about what is to be studied, not how it is to be studied.

This project was also framed as an in-depth holistic case study (Yin, 2009). More specifically, it was framed as a holistic, single case study. A holistic case study is one that focuses on the nature of the ‘case’ as a whole, in this case the family, from an entirely qualitative approach (Yin, 2014; Scholz & Tietje, 2002). This means that the family was considered the unit of analysis and the aim was to examine the experiences of the family as a whole, using qualitative data collection strategies such as interviews and field notes (Scholz & Tietje, 2002). The case that I examined can also be considered instrumental (Stake, 2000). The instrumental case is selected to advance understanding of a particular interest, or gain insight into an issue (Stake, 2000), which for this project, was to better understand the experiences of dignity. Given that the aim of my study was to understand how dignity is experienced during family leisure, by a family that experiences autism, I examined a single, typical case to "capture the circumstances and conditions of an everyday or commonplace situation" (Yin, 2009, p. 48).

Recruitment

To produce a sample that offered in-depth insight into the phenomenon, purposive sampling was utilized (Smith, J. A. et al., 2009). I contacted Mom and Dad directly to ask permission to discuss the details of the study. Mom acted as my main point of contact with the family as I saw her the most frequently. She and I met face-to-face to discuss the details of the study and what would be expected of each family member, should they consent to participate. The information letter was sent to Mom via email, and she shared the letter with Dad, Grandma, Grandpa, and Great-Grandma. From there, Mom discussed the study in private with Dad, Grandma, Grandpa, and Great-Grandma. Mom, Dad, Grandma, and Great-Grandma then contacted me individually to provide written consent to participate in the study.

Participants

Purposeful sampling focuses on selecting information-rich cases who will provide insights into the research questions of interest (Patton, 2002). Therefore, I worked with one family with a child with autism. I gained consent to engage with Mom, Dad, Grandma, and Great-Grandma to obtain diverse, multi-generational perspectives. The child, Cole, was not the focus of data collection, however his experiences were heard through the voices of his family members as they described their experiences of family leisure with him.

The Family. I met the family in March of 2014. As an employee of a local service provider for families that have children with autism, I was assigned to work with the family as a child support worker (CSW). That meant I would attend bi-weekly, in-home specialized service sessions. After working with the family for one year, they decided they no longer needed a CSW. However, at that time, the parents asked if I would like to continue working with the family as an independently- hired community aide, and I accepted.

Since working with the family in a more flexible and informal capacity, I began to feel more like a family friend than a community aide. My relationship with the family had grown strong enough that I felt comfortable asking if they would like be a part of my study. Mom, Dad, Grandma, and Great-Grandma accepted my invitation to have their stories heard and Mom and Dad consented to also having their son involved in the study.

The family's leisure interests included a wide variety of indoor and outdoor activities. The family engaged in active leisure such as bike/scooter riding, walks, playing at playgrounds, swimming, playing at indoor play places, and sledding. They also attended many city events such as parades, festivals, farmers markets, and exhibitions (monster trucks). They enjoyed accessing city attractions such as the zoo, legislature grounds, restaurants, shopping malls, science centres, and movie theatres. Riding public transit, having picnics, going to the dump, and visiting friends, family, and neighbors were also considered leisure activities for this family. This family was always on the move and tried to engage in as much family leisure as possible.

Cole. Cole was a 6 year old boy who loved monster trucks, Dr. Seuss books, and watching videos on his ipad. During my time with the family, I've celebrated so many successes with Cole and his family members. I witnessed Cole learn how to talk, become increasingly comfortable in large crowds, and master riding his scooter. I've also seen Cole chase his new puppy around the house, gain the balance to stand on one foot, and toboggan down a hill. I rode with Cole the first time he went down a water slide. I even took him to his first movie at the local theatre. For the past two and a half years, I've walked along side this young boy as his child support worker and community aide, but the whole time I've felt like part of the family; like an older sister supporting her little brother. Cole is smart, Cole is loving, Cole is generous, Cole has autism.

Mom. Mom was a 29 year old woman who was employed part time. The first time I 'met' Mom was in a training video used by the service provider for which I used to work. She and her son had been filmed during a cooking activity to demonstrate verbal and physical prompting and how it can be used to support children in various activities. My supervisor told the new trainees and I that this family would soon be needing a CSW. Shortly after I finished my training, I was placed with the family as their CSW.

Dad. Dad was a 42 year old man who was employed full time, and possessed a bachelor's degree. I first met Dad, along with Cole's Grandfather and Uncle, at a fundraiser golf tournament. He said to me, "Mom told me you would be the attendant at this hole and that I had to make sure to introduce myself, I'm Cole's Dad, and this is his Grandfather and Uncle". The four of us chatted about Cole and all of the progress he had made recently with learning to talk. Dad's face beamed as he spoke about his son.

Grandma. Grandma was a 56 year woman who had completed post-secondary education and was employed part-time. Grandma did not live in the same city as Mom, Dad, and Cole, but visited often, sometimes staying a week or two at a time. Grandma also provided support and came to stay with Mom and Cole during times when Dad was away on business.

Great-Grandma. Great-Grandma was 82 years old. She completed education at the high school level. Great-Grandma lives in the same city as Mom, Dad, and Cole, and enjoys going for lunches, shopping at toy stores, and visiting with her Great-Grandson.

Engaging With the Family as a Researcher

As an independently-hired community aide, my role was to support Cole to be active in community-based leisure activities. This involved taking Cole out into the community and providing him with support to participate in a variety of leisure activities such as swimming, baking classes, movies, shopping, going to amusement parks, and attending various city events. My role as community aide and researcher overlapped for a period of four months. Throughout that time, I continued to pick Cole up from school two days per week. During that time, I engaged with Cole as a family friend; an older sister walking alongside her younger brother. Although it was difficult to separate my roles completely, as I felt myself constantly engaged in a wakeful awareness of my own dignity and Cole's, I did my best to bracket those thoughts during our time together. Once Mom and Dad came home, we would chat about my and Cole's time together that day (e.g., how things went, how he was feeling, what we did, etc.). Then, I'd open up a conversation regarding the study, and ask if they had anything they'd like to share that day.

I determined that engaging with the family over a period of four months was appropriate for a few reasons. I had a pre-existing relationship with the family, which meant that extra time was not needed to build rapport with the family members. As soon as ethics approval was obtained, the family was comfortable to begin data collection and willingly shared their thoughts and stories. Second, as I'll speak to in the 'ethical considerations' section of this thesis, family life is sacred, therefore I did not want to intrude on the family's life by conducting my study over a longer period of time. The four months allowed for significant and sufficient conversations to occur with each family member.

Data Collection

Data was collected through a variety of techniques over a period of four months including semi-structured interviews, conversational interviews, and field notes.

Semi- structured interviews. First, I engaged each adult family member in two individual, audio-recorded semi-structured interviews. Mom, Dad, Grandma, and Great-Grandma were interviewed individually in the first two weeks of the four months spent with the family. The interviews were guided by a pre-established interview schedule (see Appendix A). The conceptual framework of dignity (i.e., types, levels, and types of violations) guided the creation of the interview guide. The framework of relational ethics also supported the creation of the interview guide by encouraging me to shift my attention to the family members. By shifting my focus to the family members, there would be more room to learn about the person, as a person, and “enhance the possibility of moral understanding” (Bergum & Dossetor, 2005, p. 149).

The interview guide was designed to enable participants to talk at length about their experiences of dignity during family leisure. Introductory questions were included to gain an understanding of the family’s leisure interests: *Tell me about your family’s involvement in leisure outside of your home? What sorts of things go into preparing for family leisure out in the community?* The middle section of the interview guide contained questions relating to how the family experiences dignity in community settings: *What sorts of things make you feel comfortable and dignified during family leisure? What role does the perceptions of others play in your decision to engage in family leisure? How would you say the people around you impact your family’s experience? What can the community do to support families experiencing autism to feel dignified during family leisure?* Lastly, a conclusory question was included at the end of the interview guide to encourage the participants to share additional stories that my questions may not have prompted: *Is there anything you would like to add that I didn’t ask you about?*

The average length of these first semi-structured interviews was approximately 40 minutes. Three of the interviews (Mom, Dad, and Grandma) took place in Mom and Dad's home at a time that was convenient for each of them. Great-Grandma's interview was also scheduled at her convenience and was conducted in her home.

The second set of interviews occurred within the last two weeks of the data collection period. I met with each family member and completed a final interview to allow for a clear end to the data collection period, signal my exit from their lives as a researcher, and check the accuracy of the emerging themes. Mom engaged in an individual, face-to-face interview, and Dad, Grandma, and Great-Grandma completed individual interviews over the telephone. The interviews were guided by the emerging themes that I had identified in the transcripts of previous conversations with each family member. In addition to responding to the theme related questions that were designed to gauge the accuracy of my preliminary interpretations, the family members were encouraged to share any last thoughts or stories about dignity. Dignity is a complex phenomenon, and often people find it difficult to articulate the meaning in concrete terms (Goodwin et al., 2014). For that reason, I decided to conduct two interviews, one at the start of the research period and one at the end. The first interview allowed the family members the chance to become wakeful to their experiences of dignity, especially if it was not something they had given much thought prior to our conversations. The time between the interviews gave the family members the opportunity to reflect on more recent experiences of dignity during family leisure. The second and final interview served as an opportunity to share additional reflections about their experiences of dignity.

Conversational interviews. In addition to the two semi-structured interviews, audio-recorded conversational interviews were conducted with Mom, Dad, and Grandma at various points in time throughout the 4 months with the family. These interviews were informal and occurred spontaneously (Markula & Silk, 2011). In these interviews, the family members were asked to describe interactions and events from recent community-based family leisure. I would often begin the conversation with an open-ended question such as: *"Tell me about the leisure activities you've done as a family since we last spoke?"* and *"Are there any stories from recent outings that stand out to you?"* From there, probe questions were asked to obtain further details from the participants regarding the activities and stories they brought forward.

Mom participated in four conversational interviews over the four month period. The average time of Mom's conversational interviews was approximately 28 minutes. These interviews produced 50 pages of conversational interview data for Mom. Dad engaged in two conversational interviews, each lasting approximately 20 minutes, and generated 20 pages of interview data. Grandma participated in one conversational interview that lasted about 17 minutes. Grandma's conversational interview produced 7 pages of interview data. Great-Grandma, due to her infrequent visits to Mom and Dad's home, did not participate in any conversational interviews.

Field notes. Lastly, field notes were recorded at various points in time during the research process. First, field notes were recorded after each semi-structured interview with each family member. Writing field notes after each participant's first individual interview enabled me reflect on areas I'd like to know more about so I could come back to those thoughts during subsequent conversations. If follow up questions specific to a particular participant emerged after the first individual interviews, those were addressed during our next conversational interview. Field notes were also recorded following each participant's second individual interview, which allowed for further reflection on emerging themes. Finally, field notes were recorded after discussions with my research supervisor, as well as spontaneously throughout the 4 month research period as I reflected on the research project's progress and my role as the research instrument.

In my thesis proposal, I had outlined a plan to conduct participant-observations, but this was not realized. It was my intention to accompany the family during family leisure outings to collect observation notes. However, after engaging in two participant-observation sessions during family leisure, these sessions felt intrusive. I began to question myself as the instrument of research and wondered how my desire to attend leisure outings might influence, or even disrupt, the family dynamic. I wondered what the ethics surrounding participant-observations with a family during their leisure time might be. All of these wonderings lead me to encouraging the family to express their thoughts around the data collection process. After communicating with the family, it was determined that participant-observations was not an ideal data-collection strategy for them, and conversational interviewing would be preferred.

Data Analysis

All interviews, semi-structured and conversational interviews, were transcribed verbatim. Any identifying material was removed and participants were assigned pseudonyms (Cole, Mom, Dad, Grandma, Great-Grandma). In the event that names of other people, places, or establishments (e.g., schools, teachers, service providers) were mentioned in the interview, those names were also removed and given pseudonyms. The child in the family was also given the pseudonym of Cole, as he was mentioned frequently by the family members. The data were then subjected to thematic analysis. Each transcript underwent a six step process, consistent with the IPA data analysis technique outlined by J. A. Smith and colleagues (2009). I began working with Mom's transcripts first.

Working from hard copies, the first step involved immersion in the transcript by reading and re-reading the first interview transcript. This step enabled me to put my entire focus on Mom's first interview. Step two built off of step one, and involved initial noting. Notes were hand-written in the left-hand margin of the transcript. These notes were generic, not interpretive, and worked to simply describe what was going on in the text to help me come into "active engagement with the data" (Smith, J. A. et al., 2009). Noting stayed close to Mom's explicit meaning.

In step three, I began to label emerging themes. Here, the analysis shifted to working with my initial notes rather than the transcript itself. In the right hand margin of the transcript, developing themes were noted. These themes were intended to reflect a "synergistic process of description and interpretation" (Smith, J. A. et al., 2009). Themes were expressed in phrases and reflected both Mom's original words as well as my interpretations. The three steps (immersion, initial noting, and noting emergent themes) were completed for each of Mom's transcripts, with the exception of the final interview transcript, before moving on to step four.

Step four involved searching for connections across emergent themes from all of Mom's transcripts. I wrote out all emergent themes chronologically and determined which themes fit together. This was done through abstraction and contextualization. Abstraction involved "putting like with like and developing a new name for the cluster" (Smith, J. A. et al., 2009, p. 96). Contextualization involved looking at connections between emergent themes to identify contextual elements. This strategy was used at this point of analysis to enable me to attend to temporal, cultural, and narrative themes that may relate to particular moments or key events in Mom's experiences. Super-ordinate and sub-ordinate themes from Mom's transcripts were then organized into a table.

The next step in my analysis, step five from J. A. Smith and colleagues (2009), was to move on to the next family members' transcripts. Here, the entire process (the four steps described above) was repeated for each transcript of each family member. I moved on to Dad's transcripts next, followed by Grandma, then Great-Grandma. At this stage, it was important for me to bracket off emerging themes from the first case, in order to commit to IPA's idiographic tenet. After each family member transcripts (with the exception of the final interview transcripts) were subjected to the four step process, a table of super-ordinate and sub-ordinate themes was produced for each participant. The second individual interviews occurred with each participant before moving on to the final step of thematic analysis. These interviews were used as an additional level of member checking, to ensure I was hearing the participants accurately and that the emerging themes I had identified were reflective of the experiences they had described in our previous conversations. At this point in the analysis, family member quotations were moved into word documents and placed below each theme.

The last step in my thematic analysis involved looking for patterns across the family members' experiences. I took the tables of themes that were produced for family members, as well as the quotations that were selected to demonstrate support for the themes, and identified aspects such as points of agreement, disagreement, convergence, and tension. I also made note of themes that seemed significantly potent. What happened was a reconfiguring and relabelling of themes until I reached a final table of super-ordinate themes.

Ethical Considerations

Ethical approval was obtained from the REB at the University of Alberta prior to the start of the study and I remained in compliance with all REB standards throughout the entire research process. Prior to engaging with the family as a researcher, written informed consent was completed by each participant. The information letter and informed consent form were created and discussed to ensure that the family members knew what the study was about, what was being asked of them by participating in the study, that they were aware of their rights within the study, and that they knew what the data collected would be used for and where it may appear. Family members were reminded that participation in the study was voluntary and confidential. Each parent provided written consent for their child's experiences to be represented in the study.

Careful consideration was taken regarding the storage of data. Audio files were stored on a password protected computer. Transcripts were also stored electronically on a password protected computer and as hard copies in a locked filing cabinet, in a locked office (Pat Austin Adapted Physical Activity Lab). Field notes were also stored on a password protected computer. Lastly, an extra copy of all of the data that were stored electronically on a password protected computer were also uploaded to an external hard drive to ensure safe keeping. When not in use, the external hard drive was kept in the same locked filing cabinet as the hard copies of transcripts.

It was also important to consider the ethics of conducting research with a family unit. Larossa, Bennett, and Gelles (1981) encouraged researchers to keep in mind the very intimate and emotional region of a family during all aspects of investigation. In addition, the authors encourage careful attention to the risk-benefit equation by considering the standard risk of human research, combined with the risk of public exposure as well as the risk of exposure of the family to itself. Larossa and colleagues (1981) cautioned: "The fact that many people consider their family both a sanctum and their most precious possession is something that qualitative family researchers should never forget and never abuse" (p. 312). Through a prolonged engagement with the family as a CSW and community aide, I built a strong relationship with the family that enabled me to balance my responsibilities as a researcher as well as a friend to the family. To gain the family's perspective on my ability to balance my responsibilities, the family was encouraged from the start of the project to offer me feedback about the research process. I also made a point of checking in with the family at various times throughout the four month period. These 'check ins' occurred twice face-to-face with Mom and Dad, and once via email with all members of the family involved with the research. During the 'check ins', the family was asked to express any hesitations or dissatisfaction with the research process. I also asked specifically about their opinions on the data collection techniques, and reminded them that other opportunities (such as journaling, talking on the phone, or engaging in conversational interviews) are available to them, should they be unhappy with the current data collection methods. As mentioned, after touching base with the family via email, Mom and Dad expressed a preference to engage in conversational interviews rather than participant- observation sessions. Subsequent face-to-face check ins, did not lead to any other changes in data collection strategies, and all family members expressed being content with the research process overall.

Although I did not interview any children for this study, I knew that stories including Cole would be shared by the family members. Therefore, I attended to important aspects related to conducting research with children. First, I wanted to remain conscious of the abilities of the child that I was engaging with and respect that child's competencies (Morrow & Richards, 1996). Furthermore, I avoided assumptions that all children experiencing autism are the same (Morrow & Richards, 1996). Lastly, Morrow & Richards (1996) cautioned that children are a powerless group in society and are therefore not in a position to challenge the ways that they are represented in the research findings, making it very important that I paid careful attention to how the child was portrayed in the presentation and dissemination of the findings. My goal has been be to represent the experiences of the family members, and Cole, as authentically as possible. To ensure that no misrepresentations have occurred, I have discussed the summary of the themes with the participants (member checking), to ensure their experiences are reflected in the results.

Lastly, I felt as though it was important for me to remain cognizant of the potential power dynamic that may exist between researcher and participant, specifically during interviews. Through a commitment to the tenets of relational ethics, I remained wakeful to the potential of this power to damage relationship. The family members were reminded that they could choose not to answer a question if it made them uncomfortable, and were offered breaks when sensitive topics arose and when they became emotional. Bergum and Dossetor (2005) maintained that "activities such as active listening, willingness to help, taking time to understanding, and being present for one another take on moral dimensions that keep power in view" (p. 93). In all of the interviews, I remained committed to these activities to ensure mutual respect and mitigate potential issues of power.

Trustworthiness of Qualitative Findings

The quality of qualitative research can be ensured in a variety of different ways. In alignment with IPA, I followed the four principles outlined by Yardley (2000) to maintain a rigorous research process and ultimately bring trustworthiness to the study findings. The principles are sensitivity to context, commitment and rigor, transparency and coherence, and impact and importance. Zitomer and Goodwin (2014) explained that these criteria are also known as reflexivity, credibility, coherence, and contribution respectively. These criteria are also relevant to case study research (Baxter & Jack, 2008; Yin, 2009). Each principle is summarized briefly, with a list of the criteria and their application to the study listed in Table 2.

Table 2

Ensuring Trustworthiness of Qualitative Findings

Principles for Rigour of Research	Application to Study
Sensitivity to Context	Completion of in-depth literature review
	Reference to multiple sources to learn about IPA and Case Study Research
	Careful attention to and appreciation of interactional nature of interviewing
	Recording of field notes
	Disciplined attention to participant accounts during data analysis
	Disclosing researcher bias in presentation of findings
Commitment and Rigour	Prolonged engagement with the family
	Investment in the interview process
	Previous experience in qualitative interviewing
	Commitment to thoroughness of analytic process
	Member checking of interview transcripts and preliminary themes
	Peer-debriefing with research supervisor
	Thick description of participants' experiences
Transparency and Coherence	Discussion with research supervisor to ensure coherence of themes and arguments
	Revisiting the research question
	Disclosure of positionality in presentation of findings
	Clear presentation of method
Impact and Importance	Description of study implications and social significance
	Demonstration of links to previous research
	Generated new insights into phenomenon of dignity

Sensitivity to context. The context of qualitative research is comprised of many features. First, there needs to be sensitivity to the relevant literature and research approach. Understanding the principles of IPA, case study, and literature deemed relevant to the topic under investigation, was crucial. This was firstly achieved by conducting an in-depth literature review and engaging with multiple sources to learn about IPA and case study research (Smith, J. A. et al., 2009; Yin 2009; 2014). Furthermore, sensitivity toward socio-cultural aspects of a setting is vital, as these aspects will influence “the beliefs, objectives, expectations and talk of all participants” (Yardley, 2000, p. 220). In the early stages of the research process, more specifically the research proposal process I demonstrated sensitivity to the sociocultural aspects by attending to dignity (Nordentfelt, 2004; Mann, 1998; Shotton & Seedhouse, 1998), families experiencing disability (Martins et al., 2013; Marshall & Long, 2010), autism (Altiere & von Kluge, 2009), and leisure (Shaw & Dawson, 2001; Shaw, 1985) in my literature review. It was also important to be open to the perspectives of the participants and to attend very closely to social context of the relationship between investigator and participant. This was accomplished by recording self-reflexive field notes to raise my wakefulness to my own assumptions and biases in order to focus on the experiences of the participants.

For J. A. Smith and colleagues (2009), the choice to adopt IPA as a research approach is in itself an act of sensitivity to the particular context in which the study is situated. This was definitely the case for me; despite outlining a qualitative descriptive approach in my thesis proposal, I chose to frame my study as an IPA case study, as I needed an approach that would allow me to bring a rich and deep level of interpretation to the family members’ accounts, and pay homage to their stories and the contexts in which they reside.

Lastly, sensitivity to context was achieved through a commitment to the interviewing process. Keeping in mind that IPA analysis is “only as good as the data that it is derived from”, I paid careful attention to the interactional nature of interviewing by showing empathy, putting the participants at ease during our conversations, and remaining wakeful to the power balance that comes into play when interviewer (research expert) and interviewee (experiential expert) engage in conversation (Smith, J. A. et al., 2009).

Commitment and rigour. The concept of commitment refers to the long term engagement with the topic. In other words, sound commitment comes from an extended investment in the topic through a development of competence in the method used and immersion in the relevant data. Commitment was also achieved through prolonged engagement with the family. I knew and worked alongside the family for 2.5 years as a CSW and more recently as a community aide. In addition, the data collection process occurred over 4 months in which I engaged with the family frequently.

Rigour speaks to the overall completeness of both data collection and analysis. Rigorous data collection was achieved by employing a variety of data collection strategies (semi-structured interviews, conversational interviews, field notes). Rigor was further enhanced by completing three levels of member checking: (a) participants reviewed both semi-structured interview transcripts, (b) participants engaged in a second semi-structured interview to check the accuracy of the emerging themes, and (c) each participant was sent a summary of the final themes to review. Moreover, rigour is achieved when interpretation addresses all of “the variation and complexity observed” (Yardley, 2000, p. 222). This was achieved by generating a thick description of the family’s experiences. The experiences have been described in detail and the results are supported by direct family member quotations to reinforce the solidity of the themes that were identified during data analysis.

Transparency and coherence. Transparency and coherence occur at the level of presentation and speak to clarity. Coherence refers to "the 'fit' between the research question and the philosophical perspective adopted, and the method of investigation and analysis undertaken" (Yardley, 2000, p. 222). To achieve coherence, a consistent adherence to research approach principles should be clear. IPA is committed to producing an interpretative account of the participants' lived experiences and is achieved in the presentation of the findings where a detailed account of the family members' experiences is presented and discussed. Case studies (i.e., one family unit) are bound by what is to be studied and helps researchers understand complex social phenomena (Stake, 2000). To adhere to the principle aim of case study, I made a point to revisit the research question at multiple points during the research process to ensure that I was working towards achieving my stated purpose. Transparency refers to "the degree to which all relevant aspects of the research process are disclosed" (Yardley, 2000, p. 222). It is important to reflect on factors that might have influenced the research process and disclose such information in the presentation of findings. Transparency was achieved in the presentation of the findings where the entirety of the research process was described and the interconnectedness among literature review, methods, and discussion was identified.

Impact and importance. For Yardley (2000), the usefulness and ultimate value of a piece of research should be assessed in relation to "the objectives of the analysis, the applications it was intended for, and the community for whom the findings were deemed relevant" (p. 223). One way that research can be deemed to be impactful is if it offers a new way of understanding a topic. Another way to demonstrate the importance is if the research shows some socio-cultural impact or social significance. The contribution of the research was achieved by creating a deeper understanding of the experiences of dignity and the impact it has on community-based family leisure for a family experiencing autism. Furthermore, links to previous research were made in the discussion of the findings. Although the findings will not generalize to other people, places, or times, the fittingness to other contexts can be determined by researchers, families, and practitioners in the field of leisure and recreation. This means that readers will interpret how well the propositions fit into other contexts, different than the one from which they were generated (Beck, 1993).

Chapter Four: Stories from the Family

The family members experienced dignity along a continuum from the dignified to the undignified self during community-based family leisure. Their experiences were intricate, multi-layered, inter-generational, and shifted over time. Their early experiences during family leisure were fraught with feelings of being singled out by others. In time, the parents adopted strategies, and passed those strategies on to Grandma and Great-Grandma, to maintain their self-respect and created a dignified identity and space for themselves in the community. A further shift in their experiences of dignity occurred when they began to see (in)dignity through the eyes of their son Cole as he was increasingly overlooked and ignored by others in the community, leaving the parents fearful for Cole's future.

The stories below describe the journey of how they experienced dignity in family leisure from when Cole was diagnosed at the age of 2 and a half years, to more recently at the age of 6. The themes are (a) living under a microscope, (b) screw your microscope; we're going anyway, (c) stories of belonging, and (d) feeling overlooked; lamenting the future.

Living Under a Microscope

Since Cole's diagnosis approximately 3.5 years ago, the family members have experienced dignity and indignity during family leisure. For some family members, dignity was brought to consciousness and became part of their day to day lives through interactions with community environments. This theme illustrates Mom, Dad, and Grandma's early experiences of community-based family leisure as being fraught with feeling singled out. Feeling singled out meant that the family was separate from the other people engaging in the leisure activity. Receiving stares, glares, judgmental comments, as well as having people remove themselves from the family during leisure activities, resulted in numerous experiences of social exclusion.

Mom explained, “It [staring] kind of took the light away from how much of a great time we were having”. Cole’s communication style and emotional responses to various environmental stimuli often garnered stares from people in the community who perceived his embodiment as inappropriate for public places. Dad explained that staring often occurred in response to Cole’s embodied behaviors, “Cole had a lot more physical ticks, where he did a lot more flapping or he used to rock his head more and stuff”. The parents noted that receiving stares was not restricted to specific places in public, but rather could occur in many settings. “You get kids staring, or you get parents that would sort of stare. That could be anywhere from a doctor’s office to the grocery store” (Dad). Cole’s embodiment was misunderstood and disrespected by some members of the community.

Grandma also noticed people staring at Cole if he became upset or expressed his embodiment in way that was considered ‘atypical’ during public outings. These stares were hurtful for Grandma, “I guess I feel more sadness for Cole...I feel like people are now staring and judging and they don’t understand”. Grandma noted that experiencing dignity during family leisure meant that her dignity remained unconscious to her. Receiving stares from people in the community brought her dignity to her consciousness, “When you’re not conscious of anything, just participating, and you don’t have your defensive up, in a sense that, is something going to go wrong? Is there going to be a melt down and are people going to stare?”

Glares were another form of gaze often reported by Mom and Dad. Glares were often received if the family’s, or specifically Cole’s, actions disrupted the flow of another family’s leisure activity. The pace of the social environment often raised the parents’ awareness of the judgment of others and impacted their sense of belonging in the community. “I never noticed how fast stuff moves until you’re with somebody that needs like an extra minute” (Mom). Mom gave an example of taking turns on a water slide, “All of a sudden he has like a panic attack at the top of the slide, that affects the people behind you, so that’s when you get the glares from them”. Many environments lacked the relational space needed for Cole to enjoy the leisure activity at his own pace. There was a certain level of tolerance toward Cole and his family members, until their actions disturbed other people’s leisure activities. Other people in the community were seen to monitor the family’s behaviour, resulting in feelings of being singled out.

Both parents described stories in which verbal comments, that questioned their parenting or their child’s behaviour, made them feel as though they didn’t belong. In their first individual interviews, Mom and Dad recounted the same story about feeling judged by a neighbour. Dad recalled:

> I remember when Cole was probably two, we were going for a walk, and we were having trouble with him staying on the sidewalk, when he was just learning to walk, cause he would like run off into the street. And there was this lady down around the corner there that um, he ran off the, he ran off the sidewalk, and this old lady on her porch was screaming and saying ‘that’s terrible parenting’ and ‘you shouldn’t let him go’”.

In this story, the neighbour may have assumed a position of authority over the situation because of her age, judgment regarding what behaviors were appropriate for children Cole’s age, and perceptions of what might have been a fitting parenting response to Cole’s running off of the sidewalk.

Mom recalled a further time when judgment from a stranger impacted her parenting, bringing dignity to her awareness. When she brought Cole into the women’s bathroom with her the decision was criticized by another parent. “A mom said to me, ‘It’s not appropriate for him to be in here'". From this other parent's perspective, Cole appeared old enough to go into the men's washroom alone and it was her moral responsibility to question Mom's decision, and make it clear that Cole's presence in the women's bathroom was inappropriate. The social, cultural, and political rules that govern public washroom etiquette, specific to age, gender, and independence, can become exclusive toward families with children that require extra support. Dad also reported experiencing discomfort when people in the community questioned his washroom decisions. When trying to access the family change room at a water park with Cole, Dad was stopped by the front desk staff member, "The lady was almost sort of taken aback, like 'why are you two going in the family one?'". Instead of engaging with Dad and Cole to understand their desire to use the family change room, this staff member used her position of authority, to make Dad and Cole feel as though they should not be using that particular change room. Dad questioned the appropriateness of the staff member's comments and the degree to which he was being monitored by strangers, "That was one thing that, I don't know, why they would care, right? Should be whatever your kid is comfortable with. Or even me? Who knows, right?" Mom and Dad both reported experiencing violations of autonomy, as an indication of dignity, when their parenting was questioned by complete strangers.

The parents were also singled out on numerous occasions through the insensitive or cruel actions of other people in the community, be it the general public or leisure staff. When at a public aquatic centre, Mom recalled, "You can go into a pool with 50 other families, but if your toddler is the only one that's being repeatedly targeted, not targeted but, repeatedly yelled at by a lifeguard, but the other kids aren't, you're singled out". Mom explained that sometimes people would even single them out by creating a physical distance between themselves and the family, "He's happy, and he's doing this thing, he's maybe flapping away and some parent notices so they'll try and herd their kids away from him". The loss of dignity experienced by Mom and Dad through the creation of distance was hurtful. "I think the worst part of it is when people don't want their kids to be around Cole" (Mom). Again, Cole's embodiment received judgment from some members of the community.

Mom and Dad would often acquiesce to the rejection of others and at times avoid engaging in particular leisure activities. Mom explained that she used to try and change Cole's behaviors if people in the community began to stare or glare, "I would try and change what he was doing, which I think was probably the worst. So if he was really happy, I would like try and get him to stop doing what he was doing". Dad recalled avoiding certain activities for fear of being singled out:

> I know when he was really little, like I would consciously avoid taking him to the playground where all of the kids were... it was harder for him to cope because there's way more noise and all of these kids, but also I didn't want other parents to think "he's weird, or he's different" or kids to stare at him.

Mom and Dad often felt external pressures from social expectations and rules that dictated 'typical' engagement in community-based leisure activities. In an attempt to protect Cole's dignity of identity, and blend in to avoid the judgement of others, Mom and Dad often modified his behaviors or abstained from engaging in certain leisure activities altogether. In doing so, Cole's embodiment was subdued, and the chance for authentic interactions, between their family and other people in the community was lost. Over time, acquiescing to the exclusionary actions of others lead the parents to feel a decrease in their own moral stature; this inflicted more harm than braving the staring and glaring from people in the community. The parents felt it was unfair to restrict Cole's expressions of embodiment and deny him the opportunity to engage in community-based family leisure activities. By acquiescing to the needs of others, and the social expectations associated with leisure in the community, the parents felt as though they lost respect for themselves.

In contrast to Mom, Dad, and Grandma, Great-Grandma reported that neither she nor Cole experienced feelings of lost dignity during family leisure, “Oh, I always feel like I belong.” Great-Grandma explained that she did not feel singled out in the community during family leisure. Further, “I have never seen people, anybody, judge him or look at him, I think that’s just my perception maybe, but I never see where we are any different than any family when we are out” (Great-Grandma). Great-Grandma added, “I think they [Mom and Dad] would be the ones that would experience those things [indignities]. I don’t seem to experience anything like that when we’re out.” During family leisure, Great-Grandma maintained her focus on her great-grandson, rather than on the place of the family unit within the community. In other words, Great-Grandma focused on enjoying the moment rather than building a sense of community.

Both Great-Grandma and Grandma reported feeling further removed from the family's day-to-day life, and therefore likely did not notice the subtleties of staring and glaring to the same extent at Mom and Dad. “I don’t see any, where we’re treated any differently. Like I said, I’m not with them all of the time eh?” (Great- Grandma). Great-Grandma felt comfortable during most family leisure activities that she participated in, perhaps because Mom and Dad, and often Grandma, were also present and the surroundings were familiar. Therefore, Great-Grandma may have felt as though there were people who understood, respected, and accepted Cole (parents, other family members, close friends) making her feel comfortable in the environment. “When I spend time with Cole, it’s usually in his environment, with his family.”

Although she reported experiencing some negative interactions with others in the community, Grandma emphasized that she likely experienced less indignities than Mom and Dad, "No, I would say a fraction of what Mom and Dad have experienced with Cole, being out, the indignity part of it." Grandma also explained that the nature of the leisure activities that she participated in with Cole were relaxed and fun. “So our role as grandparents is extremely different from the parent as we just relax, have fun, and enjoy our outing and we feel less stressed” (Grandma). She described how the outings she attended were often more positive because there was no responsibility to work on Cole’s skills, such as the ability to be comfortable in a new or intensely-stimulating environment, during the outing. “We get to do the fun stuff that he enjoys and not really do tasks that require to teach him how to handle situations that he isn’t comfortable with” (Grandma). Great-Grandma echoed, “Well I guess we do things Cole likes, you know, you go back to doing things he likes.” Grandma and Great-Grandma's leisure activities with Cole were ones that he enjoyed, in environments where he was supported and comfortable. Therefore, Cole had an easier time and often did not get upset. During these particular outings, the family was able to ‘blend in,’ rather than stand out amongst the other people in the community, enabling the Grandmothers to focus on the positive experiences, and dismiss potentially negative interactions.

Screw the Microscope; We’re Going Anyway

Through a commitment to self-respect, and a commitment to maintaining dignity in the community, Mom and Dad adopted strategies to support Cole during family leisure. The family’s two main strategies involved preparing for leisure outings in ways that would support Cole to be comfortable in public environments, and ignoring or dismissing the exclusionary actions of others. By developing and employing these strategies, they asserted their belief that they deserved to access leisure activities in the community.

The preparation often involved making a list of what activities the family was going out to do, what Cole could expect to see and hear during these activities, and remind him of his regulation strategies. Mom explained: “If it’s something brand new, we have to prepare him ahead of time”. Cole’s parents respected his abilities by preparing him for leisure activities. This preparation helped ease Cole’s anxiety around leisure activities, and protected his and his family’s dignity, “I guess it allows for Cole to be more successful. And then in turn he receives a better reaction from the public” (Mom). Dad agreed, “I guess it makes it easier right? Because we can probably forecast what’s going to happen a little better, because we know he has the support and strategies to assist in whatever we’re doing”. By putting in the work of preparation before an outing, the parents felt more control over situations and could protect Cole’s dignity. So far, the family members had been assuming the responsibility of preparing themselves and their child to face potential challenges during family leisure. For Mom and Dad, community-based family leisure, was often not experienced in environments that fostered mutual respect or a shared responsibility to support children with autism to be successful in leisure activities. Instead, the family was required to gain the confidence and self-respect needed to continue engaging in family leisure activities of their choosing, even if that meant putting in the extra work of preparation before leaving their home.

Grandma and Great-Grandma explained that Mom had taught them how to prepare for leisure outings to make the experiences positive and successful. Grandma noted, “What we learned from Mom is that prior to doing something, we’ll make a list with Cole, letting him know where we’re going and what we expect to happen” (Grandma). Cole’s family members demonstrated an understanding of Cole’s embodiment, and respected his unique needs by preparing him for the outings. Grandma discussed the benefits of preparing Cole for leisure out in the community, “Cole has less anxiety and frustration. Everyone is more relaxed. If we prepare ahead of time, it can greatly help Cole to enjoy his time out with others and others with him”. Preparation prior to leisure in the community protected Cole’s dignity of identity, and enabled Grandma and Great-Grandma to feel more relaxed during the outing. Great-Grandma talked about how the family will plan leisure outings accordingly so they can attend events and engage in activities at less busy times, “Any functions that I think we take him to, I may not be involved in a lot of them, but they try to take him when it is quieter, you know, where there’s not so many people around”. The strategies adopted by the family honoured Cole’s embodiment and abilities.

When preparation for an event wasn’t possible, or was unsuccessful, the parents and Grandma ignored the hurtful and exclusionary comments as a way to maintain dignity. After having dealt with staring, glaring, comments, and other exclusionary actions on numerous occasions, Mom and Dad began to describe their eventual rejection of these hostilities. When asked if these types of actions still caused feelings of lost dignity for her, Mom responded, “Not now it doesn’t. Before it did. So you know, before we would avoid doing certain things, right?” Dad agreed, “I think now, I think since that switch kind of went off, you just, you don’t care anymore, right? Like I don’t notice people looking as much anymore”.

Mom explained that avoiding activities, or even leaving activities, eventually felt worse than staying in situations where people might be cruel: “So us leaving, maybe because somebody else doesn’t like what he’s doing…that is less dignifying than just staying your ground”. By standing their ground in situations when the parents felt as though their family was mistreated and excluded, they decreased the moral stature of the people in the community, and were able to regain self-respect, autonomy, and dignity of identity. In her last individual interview, Mom described a recent story of maintained dignity while on a trolley ride with Cole. The trolley conductor appeared unhappy with Cole's regulation behaviors (fidgeting in his seat) and came over to speak to Cole. Cole, not realizing that the conductor was addressing him, did not respond. In this situation, the conductor may have perceived a lack of reciprocal engagement from Cole, became frustrated, and turned to Mom to resolve the situation. However, in doing so, the trolley conductor used his position of authority to humiliate Mom and Cole in front of the other riders. She explained, "He said it loud, and the trolley car is tiny so everybody on there can hear what you're saying, and he looks at me and he's like 'Does he [Cole] even understand what I'm saying?!'". Despite the actions of the trolley conductor, that distinguished the family as separate from the rest of the riders and questioned Cole's humanness, Mom reported that this situation did not result in significant feelings of lost dignity, "It's not that I don't care, it's just that it takes more out of you to spend the whole day being mad at that guy". In the moment, Mom thought to herself, "Whatever, he's just ignorant and he'll be ignorant, we're going to have fun moving forward". In this situation, Mom recognized that the conductor's actions were hostile, and once again singled out her family, but maintained a dignified self by reframing the situation and maintaining respect for Cole, and herself by dismissing the conductor's authority and insensitive actions. Mom refused to allow this interaction to challenge her dignity in a way that it could not be easily restored. She rejected the humiliation and embarrassment that could have been experienced in this situation. Mom explained that the other parents that she was with at the time, whose daughter had recently been given the label of autism, were furious over the interaction. She explained:

> But it was funny though afterwards, [child]'s Moms said to me like "I was so mad, why didn't you say anything?" And it was funny cause I thought like 'oh my god I used to'. Cause to them, their daughter has autism, so they're new to it…So like one of [the child]'s Moms, she was like fired up, she's like "I want to go talk to them, I'm going to go back in there". And I was like "no, no". Yeah, so it was kind of funny to see how she, like it was kind of ruining her day, but Cole and I had already moved passed it. Like we enjoyed our ride.

The other parents were evidently upset by the interaction. However, Mom, having experienced similar situations many times, was able to move past the potential for a significant loss of dignity due to the actions of another and enjoyed the leisure outing with her son and friends.

Dad explained that repetition made it easier to ignore people in the community and helped create space for his family to belong, "I think all of these [activities] really just come down to, just how many times you do it." The more times the family engaged in a certain activity, attended an event, or accessed a certain facility, the easier it became to feel comfortable in those settings. Instead of acquiescing to the exclusion that the community imposed on the family, Mom and Dad began to find ways to shift the role that people in the community played in their family leisure experiences. Mom and Dad chose to ignore people's assumed dignity of merit and dignity of morale stature. As a result, the parents reported experiencing less significant losses of dignity during family leisure activities. Mom explained, "I've told people to fuck off…in order to feel dignified or whatever, is just to ignore and keep on enjoying what you're doing". Recently, when out playing mini golf with friends, Mom noticed people staring and making comments that her group was playing too slowly, "I noticed people behind us were definitely gawking”. Another parent in Mom’s group let those people go ahead of them in the golfing order. Mom described the incident: “She kind of piped up and was like ‘just go ahead of us’. If it was me I probably wouldn’t, I would have been like ‘Suck it, you can wait for the next 18 holes, cause I don’t care’”. Mom ignored the judgmental comments from the community members to maintain dignity of identity.

Dad also displayed resistance to the influence of other people in the community during family leisure. He described a time when a store employee appeared bothered by Cole’s behaviour in the shop, “I could tell she [employee] was almost a little bit annoyed, cause you know Cole’s labelling, and I was just letting him go. I didn’t care”. Mom and Dad were able to experience dignity during family leisure by respecting Cole’s embodiment, allowing him to express himself, and in turn respecting themselves. By reframing the community’s role in their family leisure experiences, they rejected community imposed violations of dignity and created space for themselves in the community.

Grandma also explained that Mom taught her to stand her ground and push through situations of vulnerability. “We leave the situation on a positive note...Which is something Mom has taught us too. We don’t just run from something. We do work through the difficult part of the situation when we’re out” (Grandma). Grandma, by following Mom’s guidance, felt confident and positive when she maintained respect for Cole and respect for herself by creating space in the community for her family to belong, “He has to be able to participate and try...we just try and not let any of that affect him trying stuff, knowing that people don’t understand, or that they’ll say stuff. Just keep on trying”. Similarly to Mom and Dad, Grandma resisted acquiescing to the exclusionary actions and moral authority assumed by other people to maintain Cole’s dignity and her own dignity. Grandma maintained integrity by exerting her autonomy during community-based family leisure, understanding that they were as deserving as anyone else to engage in activities of their choice. “You just have to let it go...You just keep on keepin’ on right? Keep having fun and never let it [glares, stares, comments], stop us from doing an activity” (Grandma)

Great-Grandma also maintained self-respect and respect for Cole in situations where she and her family may have been susceptible to mistreatment from the community. She shared a story from when she took a flight with Mom and Cole:

> I flew to [city] with him once, but he was pretty small then, and he howled the whole way on the plane...some passengers were a bit upset that he was howling all of the way there, but hey, any child can do that.

Great-Grandma recognized that other young families likely find themselves in similar situations. She did not feel alone in this situation and as a result was kind to herself and to Cole. Great-Grandma recognized that this experience was shared by other families with young children, and that they also had the potential for short term loss of dignity. Therefore, she did not experience feelings of uneasiness or concern over the situation. Instead, she upheld her sense of dignity through maintaining respect for herself and Cole.

Stories of Belonging

For this family, a sense of belonging promoted dignity. Belonging was experienced during community-based leisure when they encountered engaged interactions with others, when people responded directly with Cole, and when they encountered welcoming spaces in the built-environment. In addition to describing stories of mistreatment, the family members shared stories of times when they felt as though their dignity was maintained during community-based family leisure. Acceptance was demonstrated by people in the community when they expressed a desire to understand Cole and his embodiment, and engage in meaningful relationships with them as a family. Mom explained that when family friends asked her questions about Cole, she appreciated the gesture as it gave her the sense that people were invested in understanding Cole. In those moments of shared time, there was also a shared interest and mutual respect between Mom and some members of the community. She discussed: "A few of the parents have been texting me just saying like 'My child has this question, what do I say?', and that's been awesome." Mom also talked about how this type of interaction also enabled her to maintain Cole's dignity of identity, "It's better you ask me than you giving them [other children] something you read off of the internet, cause that's not necessarily reflective of Cole." In this situation, Mom was encouraging people to see Cole as an individual and understand his personal embodiment, ensuring that he is respected as an individual rather than subsumed into a group identity.

Mom and Dad also reported experiencing a sense of belonging during community-based family leisure when other families, known or stranger, demonstrated a desire to connect with them and build relationships through engaged interactions. "When somebody's like, 'Oh I noticed he was making that loud noise, is he okay?' And I'm like 'Oh, no he has autism and he's really happy! And that's so great, I love that" (Mom). By asking questions about their child, that are framed as caring and curious, Mom felt as though people were trying to understand her son and connect with her family. Cole's parents felt as though their family was socially included when people took the time to engage with Cole. For example, when the family attended a local car show, Dad experienced feelings of social inclusion when he could see Cole connecting with people in the community, "It was pretty cool, like they were all right into sort of talking to him and engaging him and answering his questions and stuff". Shared time gave them the sense that their family belonged in the community.

When people in the community engaged with the family on a kind and accepting level, relational space to belong was created interdependently. Mom explained feeling comforted by the relationships her family had built with other parents during Cole's most recent birthday party: "I think it was good because there was no expectation that it needed to look like a typical birthday party. The parents were just happy that their kids could be there". Cole's individuality was seen and valued by the parents and children at the party. Mom felt as though mutual respect was present between her family and the party attendants. "Like I said to one Mom, 'I'm having some concerns about opening presents', and she's like 'Well then don't open presents, like who cares'" (Mom).

Engaged interactions between the family and people in the community also helped restore feelings of lost dignity. Mom described feeling anxious when Cole was having a hard time during a family leisure activity, and was upset. She talked about how an interaction with another parent in the community made her feel more comfortable and helped maintain her dignity in a situation when it could have potentially been decreased. She explained:

> It was almost like 'oh you don't need to be embarrassed, because my kid does that too.' She's like 'Oh my kid has bit somebody in public before, like it's not a big deal'. And I really, I appreciate that.

The parents' interaction caused Mom to feel as though she was not alone in the situation, and conveyed a shared humanity between herself and Mom. The support that Mom received from the other parent helped maintain Cole's dignity of identity by empathizing with Mom's uneasiness and reassuring her that her son was not being devalued.

Grandma reported experiencing a sense of belonging when her family was met with engaged interactions with people in the community. She explained how she noticed Cole's emerging desire to engage with people in the community. “He really likes to communicate with strangers...once his question is asked, he’s happy. He’s like ‘you answered my question; I’m happy, now let’s go!” (Grandma). Grandma began to recognize that having relational engagement during family leisure meant that Cole was met with respect. She explained, “I guess people can make us feel welcome and included, I guess just to communicate, to communicate with Cole”.

Great-Grandma also felt as though Cole’s and the family’s sense of dignity was maintained through engaged interactions with people in the community: “People seem to just be so good with him, like, they’ll stop and answer his questions and I think that helps [the family feel dignified] immensely”. Shared time, respect, and interest from the community were very important in enabling Grandma and Great-Grandma to have positive experiences during family leisure. Grandma shared a story about an interaction between herself, Cole, and a mother and her child at a toy store. The mother supported her young child’s interaction with Cole, and Grandma experienced a shared moment of meaningful connection. She explained:

> And the mother just warmly invited Cole into the conversation with her little child, but she helped to converse with Cole. And that, that was a great feeling because I believe she understood that Cole’s questions, the way Cole, I can’t remember what questions he was actually firing at them, were a little unusual, not what you would consider neurotypical questions coming from such a young child. And she just engaged with us as opposed to us getting that look like ‘I don’t really, why would a child be asking this?’...She didn’t seem to have any uncomfort level in it; she just seemed to engage in it. And it was, actually made you feel wonderful that somebody would take the time to make Cole feel comfortable and help with the interaction with her child.

Dad also added that on rare occasions, the physical environment was set up in a way that supported the family to feel they belonged in the community. In his last interview, he described an experience he had with Mom and Cole at a local fair. The fair had created quiet rooms, in various locations around the fairgrounds, for families and children to take breaks in should they need it. Dad explained that during their time at the fair, he experienced a sense of belonging: "I didn't feel like there wasn't a spot for us to go if he needed a time out...I look [at Cole] 'Oh maybe he's a bit dysregulated', we were able to pop into one of those little zones".

Feeling Overlooked; Lamenting the Future

When Cole was younger, the majority of the parents' and Grandma's experiences during family leisure were fraught with feelings of being singled out. Once they were able to understand the violations of dignity (staring, glaring, verbal judgments, and physical distancing), and the impact they had on their experiences of family leisure, Mom and Dad reported experiencing a shift in which they were able to distance themselves from those experiences (where mutual respect was absent) and regain self-respect. The family felt that dignity should not have to be earned, but rather they were already deserving of participation in the family leisure activities of their choice. Recently, Cole was beginning to connect with people in his community. This was demonstrated by a noticeable desire to engage people in conversations. As Cole's desire to connect with others began to increase, dignity during family leisure took on a different meaning for Mom, Dad and Grandma, and they began to once again experience significant feelings of exclusion.

Mom noted a shift in her meaning of dignity in family leisure when she noticed people ignoring Cole after he attempted to engage in conversation with them. When Cole was younger, Mom felt her son received too much attention, in the forms of staring and glaring, in response to situations that did not deserve of such intense surveillance. Recently however, Mom felt as though Cole was not being afforded the attention he deserved from others when he attempted to engage with them. She had not experienced someone blatantly overlooking her son, because he had not initiated many interactions until he got older. She explained:

> Cause when he didn't interact, I mean, if they just stare and walk away, I never notice stares [anymore], right? Cause I don't have time to worry about who's staring at anybody. But it's that, you really notice when he goes to engage somebody and they don't give it back to him. And they just kind of like walk away.

Cole's dignity was violated when he was not 'seen' by people in the community. As a result, Mom experienced social exclusion in a new way. Dad described experiencing a similar situation at an organized event with other families in a local park. He noticed Cole attempting to engage with some other children in imaginary play. When Cole initiated an interaction with another little boy, the little boy did not reciprocate Cole's engagement, subsequently resulting negative emotions for Dad. Dad said: "This other little guy just gave him a weird face and shook his head…it pulled on my heartstrings a bit…after that I did notice that same boy somewhat avoiding Cole."

Similarly to Mom and Dad, Grandma also reported experiencing a sense of lost dignity when Cole was ignored or overlooked by people in the community. In these situations, respect was absent and Cole's dignity of identity was violated. She explained that sometimes people appeared uncomfortable when Cole attempted to engage with them and often opted to ignore him rather than reciprocate the interaction:

> “You know, [the other person thinks] ‘if I don’t answer that child’s questions, or if I pretend I don’t even see that child, or I just don’t answer it, then they’ll just go away’. Those are the times when I feel we don’t have dignity in the community”.

Mom described how in certain instances, Cole will even repeat himself in an effort to be seen and heard by others in the community. Cole had been taught to repeat himself when the other person in the interaction may not have understood or heard what he said, “He was using his strategies right? [to repair what he thought was a communication breakdown] ‘Oh that guy didn’t hear me, so I need to say it again’”. However, often he is simply ignored. This has been a difficult experience for Mom, Dad, and Grandma and has shaped their experiences of dignity during family leisure. “Him interacting and being shut down, you can’t ignore that. So yeah that’s definitely changed for sure” (Mom). Dad talked about how he had noticed still feeling somewhat defensive during family leisure, and found himself monitoring other people when in public. Experiencing dignity during family leisure was dependent on how people perceived his son. He wanted his son to be recognized, instead of overlooked and devalued, in the community. He explained: “Even though I don’t care as much, I’m still watching other people for what they’re thinking…I think it’s probably because I don’t want people to think less of him”. Dad felt as though his son deserved the same level of respect as any other human. The thought of his son being perceived as less than another person was unsettling.

Dad also felt as though the community overlooked children with autism in a more general sense. In addition to witnessing his son being dismissed in one-on-one conversation situations, he also reported that event and leisure staff failed to recognize children with autism as valued members of the community. For example, at a fundraising event for an organization that supports children experiencing autism, Dad reported feeling as though Cole’s needs were ignored in favour of the needs of donors and sponsors. In this situation, the needs of children with autism were eclipsed by the needs, or preferences, of ‘able-bodied’ individuals. He explained that the music at the event was too loud, making the environment less enjoyable for Cole:

> It was just like awkwardly loud. So him and I, so I went and got his headphones so he could continue walking around and we just kind of stayed away from the stage... There you go, like there’s an inclusion thing. Who are they catering? Are they catering to the people that are coming to do that car show, the people that own the cars, or the kids that are going to see the cars? Obviously not the latter, right?

In addition to feeling as though their son is being ignored in the community during family leisure, Mom and Dad often found their stated needs being disregarded by people in the community. Mom shared a story about one of her first flights with Cole when a stewardess insisted that Cole remove his noise cancelling headphones for take-off: “When she came over I was like ‘Oh no these aren’t music headphones, they’re noise cancelling ones, he has autism’. She was like ‘No! he needs to take them off’. So that was hard because there was zero understanding”. Using her position of authority, the staff member overlooked Mom’s request to let Cole keep his headphones on. The stewardess failed to demonstrate personal responsiveness and empathy, and the chance for relational engagement was lost. Mom felt as though she was not being heard in this situation. Violations of dignity through not being seen and heard were becoming more frequent during community-based family leisure.

As Cole continued to get older, Mom specifically noticed that the label of ‘autism,’ was leading to experiences of being subsumed into a group identity. Cole was not being seen for who he was as an individual, but for others’ perceptions of the extremes of autism. “So there is two, kind of, stereotypes”, Mom explained, “He’s either going to be a super genius, and that’s what half of the people perceive him as, and then the other half were like ‘Oh my gosh, he’s so capable of walking by himself.’” When people appeared to make assumptions about Cole, based on his label, his wholeness was ignored and dismissed. Mom also reported feeling excluded in the community simply based on the label of autism. During a community event, she felt hurt when she read a sign that indicated her son could not participate in an activity with other kids, “There’s a huge sign right in front of it, I took a picture of it like a long time ago, but it says ‘people with mental or physical disabilities cannot use the bouncy house’”. The message on the sign was based on assumptions regarding people experiencing disabilities as incompetent and incapable of participating appropriately on the equipment. Cole’s autonomy was overlooked and he was subsumed into a group identity based on a label. This resulted in disappointment and significant feelings of social exclusion for Mom. “It reminds me of all the things that he’s going to be told no in his life, because he has autism, not because he can’t do it, right? Strictly because there’s just been a label that’s put on him” (Mom).

Chapter Five: Discussion

The purpose of this study was to capture the stories of how a family with a child with autism negotiated their and their child's dignity during family leisure. For this family, dignity, as a state of being, was supported but was also susceptible to violations during family leisure. The family members experienced different types, levels, and violations of dignity during family leisure. Dignity was cyclically maintained, lost, and regained. Although Cole and his family were deserving of the respect of others (dignity of Menschenwürde), the undignified self was ever present in their lives (Nordenfelt, 2004). Other researchers have documented the mistreatment and devaluation experienced by families that have children with autism (Ryan, 2005; Woodgate et al., 2008). Through this project, I have contributed to this body of knowledge by making connections to how dignity, a fundamental human right, is influenced by the actions of others and environmental factors.

When engaging in community-based family leisure, relationships to strangers become part of the leisure experience. However, families in the community may not know each other and staff at leisure facilities may not know customers. Therefore, it may be difficult for people in the community to consider one another as 'neighbours' rather than 'strangers' (Bergum & Dossetor, 2005). The parents felt as though they were often only regarded as strangers for example, when they were singled out, overlooked, judged, and excluded through distancing. The result was experienced as a sense of lost dignity, for when they were only considered strangers, the uniqueness of each person was lost, and in that, engagement was lost too (Bergum & Dossetor, 2005).

For this family, experiences of dignity during leisure were inter-generational. The family members experienced dignity in different ways. Grandma and Great-Grandma's experiences of dignity were more stable over time. Great-Grandma in particular, appeared to experience consistent feelings of the dignified self during family leisure. Grandma experienced situations that, according to Mann (1998) and Nordenfelt (2004), resulted in feelings of lost dignity at times, but she did not experience indignity to the same extent as Mom and Dad. Much of this difference is explained by the fact that Grandma and Great-Grandma were further removed from Cole's day to day life. In addition, as grandparents, Grandma and Great-Grandma engaged in activities that Cole enjoyed, in environments in which he was comfortable. In other words, Grandma and Great-Grandma perceived their family leisure time with Cole as occasional, pleasurable, and relaxed (Hillman, 2007). Great-Grandma in particular, chose to focus on her great-grandson, rather than building relationships with the community, and therefore experienced the dignified self.

Constantly Battling Against the 'Norm'

Both parents emphasized feeling consistently singled out in their early experiences of community-based family leisure. Mann (1998) explained that being distinguished as separate from the norm is a violation of human dignity. From the perspectives of many community members, the family did not reflect the norm (Shotwell, 2012). As Cole's impairment was often invisible, the perception was that he should behave in a certain way. When Cole's behaviour appeared deviant, people were quick to judge and correct the parents, subsequently challenging their autonomy, integrity, and dignity of identity (Nordenfelt, 2004). The persistence of normative views held by people in the community, be it leisure staff or other leisure participants, made it difficult for this family to experience the dignified self during family leisure. Therefore, they were required to engage in significant psychological energy to overcome and resist indignities (Scully, 2010).

For Shotwell (2012) “the term “normative” is generally taken to describe statements that make claims about how things ought to be or how they are in general” (p. 991). In the case of disability, “norms of speech, movement, mobility, pace, conversational topic, and so on” can threaten this family’s ability to feel dignified during family leisure (Scully, 2010. p. 35). Shotwell (2012) explained:

> Under conditions of oppression, norms generally do not proliferate ways of flourishing. Rather they delimit and constrain the ways of being one can take up, and they contribute to the death and degradation of people who fall outside currently normative bounds (p. 1005).

Scully (2010) added that when there are encounters between disabled and nondisabled people, the rules that govern social life are sometimes broken. For this family, attitudes from people in the public tended to favour normativity, which resulted in feelings of being singled out or humiliation that impacted feelings of control and self-respect (Mann, 1998). As a result, the parents and Grandmother experienced the undignified self (Nordenfelt, 2004). Shotwell (2012) argued for a creation of ‘open normativities’: “normativities that prioritize flourishing and tend toward proliferation, not merely replace one norm with another” (p. 1003). Many violations of dignity experienced by the family resulted from judgments of the child’s or family’s actions as deviant or strange, such as Cole’s use of gestures to communicate. This is similar to findings from Goodwin and colleagues (2014) where the embodied actions of a man named Jack were perceived as disrespectful or to be in violation of cultural norms of public interactions. Open normativities might enable this family, and other families that have children with autism, to feel more dignified during family leisure. Through a conscious effort to embrace all forms of embodiment and knowledge, an environment of mutual respect may be created.

Furthermore, open normativities may create contexts for enhanced opportunities for dignified encounters, as the comparisons that other people make are replaced by efforts to assist families in flourishing.

Taking Control Over Their Dignity

Having experienced numerous undignified situations since Cole was given the label of autism, Mom and Dad engaged in significant psychological energy to overcome and reject indignities (Scully, 2010). Over time, Mom and Dad learned to reframe their experiences of indignity. Through preparation, standing their ground to continue engaging in community-based activities, and rejecting the cruel acts of others, the parents protected Cole's dignity of identity as well as their own (Nordenfelt, 2004). In many instances, the work required to maintain, restore, or protect themselves from devastating losses of dignity fell on the family (Shotton & Seedhouse, 1998). The significant physical and psychological energy was spent by the family members to prepare for and negotiate interactions can be viewed as a family developed strategy for maintaining self-respect when mutual respect is absent (Scully, 2010). Through preparation, the family members were able to support themselves, and Cole's embodied needs, to continue engaging in community-based family leisure, ultimately promoting the dignified self in each of them.

Dignity as moral stature is realized when the agent respects others and experiences self-respect (Nordenfelt, 2004). Standing their ground to give Cole the same opportunities as other children, even in the face of the undignified self, enabled the family to maintain their dignity as moral stature (Nordenfelt, 2004). This dignity was maintained by Cole's family members by respecting him, and in turn, experiencing self-respect. In turn, in instances when their dignity, or Cole's dignity, was being violated, Mom, Dad, and Grandma perceived a lowering of dignity of moral stature of the offending other, thereby enabling them to decrease their anger toward others and refocus on the needs of their family (Goodwin et al., 2014; Nordenfelt, 2004).

The ability of the family members to reframe and reject instances of indignity, and continue to engage in leisure activities despite being in potentially degrading situations, speaks to the maintenance of self-respect of the family members. Self-respect is tied to experiencing self-worthiness (Bergum & Dossetor, 2005). Creating spaces for themselves in the community was possible through the family members' own perceptions of self-worth and acknowledging that they were deserving of engagement in community-based family leisure. Stranger imposed indignities that once caused Mom, Dad, and Grandma significant feelings of lost dignity were no longer regarded as such devastating losses and were experienced more as trivial losses of dignity (Shotton & Seedhouse, 1998). Through resistance, rather than relationship building, the family members created space for themselves and Cole in the community. Mutual respect involves "both being respectful to self and being respectful of others" (Bergum & Dossetor, 2005, p. 68). Mom and Dad recognized a lack of respect from others in the community, but prioritized self-respect, and respect for Cole by continuing to engage in leisure activities within their community. In addition, respect for Cole and the self were fostered when Mom taught Grandma and Great-Grandma how to make family leisure outings successful. Grandma and Great-Grandma learned from the examples set by the parents and were able to ignore potential violations to their, the parents, and Cole's dignity. In addition, it is likely that Grandma and Great-Grandma's ability to ignore potential violations of dignity supported Mom and Dad to feel more comfortable in the community. The positive relationships that exist between the three generations provided social support, protection, and safety for the dignity of all of the family members involved in the leisure outing (D'Astous et al., 2013; Harris et al., 1985; Trute, 2003).

Bayat (2007) claimed that many families of children with autism display factors of resilience. The labour taken on by this family to prepare for, reframe, and reject instances of indignity speaks to the resilience of the family members. In their review article, Bekhet and colleagues (2012) argued that the authors of the 22 studies included in their review showed that "parents of children with ASD [autism spectrum disorder] who possess indicators of resilience are better able to manage the adversity associated with caring for children with ASD" (p. 654). However, the family of this study appeared to demonstrate resilience in managing the adversity associated, not with caring for their child, but with social and environmental threats to their dignity during family leisure. Resilience has been conceptualized as "the ability to withstand hardship and rebound from adversity, becoming more strengthened and resourceful" (Walsh, 1998, as cited by Bayat, 2007, p. 702). The family members seemed to be resilient in their efforts to access and maintain participation in community-based leisure activities. Despite numerous negative interactions with both service providers and the general public that violated their dignity, the family rebounded from the adversities associated with feeling singled out, ignored, and mistreated. Through preservation of self-respect, diligent preparation, and rejection of exclusionary practices, the family continued to access leisure in the community.

Unforgiving Environments

Consistent with findings from Ryan (2005), the family found that "public spaces are not open to all but are, in fact, regulated and hierarchically arranged" (p. 302). Often, public leisure contexts lacked the relational space for Cole to work on his skills, subsequently making the parents and Grandmother feel like they were a burden to, and less dignified than, others in the community. Participants in a study from Johnston and colleagues (2015) shared similar sentiments, reporting that they often felt like they were ‘in the way’ of other people in exercise settings.

Many leisure environments were not socially or politically welcoming (Bergum & Dossetor, 2005). Similar to findings from Johnston and colleagues (2015), washrooms and change rooms appeared to be particularly threatening environments for Mom and Dad during family leisure. Leisure staff and service providers often used their dignity of merit to remove the dignity of the family in their parenting decisions (Nordenfelt, 2004). The parents specifically felt as though they could not exert control over their decision, thus undermining their integrity and violating their dignity of identity (Mains, 1994). When Mom and Dad’s parenting practices were questioned, it created a critical environment in which there was no room for connection or relationship. Bergum and Dossetor (2005) offered that “when social and cultural ranking and status, especially, are attributed to roles, relationships may be limited and destroyed” (p. 90). Through a commitment to relationship building, determining the most fitting action in a particular environment is possible (Bergum & Dossetor, 2005).

True Engagement Promoted the Dignified Self

The dignified self was experienced by all of the family members when true responsiveness and empathy were displayed by other people in the community. Shared time in conversation was one of the main ways that people in the community demonstrated engagement toward the family. **“**Relational engagement is found in the shared moment in which people have found a way to look at something together” (Bergum & Dossetor, 2005, p. 103). For the family, true engagement was experienced when people in the community demonstrated a reciprocal desire to connect with Cole and his family members. Questions framed as caring were interpreted positively and enabled the family members to maintain feelings of the dignified self.

This finding is consistent with findings from Lohne and colleagues (2010) where patients living with multiple sclerosis reported feeling as though their dignity was maintained when healthcare professionals took the time to engage in caring conversations with them. Bergum and Dossetor (2005) maintained that “although time is important, engagement is not time-limited” (p.121). Even if interactions were not lengthy, the family felt dignified when people demonstrated a willingness to meet Cole, and each family member, with an attitude of respect and attention (Bergum & Dossetor, 2005).

Seeing the Whole Person

Bergum and Dossetor (2005) maintained that respect is given to something or someone by paying attention to it and taking it seriously. The authors argued that when someone is neglected or dismissed thoughtlessly, they are not respected. As Cole’s desire to connect with others in the community became more noticeable, his parents and Grandmother experienced new violations of dignity. When Cole was ignored, singled out, or stereotyped by people in the community, there was an absence of mutual respect, and his dignity of identity was violated (Bergum & Dosstetor, 2005; Nordenfelt, 2004; Mann, 1998). For Bergum and Dossetor (2005) respect can be given in several ways, with one way being providing respectful acknowledgment. Feelings of lost dignity were felt by Cole’s parents and Grandmother, for him. Even in instances when Cole was not aware of the mistreatment from others, his family members felt the loss of dignity and also perceived a lowering of dignity of moral stature of the offenders (Nordenfelt, 2004). Nurses that participated in a study by Lindwall and von Post (2014) felt similarly when they saw other healthcare professionals mistreating a patient that should be in their care. When the parents and Grandma witnessed Cole being mistreated, overlooked, or excluded, this kind of interaction, according to Mann (1998), resulted in a loss of dignity. What appeared to be missing in the community was people’s ability to recognize each other’s shared humanness (Goodwin et al., 2014). As a result, people appeared reluctant to engage and the chance for relationship and connection was lost (Bergum & Dossetor, 2005).

Decisions regarding the disclosure of Cole’s diagnosis of autism were influenced by how Mom thought it might impact his dignity of identity (Nordenfelt, 2004). Bergum and Dossetor (2005) explained that “labelling splits people apart, making it easier to choose ‘parts’ of the person to know about” (p. 113). Labelling can lead to ignoring the wholeness of a person (Bergum & Dossetor, 2005). Mom recognized this and had difficulty deciding when to disclose her son’s diagnosis. She recognized that in some cases, it may benefit Cole by helping people to understand him. However, it had also lead to the dismissal of Cole as an individual. The decision not to share Cole’s diagnosis was often based on the intention of maintaining Cole’s dignity of identity as people did not see past the label. In addition, the family had experienced exclusion based on the label of autism. This resulted in a significant loss of dignity for Mom, as her son was being denied participation in the community based on a label. Therefore, another reason disclosure of the label was withheld was so the family could maintain dignity of identity in the community (Nordenfelt, 2004). Bergum and Dossetor (2005) offered that “[t]hrough integration of body and mind, in embodiment, the meaning of being a person is claimed through understanding the relational quality of self, other, and the context within which self and other are located” (p. 151). The commitment to understanding and honoring Cole’ embodiment was often absent in the community as demonstrated by people’s focus on the label of autism.

Chapter Six: Implications and Future Directions

Practical and Theoretical Implications

The experiences of this family, and the stories they shared, have illustrated how this family navigated family leisure and the different ways in which they experienced dignity during leisure activities. It is clear that experiences of dignity and indignity need to be discussed as part of professional preparation and practice in adapted physical activity, as well as other recreation and leisure contexts (Johnston et al., 2015). Understanding how people experience dignity in leisure is paramount in creating open and welcoming environments in which all families can participate. For recreation and leisure practitioners, other staff involved in recreation and leisure services, and the general public, I have highlighted the challenges that families with children with autism face when accessing community-based family leisure. The perspectives of Cole's family members bring attention to the extreme importance of increasing awareness of autism in society. Importantly, leisure and recreation practitioners should receive training that encourages them to remain open to different forms of embodiment, as well as the skills to adapt environments to meet the needs of all individuals that access their services and programs. A self-reflexive awareness should be instilled in practitioners to support them in building reciprocal relationships with the families they encounter.

Findings from this study may be helpful in creating dignity sensitivity training for recreation and leisure practitioners, both in and outside of the field of adapted physical activity. On a similar note, dignity sensitivity training for recreation and leisure practitioners should include more specific dignity modules that outline dignity as a state of being, the different types of dignity, the various levels of dignity, and the ways that dignity can be violated. Bringing this type of training to the fields of recreation and leisure may promote the necessary wakefulness needed to become open to all forms of embodiment, and support practitioners to erase any assumptions they may hold regarding normative ways of being.

If we return to the framework of relational ethics, it is simple to see that when mutual respect and engagement are absent from relationships, the dignified self may be lost and the undignified self becomes present. According to Bergum and Dossetor (2005), mutual respect is central to relationship building. Through respectful relational engagement, relationships are created and sustained. In addition, the authors contended that embodied knowledge informs what relationships mean, and only through the creation of a relational and interdependent environment, can relationships be sustained. As I think deeply about relationships, and relational ethics, it becomes apparent that a focus on interdependence and creating relational spaces may be important aspects to consider when educating APA professionals as well as recreation and leisure practitioners in general. Links to relational ethics could be included in dignity sensitivity training as a framework to support relationship building in recreation and leisure contexts.

The findings of this study might also be helpful in pushing the theoretical understandings of the phenomenon of dignity. Mann (1998) presented four violations of dignity: not being seen, being subsumed into a group identity, violations of personal space, and humiliation. However, when Cole was mistreated or devalued in the community, the loss of dignity experienced by Cole’s family members might reflect a different type of dignity violation. When his family members felt as though Cole’s dignity was being violated, they felt the loss of dignity as well. This loss of dignity was experienced as devastating for the family members, almost worse than if their own dignity had been personally violated through direct mistreatment (Shotton & Seedhouse, 1998).

In addition, this project can help us reflect on the types of dignity experienced by different people, such as leisure and recreation practitioners, families and children experiencing disabilities, and people that identify as ‘able-bodied’, and why certain dignities are assigned to and experienced exclusively by some, and not by others. Specifically, dignity of merit assigns rights and respects depending on a person’s position or rank. As a result of the merit often assumed by others, this family appeared to have a low level of dignity of merit, and even questioned their dignity of merit within society and various community spaces. This questioning of dignity might be explained by the “pervasiveness of prejudicial opinion” that may be maintained by people in public places which can “cause persons with disabilities to effectively minimize their own expectations of equality and dignity” (Shannon, 2007, p. 41). A move toward interdependence may shift the experiences of dignity as merit. By recognizing the ways in which rights and respects benefit some and simultaneously disadvantage certain groups, the project of interdependence may progress, exclusionary practices may fade, and the responsibility to create environments in which all humans can flourish will become a shared one responsibility.

Study Limitations

I would like to acknowledge the limitations of this study. Firstly, I am cognizant that in many instances, questions posed to the participants in their initial semi-structured interviews were worded as such that the participants were required to engage in memory recall. However, the addition of conversational interviews added the opportunity for the participants to describe more current experiences which may have minimized the potential limitation of memory recall that arises in semi-structured interviews. Another limitation to my study is the extent of contribution from each family member. Mom engaged the most in the interviews because she had the most availability, but also likely because she had the most to share as Cole's primary caregiver (Phetrasuwan & Miles, 2009). She also engaged in the most family leisure with Cole.

Choosing to conduct a case study limits the extent to which the findings of this study may be generalized beyond the experiences of this one family. However, the goal of qualitative research is not necessarily to generalize. Rather, qualitative research aims to explore and report "particularities of locally defined knowledge" (Chenail, Duffy, George, & Wulff, 2011, p. 272), which has been achieved in the presentation of the findings.

Lastly, I'd like to acknowledge the potential limitations that arise as a result of my role as the instrument of research. My roles as a researcher and community aide overlapped throughout the entire research process. Therefore, there is a possibility that I may have been 'too close' to the family and their experiences. As a result, I may have overlooked certain instances, situations, or interactions. In addition, there is a possibility that my assumptions or biases clouded my ability to interpret the participants' experiences in an accurate and representative manner. However, my diligent dedication to field note writing throughout the whole of the research process minimized potential researcher bias and helped me remain wakeful to things that may have otherwise been taken-for-granted.

Future Research Directions

The experiences of this family are not representative of all families that have children with autism; however their stories are insightful and deserving of attention. This family may have been unique in that they are fortunate to have extended family members engaged in their family life. However, this family provided me the opportunity to think deeply about dignity. I discovered that the parents experienced indignity almost on a day-to-day basis. It makes me consider how other family units (for example single parents of children with autism) address indignity without the kind of intergenerational support experienced by this family. Therefore, further investigations into the experiences of dignity for families that have children with autism are required.

In addition, this project failed to capture fully the experiences of the individual living with autism. Although the purpose of the study was to understand the family members' experiences of dignity, the experiences of dignity of the individual living with autism should not be overlooked. Researchers should walk alongside people experiencing autism to understand how dignity is experienced and what it means to them.

It would also be valuable and important for researchers to conduct longitudinal studies to gain an understanding of how dignity is experienced at different points in the family members' lives. For example, if we return to Mom's story about the trolley conductor, she experienced the interaction very differently than the other parents she was with at the time (whose daughter had recently been given the label of autism). The differences in reactions might be explained by how far along each parent is in her or his journey. For Mom, the interaction was fleeting and only resulted in a trivial loss of dignity. However for the other child's parents, the loss of dignity was significant, and they may have wanted to follow up with the trolley conductor as a way of regaining their dignity. Therefore, further work is needed to understand how dignity is experienced during family leisure at different points in families' lives. This notion is supported by Al-Oran and Al-Sagarat (2016) for in their review of parenting stress of children with autism, all researchers agreed that mothers whose children have just recently been diagnosed experience higher levels of parenting stress.

Similarly, researchers should aim to conduct longitudinal studies that gain a deeper understanding of what it means to be resilient as a family unit. Researchers conducting longitudinal studies might be able to provide new insights on whether resilience should be considered a state or a trait, and how it is experienced over time for families that have children with autism.

Although this study was bound by the concept of ‘community-based family leisure’, stories related to school settings were brought up by each family member. Therefore, future researchers should examine experiences of dignity when interfacing with the school system.

Lastly, future researchers should aim to explore the meaning of the ‘gaze’ in experiences of (in)dignity (Hall, 2002; Reeve, 2002). This family, specifically the parents, felt singled out when others in the community stared or glared at their son or family unit. Reeve (2002) argued that the ‘gaze’ can become a technology of power in which the observer gains control over the observed. Furthermore, the gaze “exerts power over disabled people within everyday social situations” (Reeve, 2002, p. 499), which resonates with the experiences of this family. Future researchers should seek to understand how the gaze of community members (enacted through staring and glaring) may impact experiences of dignity during family leisure for families with children with autism.

Chapter Seven: Conclusion

Exiting the Field and Concluding Thoughts

The final one-on-one, semi-structured interviews conducted with each family member was not only used to gather data and serve as an opportunity to discuss preliminary themes, but was also used to signal a closing off of the data collection portion of the research process. Since then, I have touched base with the family through email communication, to complete the last step of member checks. Once I received each family member's response regarding the summary of the themes, I thanked them for their contribution to my study and let them know that their responsibilities were complete. For me, exiting the field was likely different than other researchers. Although I have transitioned away from the family as a researcher, my life will continue to be enmeshed with them as I will remain engaged with the family as a community aide for Cole.

My hope is that this project will be a catalyst for conversations between researchers, families, and leisure and recreation practitioners regarding the importance of dignity in people's lives. I also want to recognize the potential danger that my project may perpetuate the notion that experiencing disability, or raising a child that experiences disability, is an unfortunate life circumstance. Rather, I hope that to have illustrated the important role that relationships play in how dignity is experienced. By understanding how this family with a child with autism experienced dignity in community-based family leisure, we have gained insights into promoting the flourishing of families experiencing autism. Although more work is needed to understand the ever complex phenomenon of dignity, this project was a starting point for me.

Responding to Questions at a Poster Presentation

The first time I presented the findings of this study was at a poster session at a faculty conference. During my poster presentation, I was met with mixed reactions and comments. Some people I spoke with appeared receptive to my project and expressed their appreciation for works that share stories. Others did not appear to be impacted in the way that I had hoped; their focus was on the child's diagnosis of autism (medical model), rather than the experiences of the family. I received some thought-provoking and difficult questions from a few conference delegates. Two questions in particular really struck me, *"So, how high functioning is the kid?"* and *"Is there any research on early intervention strategies to help these kids so they just don't have tantrums in public?"*

The questions shocked me and each time, I froze momentarily. Of all of the questions I had predicted people might ask me during my presentation, these had not crossed my mind. As I spend most of my days on campus, in my office with other APA graduate students, I understand that sometimes I get stuck in my own little bubble, and often forget that other people, students, researchers, and professors from other departments, think very differently than I do about disability and society. Perhaps it was naive of me to be startled by such questions. I guess I was wrongfully optimistic that at least in our faculty, we had made progress toward exposing our ableism.

Let me unpack the first question and explain why it evoked feelings of discomfort for me; *"How high or low functioning is the child?"* I received this question numerous times, and each time it made me very uncomfortable. I had not prepared an answer to this question. I guess to me, the level of Cole's functioning should not matter. 'Functioning' is deemed to be high or low when compared to normative criteria. Therefore, by answering the question, and giving Cole a label of high or low functioning, made me extremely uncomfortable as I would be perpetuating the notion of an ideal normate. One conference delegate said to me, “Well I just want to know like what his behavior looks like so I can understand the types of reactions he might get in public”.

Mallett and Runswick-Cole (2016) discuss the “urge to know” (p. 95). For the authors, the casual request for an impairment label is part of the everyday life for people experiencing disability, their friends, and family members. It is often not enough for people to know that an individual experiences disability, they desire to know their impairment label and how high or low functioning that individuals is considered, as if that would provide them with the key to that individual’s social identity (Mallett & Runswick-Cole, 2016). The denial of such information can often be interpreted as “unreasonable, unnecessary, and rude” (p. 96), which was my biggest fear when attempting to respond to the question. Although I am proud of myself for not succumbing to labelling, I hope that I handled the situation with enough grace, and that my denial to label Cole as low or high functioning did not come off as rude.

The second question was just plain frustrating*: “Is there any research on early intervention strategies to help these kids so they just don’t have tantrums in public?”* It was disheartening to hear this question. One of the aims of my research was to understand how a family experienced dignity, and identify what might be lacking or evident in relationships to cause them to experience the undignified and dignified self; I am interested in how communities can support families that have children with autism, not how children with autism can change to fit in within their communities. However, this delegate was more interested in ways to ‘fix’ children that experience autism. I understand that this person’s question was not intended to send a malicious message that children with autism should be cured, however, he seemed to miss the message of my study. I attempted to respond as diplomatically as possible (ironically, to ensure the other delegate's dignity), and said: *"There is an abundance of research being done regarding best practices for early intervention and early detection of autism in children. That being said, I think there needs to be a balance between 'intervention' for children and society. The world will never be set up perfectly for each individual person, diagnosis or not, and therefore it's important to support children in working toward skills that will allow them to flourish in their communities. However, if families fear going out in public, their children will not be afforded the opportunity to work on their skills. Essentially, I feel as though there needs to be a balance: children should be supported to learn the skills needed to flourish, but society needs to improve so that families experiencing disabilities can feel comfortable taking their kids out into public spaces to work on those skills."* And that is how I truly feel.

As I reflect on these ableist questions, and wonder how I might respond should they be posed again, I still find myself struggling to come up with an eloquent answer. Instead, I may simply shift the conversation by asking the other person, "*Help me understand why it's important for you to know this?"* It might also be helpful to explain how labelling someone as high or low functioning, or understanding best practices for 'intervention', are practices embedded within a deficit (medical) model which do not align with my position and values as a researcher.

Although these questions flooded me with various, mostly negative, emotions, I am also grateful that I was challenged. These interactions reminded me that I do not exist in a bubble and I should remain cognizant of my own assumptions and paradigmatic stance. These questions also provided the opportunity for dialogue between people that may not necessarily see 'eye to eye'. With dialogue comes the opportunity for change or at least a broadening of perspectives.

My additional reflections: Where do we go from here?

Please go forward with kindness and reflect upon the ways that your actions affect others. I once read a blog posting that described emotions that people can feel, but cannot easily articulate. One of the emotions, coined by John Koenig, was ‘sonder’ or “*the realization that each passerby has a life as vivid and complex as your own*” (Koenig, n.d.). Through this realization, we can be humbled by that which we do not know about others as they pass through our lives fleetingly. By experiencing sonder, we can be reminded of our shared common humanity. As humans, we do not exist in isolation from one another but rather in relation to one another. Ignoring our interconnectedness means ignoring our shared humanness. By embracing interdependence and being wakeful to our feelings of ‘sonder’ we are open to engaging and connecting with others, creating communities in which all humans can flourish.

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APPENDICES

APPENDIX A: Interview Guide

I am interested in understanding more about your family leisure experiences in the community and how dignity plays a role in those experiences. What I mean by 'family leisure' is the time that you and your (grand)child, and potentially other family members, spend together in free time or recreational activities outside of your home. These activities can include anything you do as a family: from going to the playground, going swimming, to going to the grocery store, going to a movie theatre, or visiting with friends. There are no right or wrong answers; I am simply interested in your experiences.

1. Tell me about your family's involvement in leisure outside of your home?
    - a. What activities do you do together?
    - b. Where do these activities take place?
    - c. How often do you engage in family leisure?
    - d. What drew you to the particular activities that you've chosen?

2. What sorts of things go into preparing for family leisure out in the community?
    - a. courage/ determination/ self-assurance/ tolerance/ persistence
    - b. What decisions need to be made?
    - c. What goals need to be set?
    - d. How would you say these things contribute to your family's dignity during leisure?
    - e. Can you tell me about how you go about ensuring your child's dignity during family leisure?

3. What sorts of things make you feel comfortable and dignified, during family community leisure? (autonomy, choice, control)
    - a. Has there ever been a time when you felt that your family 'didn't belong' during particular community leisure endeavors?
        - i) What made you feel that way? (humiliation, embarrassment, decrease sense of autonomy or control, foolish, incompetent, vulnerable)

4. What role does the perceptions of others play in your decision to engage in family leisure in the community?
    - a. How would you say the people around you impact your experience?
    - b. How are you and your family treated in the community?
        - i) And how does it make you feel?

5. When engaging in community based family leisure, what do you hope to gain from of the experience?
    - a. What keeps you coming back to certain activities?
    - b. Have there been times when you avoided certain activities?
        - i)What caused you to avoid those activities?

6. What can the community do to support families experiencing autism to feel dignified during family leisure? (community at large, researchers, practitioners)

7. Is there anything you would like to add that I didn't ask you about?

APPENDIX B: Parent Information Letter and Consent Form

PARENT PARTICIPANT INFORMATION LETTER

Study Title:	Dignity in Leisure: The Story of a Family Experiencing Autism
Principle Investigator:	Kassi Boyd, Master's Candidate Pat Austin Adapted Physical Activity Lab Faculty of Physical Education and Recreation, University of Alberta (780) 222-8076, boyd@ualberta.ca
Program Supervisor:	Donna Goodwin, PhD Professor and Associate Dean (Graduate Programs) Faculty of Physical Education and Recreation, University of Alberta 780-492-4397, donna.goodwin@ualberta.ca

Background: We invite you to be part of a research study. Your stories are of great interest as they will help us learn about the impact that dignity may have on family leisure.
We would like to hear your stories if you:

- Have a child, nephew, or grandson that has been diagnosed with autism
- Engage in community-based family leisure

Purpose: The purpose of this study is to learn about how dignity is experienced by a family with a child with autism as they engage in community-based family leisure. The findings will assist enhancing the accessibility of community-based family leisure.

Study Procedures: Should you agree to participate in the study, you will complete the following over a period of 4 months:

- Two one-one-one interviews (approximately 60 minutes each)
- Conversational interviews during/after community-based family leisure
- Participant observations that will be recorded as field notes
- The principle investigator will be accompanying your family twice weekly over 16 weeks to gather information about your experiences of dignity

Each conversation will be audio-recorded. We will type out the tapes. We will return them to you for verification. We will also keep written notes during the interview, and create interview related field notes. Observation notes will be recorded after each family outing that the principle investigator attends. Finally, we will forward a summary of the study findings for your review and input.

Benefit: There is no direct benefit from being in the study. However, by sharing your stories you are helping professionals, practitioners, and researchers. They will better understand how dignity is experienced during family leisure which may contribute to greater leisure accessibility. Our aim is to increase the number of families engaging in community-based family leisure.

Risk: There are no physical risks to being involved in the study. You may become tired due to the length of the talks and the topic. We will direct you to an appropriate community organization or counseling service if you would like to discuss topics raised further. You can refuse to answer any question you are asked.

Confidentiality: We intend to present the research findings at a conference and publish the study in a research journal. We will use direct quotations in the presentations and publications. We will take every step possible to protect your identity and privacy. No names or any other identifiers will appear in public or stored information. Only research team members will have access to the information.

Study data, including personal information will be safely stored (i.e., a locked filing cabinet in a locked office and a password protected computer with non-identifying file names). Five years following the end of the study, the information will be shredded and double deleted from the computer.

Voluntary Participation: Your participation is voluntary. You may refuse to answer any question and ask to have the audio-recorder turned off at any time. Even if you agree to be in the study, you can change your mind.

Freedom to Withdraw: You can withdraw at any time during data collection and up to one week following the completion of active data collection. There will be no penalty of any sort. If you withdraw prior to the one-week time limit, we will destroy all information provided. If you wish to withdraw, contact any member of the research team by telephone, email, or in person.

Additional Contacts: The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615

Sincerely,
Kassi Boyd

Parent Informed Consent Form

Title of Project: Dignity in Leisure: The Story of a Family Experiencing Autism

Principal Investigator: Kassi Boyd, University of Alberta, boyd@ualberta.ca, (780) 222-8076

Program Supervisor: Dr. Donna Goodwin, University of Alberta, (780) 492-4397

To be completed by the research participant:

Do you understand that you have been asked to be in a research study?	Yes	No
Have you read and received a copy of the Information Letter?	Yes	No
Do you understand the benefits and risks involved in taking part in this study?	Yes	No
Have you had an opportunity to ask questions and discuss this study?	Yes	No
Do you understand that you are free to refuse to participate, or to withdraw from the study at any time one week post active data collection, without consequence, and that your information will be withdrawn at your request?	Yes	No
Has the issue of confidentiality been explained to you? Do you understand who will have access to your information?	Yes	No
It is clear to you that your participation in this study will in no way jeopardize the involvement with your employed community aide?	Yes	No
I give permission for my son, as a member of the family, to be involved in the study knowing that he will observed during family leisure outings and may be asked to talk about leisure experiences during those outings and those conversations may be recorded as outlined in the information letter.	Yes	No

Any questions you may have about this study may be directed to Kassi Boyd [boyd@ualberta.ca]

This study was explained to me by: ______________________________

I agree to take part in this study: ______________________ ____________

Signature of Research Participant Date

____

Print Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

______________________________________ ____________

Signature of Investigator or Designee Date

APPENDIX C: Extended Family Information Letter and Consent Form

EXTENDED FAMILY MEMBER PARTICIPANT INFORMATION LETTER

Study Title: Dignity in Leisure: The Story of a Family Experiencing Autism

Principle Investigator: Kassi Boyd, Master's Candidate
Pat Austin Adapted Physical Activity Lab
Faculty of Physical Education and Recreation, University of Alberta
(780) 222-8076, boyd@ualberta.ca

Program Supervisor: Donna Goodwin, PhD
Professor and Associate Dean (Graduate Programs)
Faculty of Physical Education and Recreation, University of Alberta
780-492-4397, donna.goodwin@ualberta.ca

Background: We invite you to be part of a research study. Your stories are of great interest as they will help us learn about the impact that dignity may have on family leisure.
We would like to hear your stories if you:

- Have a child, nephew, or grandson that has been diagnosed with autism
- Engage in community-based family leisure

Purpose: The purpose of this study is to learn about how dignity is experienced by a family with a child with autism as they engage in community-based family leisure. The findings will assist enhancing the accessibility of community-based family leisure.

Study Procedures: Should you agree to participate in the study, you will complete the following over a period of 4 months:

- Two one-one-one interviews (approximately 60 minutes each)
- Conversational interviews during/after community-based family leisure
- Participant observations that will be recorded as field notes
- The principle investigator will be accompanying your family twice weekly over 16 weeks to gather information about your experiences of dignity

Each conversation will be audio-recorded. We will type out the tapes. We will return them to you for verification. We will also keep written notes during the interview, and create interview related field notes. Observation notes will be recorded after each family outing that the principle investigator attends. Finally, we will forward a summary of the study findings for your review and input.

Benefit: There is no direct benefit from being in the study. However, by sharing your stories you are helping professionals, practitioners, and researchers. They will better understand how dignity is experienced during family leisure which may contribute to greater leisure accessibility. Our aim is to increase the number of families engaging in community-based family leisure.

Risk: There are no physical risks to being involved in the study. You may become tired due to the length of the talks and the topic. We will direct you to an appropriate community organization or counseling service if you would like to discuss topics raised further. You can refuse to answer any question you are asked.

Confidentiality: We intend to present the research findings at a conference and publish the study in a research journal. We will use direct quotations in the presentations and publications. We will take every step possible to protect your identity and privacy. No names or any other identifiers will appear in public or stored information. Only research team members will have access to the information.

Study data, including personal information will be safely stored (i.e., a locked filing cabinet in a locked office and a password protected computer with non-identifying file names). Five years following the end of the study, the information will be shredded and double deleted from the computer.

Voluntary Participation: Your participation is voluntary. You may refuse to answer any question and ask to have the audio-recorder turned off at any time. Even if you agree to be in the study, you can change your mind.

Freedom to Withdraw: You can withdraw at any time during data collection and up to one week following the completion of active data collection. There will be no penalty of any sort. If you withdraw prior to the one-week time limit, we will destroy all information provided. If you wish to withdraw, contact any member of the research team by telephone, email, or in person.

Additional Contacts: The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615

Sincerely,
Kassi Boyd

Extended Family Member Informed Consent Form

Title of Project: Dignity in Leisure: The Story of a Family Experiencing Autism

Principal Investigator: Kassi Boyd, University of Alberta, boyd@ualberta.ca, (780) 222-8076

Program Supervisor: Dr. Donna Goodwin, University of Alberta, (780) 492-4397

To be completed by the research participant:

Do you understand that you have been asked to be in a research study?	Yes	No
Have you read and received a copy of the Information Letter?	Yes	No
Do you understand the benefits and risks involved in taking part in this study?	Yes	No
Have you had an opportunity to ask questions and discuss this study?	Yes	No
Do you understand that you are free to refuse to participate, or to withdraw from the study at any time one week post active data collection, without consequence, and that your information will be withdrawn at your request?	Yes	No
Has the issue of confidentiality been explained to you? Do you understand who will have access to your information?	Yes	No
It is clear to you that your participation in this study will in no way jeopardize the involvement with the employed community aide?		

Any questions you may have about this study may be directed to Kassi Boyd [boyd@ualberta.ca]

This study was explained to me by: ______________________________

I agree to take part in this study: ______________________________ ________

Signature of Research Participant Date

____

Print Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

______________________________ ________

Signature of Investigator or Designee Date

APPENDIX D: Participant Demographic Form

Participant Information Form

Dignity in Leisure: The Story of a Family Experiencing Autism

Please take a moment to fill in the participant information form. All information collected will support the research outlined in the information letter and will only be seen by the research team. If you are not comfortable answering any of the questions, leave them blank.

Participant Profile

Name: ____

Relationship to child: ______________________

Phone: _________________________ (home)

_________________________ (mobile) Email: _______________________________

Address: ___________________________

Age: ___________

Grade or Education Level Completed: grade school ☐ high school ☐ post- secondary ☐ other________

Gender: ___________________

Ethnicity: ___________________________

Employed? Full time ☐ Part Time ☐ Retired ☐

Income: 10,000 – 30,000 ☐ 30,000-50,000 ☐ 50,000- 80,000 ☐ 80,000+ ☐

Family leisure interests:

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____

____