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Inclusion, community, and social relationships: A phenomenological study of the experiences of adults with intellectual and developmental disabilities

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Inclusion, Community, and Social Relationships: A Phenomenological Study of the Experiences of Adults with Intellectual and Developmental Disabilities

by

Chloe Wilson

Dissertation

Submitted to the College of Education
Eastern Michigan University
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY
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Concentration in Urban Education

Dissertation Committee:
Valerie Polakow, Ph.D., Co-Chair
Alane Starko, Ph.D., Co-Chair
Derrick Fries, Ph.D.
Sylvia Jones, Ph.D.

January 19, 2017
Ypsilanti, MI
Dedication

This work is dedicated to my family, friends, and community.
Acknowledgments

I would like to thank my family and friends for their support during my doctoral journey. I am also very grateful to the individuals who participated in this study for letting me into their lives and sharing their stories with me. I would also like to say a huge thank you to my wonderful committee members: Dr. Valerie Polakow, Dr. Alane Starko, Dr. Derrick Fries, and Dr. Sylvia Jones. Dr. Polakow, I don’t know how I could have made it this far without you. You have been an amazing chair, advisor, and mentor, and I am so grateful for the opportunity to have studied under you. You are my hero. Dr. Starko, I’m so happy and grateful you are my co-chair, and I really appreciate the kind support, intellectual stimulation, and warm welcome you always offered when I needed to stop by your office to talk. It’s been an honor to learn from you. I also want to thank Dr. Fries for bringing his expertise in disability and policy to this process and helping me to develop my understanding of disability law. You’ve challenged me to be a better scholar and advocate, and I’m grateful. And Dr. Jones, I want to thank you for helping me to stay sensitive to the lives beyond the research, focused on advocacy, and mindful who I am doing this research for. Your kindness and support are deeply appreciated and I miss our talks.
Abstract

Individuals who are ascribed the label of disability must face the stigma and assumptions of inability that it carries, and those with intellectual and developmental disabilities (IDD) are subjected to speculation that calls into question their capacity for reason, reflection, and morality. The purpose of this research was to explore the perspectives and experiences of adults with IDD and their family members. This study primarily focused on the ways in which participants create meaning around community and relationships in addition to examining the factors that inhibit or encourage inclusion and accessibility.

This phenomenological study examined the perspectives of five individuals—three adults with IDD and two of their mothers. Audio-recorded interviews consisted of semi-structured questions that focused on experiences of social relationships, community, and inclusion. Interview guides and visual supports were made available to participants with IDD. Participants shared their stories of the ways in which interpretations of disability have framed their lives and their endeavors to find a place to belong. Thematic analysis identified the key findings that emerged from the narratives. Primary themes that emerged from the parents’ perspectives were (a) shifting expectations, (b) navigating supports and services, and (c) managing vigilance and fear. The primary themes from the narratives of the adults with IDD were (a) social isolation, (b) bullying, (c) opportunity for meaningful choice, and (d) defiance of expectations.

The narratives shared by the participants of this study illuminate our understanding of the ways in which individuals with IDD and their families experience disability, community, and exclusion. Recommendations include U.S. ratification of the United Nations Convention on the Rights of Persons with Disabilities, improved supports and services for adults with IDD with a focus on fostering rights awareness and self-advocacy skills, better coordination and
communication among adult service providers, and improved access to information and resources for the families of adults with IDD. There is a great need for transformative actions and practices that foster inclusive community and create opportunities for challenging the stigma and ignorance around disability while promoting affirmation of the qualities and skills that individuals with disabilities display.
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Chapter 1: Introduction

There are approximately 53 million adults with disabilities living in the United States. An estimated 15 million (10.6%) of these individuals are living with disabilities that impair their cognition—physical, mental, or emotional conditions that result in serious difficulty concentrating, remembering, or making decisions (Courtney-Long et al., 2015; Yang & Tan, 2016b). While the passage of the Americans with Disabilities Act (ADA) of 1990 has made great strides in removing social, economic, and physical barriers for people with disabilities, many challenges remain. This is especially true for individuals with intellectual and developmental disabilities (IDD) who experience large disparities in education, employment, and health outcomes, as well as disproportionate rates of poverty and victimization (Courtney-Long et al., 2015; National Center for Education Statistics, 2016; Office for Victims of Crime, 2016; U.S. Bureau of Labor Statistics, 2016; Yang & Tan, 2016a). While communities have made progress in becoming more accessible, many adults with IDD continue to struggle with social isolation, loneliness, and a lack of choices about how they can engage with their communities (National Council on Disability, 2015; Stancliffe, Lakin, Taub, Chiri, & Byun, 2009).

This study seeks to explore the ways in which adults with IDD and their families experience community, inclusion, and social relationships. This chapter presents a brief overview of the conditions, policies, and challenges that inform the experiences of individuals with IDD and their families, with a focus on interpretations of disability and the ways in which these interpretations influence perceptions of individuals who are ascribed this label. In addition, this chapter also addresses the theoretical frameworks employed in this research, the purpose and justification for the study, and the research questions that guided the study.
Conceptualizing Disability

The evolving, contextually-dependent construct of disability has grown out of a specific historical legacy that deeply informs conventional beliefs and taken-for-granted assumptions about how disability functions within our society. It is important to examine the often-unquestioned expectations we carry about personhood, normalcy, and disability. The concept of *personhood* relates to the inherent value of the individual and is an indicator of one’s status or position within a community (Davis, 1995; Feder-Kittay, 2008). The recognition of an individual’s personhood accords him or her full rights, access, and social membership within a community. Conversely, the denial of personhood classifies an individual as being less than fully human and incapable of exercising full rights of social membership. Personhood relies upon the construct of *normalcy* to distinguish those who merit this status from those who do not.

The social construct of normalcy or sameness defines, confines, and regulates acceptable ways of existing within society (Davis, 1995; Wolbring, 2008). This culturally-referenced concept refers to the capacity or ability to fulfill the narrow cultural expectations for what it means to be fully human. Normalcy is an unstable and context-dependent construct that delineates the limits of society’s tolerance for difference and relies upon the notion of the *Other* to act as its boundary. At its essence, disability is difference as perceived and interpreted by human communities. It is a category or label ascribed to those who cannot or will not conform to dominant notions of what it means to be a whole person (Feder-Kittay, 2008; Wolbring, 2008). All humans have characteristics, abilities, ways of perceiving and interacting with the world that differ from those around them. In a culture that privileges some bodies, abilities, ways of thinking, and ways of perceiving the world over others, deviating from the norm can have a
profound impact on the ways in which one is able to function within society (Davis, 2013; Feder-Kittay, 2008; Wolbring, 2008).

Theoretical Frameworks

The interpretive frameworks used in qualitative research serve to clarify the focus of inquiry while highlighting key premises or assumptions on the part of the researcher regarding the nature of the phenomena being studied (Schram, 2006; Watt, 2007). Examining interpretations of disability, difference, and inclusion, this dissertation focuses on concepts such as the nature of power, privilege, voice, and participation within communities. The theoretical approaches employed for this dissertation research are critical disability theory (CDT) and the human rights framework.

**Critical disability theory.** CDT confronts the nature of disability as a social construct used to deny full participation and citizenship to individuals exhibiting characteristics or needs outside of the boundaries of normalcy (Davis, 1995; Devlin & Pothier, 2006). Attentive to the nature of power and context, CDT is particularly focused on the roles of language, perception, and individual voice in the context of how difference is perceived, interpreted, and valued (Hosking, 2008; Tremain, 2005). The primary objectives of critical disability theory are to identify and challenge barriers to full inclusion for all community members and to foster practices and supports that allow individuals with disabilities to participate and engage with their communities (Devlin & Pothier, 2006). CDT helps inform an understanding of the nature of the divide between individuals with disabilities and their communities as grounded in the denial of voice, value, and personhood. When perceived as *Other*, one’s personhood—or self—remains shrouded.
The concept of CDT grew out of critical theory and its focus on confronting the ways in which social, political, and ideological structures serve to frame and construct meanings that privilege some over others. Critical theory was a term coined by sociologist and cofounder of the Frankfurt school Max Horkheimer (1937/1975) in his essay “Traditional and Critical Theory.” Disability scholar Marion Scott-Hill (née Corker) is considered to be one of the first to put forward the primary ideas that would develop into CDT (Vehmas & Watson, 2014). In what she referred to as a social theory of disability, Scott-Hill focused on the multidimensional and multifunctional role of language and discourse to challenge and highlight inequity and foster more inclusive communities (Corker, 1999; Corker & French, 1999). She also argued against the false dichotomy of able/disabled and its role in constricting the development of identity within normative boundaries (Corker, 1999). Scholar of queer and crip (an area of disability scholarship that arose as a subversive reclamation of cripple) cultural studies Robert McRuer (2006) and disability scholar Dan Goodley (2010) further developed these ideas to confront the nature of normalcy as a restrictive construct and explored the ways in which disability is framed by cultural knowledge, values, and power.

Legal and disability scholar David Hosking (2008) identified seven elements of CDT: models of disability, multidimensionality, valuing diversity, rights, voices of disability, language, and transformative politics. Hosking described CDT as sharing the social model of disability’s emphasis on disability as a social construct and the ways within which it is interpreted, but he highlighted CDT’s focus on the role of normativity and understanding both disabled and able as constructs as well as CDT’s attention to rights, dignity, and the value of diversity (the social model of disability is explained in greater detail in Chapter 2). He noted that the multidimensional nature of CDT allows for an understanding of diversity and disability that is
inclusive of all differences and acknowledged the layered nature of intersectionality. Hosking also highlighted CDT’s commitment to the value of diversity in the way in which it recognizes and welcomes what he referred to as “the inevitability of difference” (p. 11). He continued, “Any systematic response to disability which purports to make disability invisible is inherently incapable of effectively protecting the rights of disabled people to be full participants in their communities” (p. 11). Hosking described the ways in which CDT focuses on the tensions that exist between individual and social rights, bringing the often silenced voices of individuals with disabilities forward to speak for themselves—as opposed to being spoken for—and analyzing the ways in which our language frames meaning and assigns value. Hosking concluded with transformative politics as the seventh element of CDT and the ways in which it links theory and practice to confront social and political structures that maintain inequity.

Conceptions of CDT have not been without criticism. Vehmas and Watson (2014) noted that while CDT provides a tool for identifying and confronting the exclusion and silencing of individuals with disabilities, it does not address the ethical tension that can exist between striving to become inclusive of all difference and the elimination or prevention of conditions considered harmful. For example, how can we reconcile valuing and accepting all individuals with blindness or Down syndrome with the ongoing efforts to identify a way to prevent or eliminate these conditions? At what point is a condition considered detrimental enough to warrant the elimination of difference, and who should decide? The authors also raised issue with the focus of CDT on identifying and confronting the economic basis for disability without providing alternatives to replace unjust policies and practices. While these are all valid criticisms, CDT excels as a tool for analyzing the personal experience of disability and the ways in which disability is enacted and understood within the individual and social context. For the purpose of
this research, CDT is used in conjunction with the human rights framework to extend and complement its analysis of the disability experience.

**The human rights framework.** Conceptualized as a set of equal, inalienable, and universal entitlements, the human rights framework provides a standard of well-being grounded in the inherent dignity of all people (Degener, 1995; Donnelly, 2013; Shakespeare, 2014). This framework establishes both the protections toward exercising one’s human rights, as well as the pursuit of rights-based demands for change when they are violated or denied. Donnelly (2013) described two components that make up human rights:

Human rights are a) the minimum set of goods, services, opportunities, and protections that are widely recognized today as essential prerequisites for a life of dignity, and b) a particular set of practices to realize those goods, services, opportunities, and protections. (p. 17)

The human rights framework encompasses both negative rights and positive rights. Negative right pertain to actions or events that are prohibited and are often conceived as *freedom from* an aspect of society—examples could be protecting an individual from employment discrimination, freedom from violence or abuse, or freedom from exploitation. Positive rights refer to an individual’s *right to* an aspect of society—for example, an individual may have the right to freely express their views, a right to participate in and engage with one’s community, or a right to choose where one lives (Donnelly, 2013; Shakespeare, 2014).

The human rights framework was developed through and influenced by a series of established principles and declarations by the League of Nations, the International Labor Organization, and the United Nations (Donnelly, 2013). Donnelly (2013) asserted that while many individual nations had established legal and civil rights for citizens, it was not until the
United Nations Declaration of Human Rights adopted in 1948 and the binding covenants that followed—the International Covenant on Economic, Social and Cultural Rights (ICESCR), and the International Covenant on Civil and Political Rights (ICCPR) in 1966—that the notion of universal human rights entered international discourse. These three documents have been referred to the International Bill of Human Rights and establish protections such as freedom from slavery, arbitrary arrest or detention, and debtor’s prison. They also establish entitlements such as a right to life, legal protections, humane treatment, education, and self-determination. There are now a number of United Nations human rights treaties that target populations considered vulnerable to human rights violations, such as the Convention on the Rights of the Child (CRC), the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), International Convention on the Elimination of All Forms of Racial Discrimination (ICEAFRD), and Convention on the Rights of Persons with Disabilities (CRPD). It is important to note that while these treaties act as binding standards for rights, they rely on the commitment of each ratifying country to implement and enforce these provisions enshrined with the international treaties (Newman, 1995; Shakespeare, 2014). The United States has signed—but not yet ratified—all conventions except the ICCPR and ICEAFRD which were ratified in 1992 and 1994 respectively.

Human rights are grounded in human needs (Donnelly, 2013). A useful tool in identifying and characterizing these needs is the capabilities approach. The capabilities approach is derived from the work of economist Amartya Sen (1999) and philosopher Martha Nussbaum (2006, 2010, 2011). This approach emphasizes opportunity for choice and participation while upholding freedom and human dignity as protected human rights. Focused on the unique capacity of each individual, this approach begins with the question “What are people actually
able to do and to be?” (Nussbaum, 2011, p. x). Identifying functionings (all potential actions and conditions that can occur in a life, such as breathing, eating, or being healthy) and capabilities (what people are actually able to do and be given the circumstances of their lives), this approach highlights the importance of policy guided by ethical and contextual considerations regarding the human rights of all citizens. Nussbaum (2006) listed 10 core capabilities that should be valued by democracies: life; bodily health; bodily integrity; sense, imagination, and thought; emotions; practical reason; affiliation; interaction with other species; play; and control over one’s environment (both political and material). The capabilities approach maintains that everyone is or should be able to participate and engage these capabilities and that the degree to which they are able to do so is embedded in socio-political conditions that foster or truncate capabilities. The capabilities approach attends to the complexity of the individual and his or her context while remaining flexible and grounded in the inherent value and dignity of every individual life.

While the human rights framework provides a powerful tool for establishing a standard of universal rights for all people, it is based on ideals and relies upon a commitment by nations to uphold and enforce these ideals (Shakespeare, 2014). It also requires the recognition of personhood, inherent dignity, and value of all individuals and the dedication to the universal protection of rights for everyone. There are challenges associated with the implementation of these protections, such as the political and social hurdles that can arise in the unique cultural context of a given nation; however, the human rights framework is a means to an end, not an end on its own (Shakespeare, 2011, 2014). It contributes to a process of identifying systemic inequity and confronts social, economic, gender, ethnic and disability barriers by setting a bar for universal rights and offering standards towards which nations can strive.
**Critical disability theory and the human rights framework.** The CDT and the human rights framework provide a complementary approach to examining the experience of disability due to their shared focus on rights, inherent value, and dignity. While CDT emphasizes the identification and confrontation of systemic injustice, the human rights framework provides an approach to demanding and enacting rights-based change.

**Problem Statement**

Those who are ascribed the label of disability face the stigma and assumptions of inability that it carries. Individuals with IDD in particular are subjected to speculations that call into question their capacity for reason, reflection, and morality. The experience of disability is deeply informed by the construct of personhood. Similar in some ways to the notion of self-determination, personhood also entails the conferral of status denoting full rights of citizenship and the recognition of one’s inherent value (Feder-Kittay, 2008). While self-determination is grounded within the individual and experienced in the social world, personhood is both an internal experience as well as a sociopolitical designation that relies upon external recognition to be enacted within the social context. The nature of personhood as an assigned status has profound implications for the ways in which IDD are interpreted and experienced. The denial of personhood has historically been used to justify the denial of rights, freedom, and life. Conversely, the recognition of one’s personhood confers the status of a natural bearer of human rights—signifying a right to being valued and to having one’s voice heard. It is important to note that the denial of personhood does not necessarily entail a loss of agency. Rather its denial can spur individuals to fight against imposed interpretations of ability on a broader political scale and work to foster personal relationships within inclusive communities that recognize the personhood of all members.
The notion of moral personhood developed in response to ongoing philosophical debates about the value of human life and the ways in which significant IDD$s$ conflict with dominant expectations of the typical human experience (Carlson & Feder-Kittay, 2010). Rising out of the debates over Baby Doe laws, the investigation of moral personhood explored how cultures conceived the threshold of humanity (Carlson, 2010). As one’s cognitive capacities diminish, at what point does one cease to be a functioning human? As a social construct, personhood is deeply informed by one’s beliefs and values around what it means to be a person—and is therefore deeply dependent upon cultural context. This has led to a great deal of contention over the definition of moral personhood, but it can be generally understood as the conferral of a full moral status on humans that signifies that an individual is deserving of life and rights (Feder-Kittay, 2008; Ralston & Ho, 2007). Conceptions of moral personhood are typically dependent upon one’s capacity for rational thought. This conception carries particularly important implications for individuals with IDD who are often perceived as being incapable of, or having a greatly diminished capacity for, reflection and reason (Carlson, 2010).

Personhood and disability are social constructions based upon human interpretations of difference. The devaluation and marginalization of those who are labeled with IDD are socialized responses and interpretations of ability that are influenced by an extremely complex set of cultural meanings and associations that shape perceptions of what it means to fully comply with dominant interpretations of existence as a normal human (Wolbring, 2008). Wolbring (2008) maintained that standards for normalcy correspond with an emphasized homogenization of human experience in this culture that deprives communities of unique expressions of diversity. Disability scholars Ingstad and Whyte (1995, 2007) focused their research on the shifting interpretations of disability within specific cultures. They noted that the challenge of
understanding personhood in relation to disability “lies in understanding the way particular characteristics, be they impairments or gifts, inhibit or facilitate individual achievements and relational integration in a given cultural world” (Ingstad & Whyte, 1995, p. 11). These culturally and context-specific factors frame the ways in which meaning is created and interpreted around personhood and ability.

**Disability and intelligence.** Individuals with disabilities—especially IDD—may experience social marginalization and exclusion due to the perception that they lack sufficient reason and therefore moral personhood (Feder-Kittay, 2008). The construct of rationality has become analogous to intelligence and powerfully mediates perceptions of personhood (Plumwood, 2002). While its meaning has shifted over time and varies by culture, definitions of intelligence are responsive to prevailing social ideals and behavioral expectations (Kaufman, 2013; Trent, 1994). The concept of intelligence acts as a descriptor for actions and interactions, evaluating the effectiveness, consideration, and adaptive capacity of the individual. IDD is conceived in similar terms—though framed by a deficit paradigm—as the individual’s failure to display these qualities in conformity with prevailing cultural standards and norms (Ingstad & Reynolds-Whyte, 1995). When used as a justification to afford some individuals the rights of voice and dignity, while denying these same rights to others, these constructs become tools for the conferral or denial of personhood (Feder-Kittay, 2008).

An alternative interpretation of intelligence utilized in this research draws from the works of Kaufman (2013), Sternberg (2014), and Immordino-Yang and Damasio (2007). Scott Kaufman’s emphasis on the interactive and intentional nature of intelligence recognized the complexity and interdependence of engagement and ability as they inform lifelong development. Asserting the need to recognize the great variety in abilities and paths for successfully pursuing
personal goals, Kaufman’s work reflected the influence of his mentor Robert Sternberg. Sternberg’s (2014) theory of successful intelligence is attuned to the individual and the contextual characteristics that frame purposeful and goal-oriented learning. He grounded his conception of intelligence in the adaptive capacity of the individual to shape or be shaped by his or her context while drawing conclusions from these interactions to create meaning that informs perception and behavior. Strengthening the linkages between intelligence, emotion, and behavior, Mary Helen Immordino-Yang and Antonio Damasio (2007) emphasized the vital role of emotion in connecting rational and analytical thought to prosocial behaviors. Intelligence in isolation is meaningless. It is through interaction that meaning is created and reflects the intelligence that informs it.

In developing a definition of intelligence that strives to be inclusive of individuals with varying abilities and capacities, there must be a recognition of the heterogeneous nature of humans. Just as biodiversity is a necessary quality for the health and resilience of ecosystems, so too is human diversity necessary for stable and resilient communities. While there has always been a measure of discomfort with difference and a human propensity for Us/Them categorizations, these boundaries are socially constructed and mediated by prevailing notions of normalcy (Davis, 1995; Turnbull, 2013). Difference becomes disability when it crosses this threshold.

Disability activist Jonathan Mooney (2007) provided a sharp critique of normalcy and emphasized the individual gifts diverse learners bring to their learning relationships. In his analysis of the nature of normalcy and traditional interpretations of intelligence as mechanisms for policing acceptable behaviors and ways of being, Mooney offered an alternative conception of intelligence that is committed to the notion of diversity as a source of strength and
perspective. He asserted that inclusive definitions of intelligence require an emphasis on the unique potential of the learner as developing in interaction within a stable environment and an educator who is able to honor the voice, perceptions, and abilities of the learner. Within this conceptualization, intelligence is a variable and context-specific quality that may require a suitable format, environment, and community to reveal itself.

**Purpose of the Study**

The purpose of this research is to explore the perspectives of adults with IDD and their family members. While much of the previous research in this area has focused on the ways in which perceptions and experiences of disability interact with identity and the social experience, this study primarily focuses on the ways in which participants create meaning around community and relationships in addition to examining the factors that can inhibit or encourage inclusion and accessibility. Given the inductive and generative nature of qualitative research, this study was guided by and grounded in the perspectives and interpretations of participants (Seidman, 2006).

This research study is grounded in a commitment to rights and justice and envisions that individuals with IDD are deserving of voice and participation within their communities. It sought to understand the conditions and accommodations that may provide voice, inclusion, and social connection to those with disabilities and their families. In examining the role of power and voice, the value of diverse perspectives and experiences, and the rights of individuals with IDD, this research aimed to foreground the narratives of participants while situating their stories within the broader theoretical and political context of disability, inclusion, and community in the United States.
Justification and Significance

Within the United States, the passage of the ADA (1990) took place 26 years ago. The ADA has resulted in great gains in terms of fostering accessible community spaces and mandating appropriate support services. However, the years following the implementation of the ADA have demonstrated the faltering support for equity. Individuals with disabilities are disproportionately poor and under-employed. A report released by the United States Senate Committee of Health, Education, Labor, and Pensions (2014) found that nearly a third of individuals with disabilities live in poverty and only 30% of the working-age population were employed. Drawing from data from the American Community Survey (ACS), Yang and Tan (2016a) estimated that 2.8 million (34.4%) Americans with cognitive disabilities between the ages of 21 and 64 lived below the federal poverty line in 2014. This is more than twice the official poverty rate of 13.5% for the United States (Proctor, Semega, & Kollar, 2016).

The unfortunate reality is that individuals with disabilities in the United States continue to face widespread social and economic barriers. Persistent difficulties remain regarding accessible public transportation and community spaces (Golden, Chia, Ellis, & Thatcher, 2014). There are continuing problems regarding the lack of accessible housing. There are very few accessible single-family rental units as they are not required to include accessible features and only 1% of all rental units in the United States meet the standards for Universal Design (Joint Center for Housing Studies of Harvard University, 2015). Additionally, the increasing cost of housing places independent living within the community even further out of reach for many individuals with disabilities. In a joint report by the Technical Assistance Collaborative and the Consortium for Citizens with Disabilities that examined the housing crisis for individuals with disabilities, the authors stated:
The national average rent for a modest one-bedroom rental unit was $780, equal to 104% of the national average monthly income of a one-person SSI [Supplemental Security Income] household. This finding confirms that, in 2014, it was virtually impossible for a single adult receiving SSI to obtain decent and safe housing in the community without some type of rental assistance. (Cooper, Knott, Schaak, Sloane, & Zovistoski, 2015, p. 11)

While the decision in *Olmstead v. L.C.* (1999) secured the right of individuals with disabilities to live within their communities, the inadequate development of community-based supports and services (including supportive housing) has left many individuals with disabilities isolated and marginalized. Unaffordable and inaccessible rental housing, in addition to difficulties in obtaining affordable attendant care and reliable transportation, have coincided with an increase in the number of non-elderly individuals with disabilities living in nursing homes (Cooper et al., 2015).

In addition to the social isolation caused by structural factors, individuals with disabilities face much higher rates of discrimination, victimization, incarceration, and exploitation than their typical peers (Carey, 2009; Erevelles & Minear, 2010; Office for Victims of Crime, 2016). In the United States, individuals with disabilities are more than twice as likely to be victims of violent crime than those without disabilities, and people with IDD are nearly twice as likely to be victimized than any other disability group (Harrell, 2015; Office for Victims of Crime, 2016). This is a population that faces many challenges and barriers to participation in equitable and inclusive communities. Often marginalized and isolated, their voices are rarely heard, and even when physically present in the community, they remain excluded. Individuals with disabilities have reported feeling invisible or being spoken to as though they were children (J. Burke, 2005;
Felt & Walker, 2000; Rubin, 2005; Ward & Shoultz, 2000). This is especially true for individuals with IDD. Many individuals with IDD only have access to social relationships with family members, professionals who are paid to spend time with them, and other individuals with disabilities (Levinson, 2005; Pelka, 2012). The assumption that these individuals are incapable of thought or undeserving of voice is unjust, marginalizing, and deprives communities of diverse perspectives.

The significance of this research lies in its focus on the unique perspectives of participants and their families. The findings from this research are grounded in their personal truths and experiences and contribute to the sparse existing literature that foregrounds the perspectives and experiences of individuals with IDD. These findings are in many ways exemplaric of the broader disability community—or as Geertz (1973) argued, “Small facts speak to large issues” (p. 23). By exploring these lives in the microcosm, it is anticipated that their perspectives will enhance our understanding of the ways in which social values, beliefs, and policies frame the experience of disability and the nature of community.

**Research Questions**

1. How do participants with IDD perceive their lived worlds and their communities?
2. In what ways has disability shaped the lives and relationships of participants? How do they perceive their social connections?
3. How do family members perceive disability in relation to inclusive or accessible community?
4. How does the lived experience of disability interact with the policies that frame it?
Organization of the Dissertation

This chapter has provided an overview of IDD and the challenging circumstances faced by the individuals ascribed this label. Chapter 2 presents a literature review of research relevant to IDD as well as the constellation of issues that inform the way it is experienced and interpreted. The methodology of the dissertation research is addressed in Chapter 3. Chapters 4, 5, and 6 present the case studies of the dissertation participants. Chapter 7 offers an analysis of major themes emerging from the narratives and their significance in terms of broader educational and policy issues impacting individuals with IDD and their families. Chapter 8 concludes the study with a brief discussion of recommendations and future areas of research.
Chapter 2: Literature Review

This chapter provides a review of prominent literature and research informing the dissertation study. These areas of research include conceptions of disability and the policies, theories, and contexts that frame it as well as an examination of disability and human rights in the international context. The role of stigma in interpretations and experiences of disability is examined and the chapter concludes with an analysis of the complex interaction between disability and voice. By examining these diverse perspectives and approaches to understanding disability and difference, one is able to gain a broader perspective of the ways in which disability is framed and enacted within its cultural context.

Disability is an unstable construct informed by one’s sociopolitical, cultural, and historical context. Interpretations of disability have evolved over time in response to changing social perceptions and shifting legal conceptions. Intellectual and developmental disability (IDD) has historically been linked to dependency, helplessness, and deviancy within the United States (Nielsen, 2012; Trent, 1994). However, a dramatic reconceptualization of disability began to take place in the mid-20th century that shifted perceptions of disability away from inherent deficits or deviancy and drew attention to disability as a stigmatized difference enacted within exclusionary or inaccessible social and relational spaces (Carey, 2009; Shapiro, 1994; Zames-Fleischer & Zames, 2011). This shift was reflected in changing policies that focused on disability framed within a rights model, rather than the previously dominant welfare model (Heyer, 2015; Shakespeare, 2014).

Models of Disability

Dominant perceptions of disability have shifted over time, but all have a powerful influence over the ways in which disability is interpreted and enacted within its cultural context.
Speaking to cultural values and the shifting expectations of normalcy informed by them, models of disability highlight the nature of disability as an ascribed or adopted status. The examination of models of disability provides a deeper understanding of the contextual nature of disability as well as an illustration of the ways associations or assumptions embedded within these models shape perceptions of disability. The primary models of disability examined here are the moral/religious model, the medical/welfare model, the social model, and the human rights model.

**The moral/religious model.** A dominant perspective with deep historical roots, the moral/religious model situates disability as a justified consequence of sinful or deviant behavior (Ingstad & Reynolds-Whyte, 1995; Trent, 1994). This perspective interprets disability as a punishment that brings shame to an individual or family that has failed to conform to social or religious expectations. A contemporary example of a situation informed by this model could be the assumption that a mother had failed to maintain a healthy lifestyle during pregnancy after her child was born with a disability. Fundamentalists may argue that this was God’s punishment. Often aligned with the medical model of disability, the moral/religious model continues to inform interpretations and experiences of disability around the world (Ingstad & Reynolds-Whyte, 1995; Snyder & Mitchell, 2006).

**The medical/welfare model.** Dominant for much of our nation’s history, the medical/welfare model interprets disability as an internal or inherent deficit and focuses on individual cures, treatments, or therapies to address these deficits. This perspective situates individuals with disabilities as passive patients or victims in need of care due to the ways in which their bodies, minds, or genomes fail to operate in expected ways (Snyder & Mitchell, 2006). This conceptualization of disability is predominantly referred to as the medical model, while it is called the welfare model when specifically applied to policy (Heyer, 2015). While all
people require care at some stage of their lives, the medical/welfare model of disability is criticized for failing to address the ways in which culture and context inform the experience of disability (Barnes, 2012). For example, under the medical/welfare model the best course of action in addressing the needs of a student with attention deficit hyperactivity disorder (ADHD) would be to provide him or her with medication to improve attention and impulse control within the classroom, rather than modifying the delivery of instruction or altering the classroom environment to accommodate the needs of the learner.

**The social model.** A result of the conceptual shift of disability in the mid-20th century and developed in response to the medical model disability, the social model of disability focuses on societal organization and the ways in which factors in the environment inhibit or promote accessibility (Barnes, 2012). This model differentiates the individual physical, neurological, or emotional experience of impairment from the social experience of disability. Within the social model, disability is interpreted as a consequence of environmental barriers that privilege some abilities, behaviors, and ways of interacting with the world over others (Scotch, 2009). An example could be addressing the inaccessible nature of a building to a wheelchair user due to a lack of ramps or elevators, rather than focusing on curing the individual of his or her impaired mobility. The social model has been criticized for creating a false dichotomy of impairment and disability, as one’s individual experience is interpreted through language and assigned meaning grounded in culture and is therefore never entirely free from social influence (Barnes, 2012). Further Shakespeare (2014) cautioned that the social model of welfare’s narrow focus on social interpretations of disability risks erasing the diversity of individuals with disabilities and the unique needs their conditions present. He also noted that if disability is considered solely a result of social arrangements, then efforts to prevent, treat, or eliminate disabilities would stand in
opposition to ideals of inclusion—which could be detrimental to the well-being and circumstances of individuals with disabilities who depend upon them. Despite these criticisms, the social model and its emphasis on socially-constructed barriers has helped to inform disability policy and continues to offer a powerful tool in examining the ways in which attitudinal, institutional, and environmental factors mediate the experience of disability in society (Scotch, 2009).

**The human rights model.** The human rights model of disability frames inclusion and access as fundamental human rights. This model grew out of the Universal Declaration of Human Rights of 1948 and interprets disability as a manifestation of human diversity (Donnelly, 2013; Quinn et al., 2002). Individuals with disabilities are considered to be a minority group deserving of rights and protections within this model. As stated by Quinn and Degener (2002),

The human rights model focuses on the inherent dignity of the human being and subsequently, but only if necessary, on the person’s medical characteristics. It places the individual centerstage in all decisions affecting him/her and, most importantly, locates the main “problem” outside the person and in society. (p. 14)

Recognizing the impact of socially constructed barriers to inclusion highlighted by the social model, the human rights model focuses on opportunity, agency, and empowerment while upholding the doctrine of differentiation to support participation (Donnelly, 2013; Quinn et al., 2002). These rights are protected by laws and policies as part of a focus on the role of social and legal institutions as catalysts for change. The human rights model has a strong focus on the participation of individuals with disabilities in the development and implementation of disability policies and practices through consultation and collaboration with organizations of self-advocates (Quinn et al., 2002). Perhaps the most important document addressing disability
through the human rights model is the United Nations Convention of the Rights of Persons with Disabilities (CRPD; United Nations, 2006). This international treaty provides a comprehensive framework establishing specific protections for the human rights of people with disabilities.

**A Brief History of Disability Policy in the United States**

This section examines the changing construct of disability as it has evolved from the 1960s to the present while highlighting the ways in which this concept has informed and been informed by disability policy, case law, and disability rights activism. Disability policy is shaped by social factors such as campaigns by disability advocates and allies, economic conditions, and dominant perceptions regarding the natural rights of the typical citizen (Shakespeare, 2014).

Historically, individuals with IDD were perceived as inherently incapable of exercising the rights and responsibilities of citizenship (Carey, 2009; Power, Lord, & DeFranco, 2013). The examination of disability law from the 1960s to the present offers insight into how and why interpretations of IDD and personhood have changed over time.

Disability policy experienced a radical shift in the 1960s as issues of civil rights and discriminatory treatment entered discourses around disability and citizenship. The efforts of powerful parent groups and disability allies to lobby for supports and services of individuals with disabilities within their communities while protesting inhumane treatment within the institutions helped to implement dramatic policy reforms. However, these changes in policy often collided with the prevailing social stigma of disability and state-level attempts to deny individuals with disabilities access to the community. While great strides have been made in securing civil rights and protections against discrimination for individuals with disabilities, many challenges remain. The following is a brief examination of prominent legislation and case law that has shaped the ways in which IDD has come to be interpreted in disability policy.
1960s: The struggle for supports and services. In the United States in the 1960s, individuals with IDD were primarily perceived as defective and helpless and were often confined to institutions where they were afforded few rights and protections (Trent, 1994). Disability legislation was dominated by the welfare model (Heyer, 2015). During this period, individuals with disabilities were primarily considered defective patients in need of care. The social stigma of IDD weighed heavily on individuals and their families. Many parents were urged by medical professionals to send children with IDD to live in institutions that often provided them with little more than food, clothing, and substandard medical care (Carey, 2009; Trent, 1994). Further, this demand for custodial care in institutions far outweighed the capacity. Out of the estimated 400,000 individuals with IDD who were considered in need of constant care and incapable of work, approximately half resided within institutions (President’s Panel on Mental Retardation, 1962). As parents’ groups (such as the National Association of Parents and Friends of Mentally Retarded Children—now known as the Arc) grew in membership and lobbying power, much of the legislation pertaining to disability during this period addressed the need for care and support of individuals with disabilities and their families (Schalock & Wehmeyer, 2013).

In October of 1961 President Kennedy appointed 27 experts to a panel to examine and address the needs of individuals with intellectual disabilities and their families. The President’s Panel on Mental Retardation published the results of their research in a report titled A Proposed Program for National Action to Combat Mental Retardation (1962). Firmly embedded within the medical model of disability as deficit, the report emphasized the prevention and elimination of intellectual disability. Addressing the cost of care and support for individuals with intellectual disabilities, the report stated, “The Nation is denied several billion dollars of economic output because of the under-achievement, under-production and/or the complete incapability of the
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mentally retarded” (p. 2). The authors also described the personal experience of families of individuals with intellectual disabilities: “The untold human anguish and loss of happiness and well being which results from mental retardation blights the families in the United States” (p. 2). However, the report also provided an unprecedented and comprehensive assessment of the need for improved clinical care and social services, education and vocational rehabilitation, and residential care. Perhaps most surprising was the report’s admonition of the treatment of intellectual disability under the law while affirming the citizenship of individuals with intellectual disability. The authors acknowledged the heterogeneous nature of intellectual disability and were critical of ways in which an individual was framed within the absolutes of competent or incompetent under the law.

In 1963 President Kennedy signed into law the Maternal and Child Health and Mental Retardation Planning Amendment to the Social Security Act (1963). This primarily focused on the prevention of intellectual disability though maternal and child healthcare and provided funding for state programming to implement some of the President’s Panel on Mental Retardation’s proposals regarding community support and care. It was the first major law to address the needs of individuals with intellectual disabilities. Days later the Mental Retardation and Community Mental Health Centers Construction Act (1963) was signed into law. This law provided funding for research facilities and institutions addressing the prevention, care, and treatment of intellectual disability. It also established University Affiliated Facilities (UAFs) to supervise and implement an increase in trained professionals to work with individuals with intellectual disabilities. Marking the first major initiative to establish comprehensive community mental health centers throughout the country, the Mental Retardation and Community Mental Health Centers Construction Act established the basis for community-based care. The law was
amended with the passage of the Developmental Disabilities Services and Facilities Construction Amendments (1970) to situate intellectual disability within the category of developmental disability while expanding the services to include those with epilepsy, cerebral palsy, dyslexia, and autism spectrum disorder.

**1970s: Deinstitutionalization and the limits of acceptance.** The implementation of disability laws strengthened efforts to improve access to supports and services for individuals with disabilities living within the community. During this same period, several court rulings had a profound impact on the state of custodial institutions. The decision in *Wyatt v. Stickney* (1974) by Federal Judge Frank Johnson resulted in a ruling that institutionalization without treatment or education was unconstitutional. When the parents of Willowbrook inmates protested abusive treatment and neglectful conditions in *New York ARC v. Rockefeller* (1973), the judge disagreed with the legal precedent established in *Wyatt v. Stickney* (1974) and ruled that inmates of institutions were not entitled to rehabilitation and should be afforded the same rights as prison inmates. Despite this defeat, conditions at Willowbrook actually improved as prison inmates were still considered entitled to protection from harm and neglect as well as living standards such as adequate heat, basic medical care, and access to the outdoors (Carey, 2009). Given the terrible conditions at Willowbrook—and a televised series exposing these conditions to the public—this ruling successfully forced administrators to improve living conditions and hire additional support staff (Carey, 2009).

Conditions within institutions were again challenged in *Halderman v. Pennhurst* (1974). The case was brought on behalf of the residents of the Pennhurst State School and Hospital and exposed the horrific and overcrowded conditions they endured. Due to understaffing, residents were subjected to physical restraints and tied to beds and chairs, some for weeks at a time.
Chemical restraints were also utilized in the form of tranquilizers. A seclusion room was used to detain residents as punishment where they were sometimes kept for days. The physical conditions within Pennhurst were dangerously unhygienic and outbreaks of disease and parasites common. Further, illness and injury would often go untreated. Residents were also subjected to violence and sexual abuse from staff and other residents (Halderman v. Pennhurst, 1974). During this case, Congress passed the Developmental Disabled Assistance and Bill of Rights Act of 1975 (DD Act), which upheld the rights of individuals with developmental disabilities to receive individualized treatment within the least restrictive environment. The judge in *Halderman v. Pennhurst* (1974) ruled that confinement within the institution was unconstitutional when similar services were available within the community. This ruling effectively closed the institution by ordering the release of all residents and set a precedent for deinstitutionalization while establishing a right to community services for people with developmental disabilities (Carey, 2009).

The passage of the Rehabilitation Act (1973) also had powerful implications for the civil rights of individuals with disabilities. Section 504 of the Rehabilitation Act prohibits discrimination of individuals with disabilities by agencies and organizations receiving federal funding. Disability advocates and allies quickly recognized the importance of this legal precedent as a tool for mandating accessibility (Pelka, 2012; Shapiro, 1994; Zames-Fleischer & Zames, 2011). However, the potential of section 504 of the Rehabilitation Act was uncertain as the Department of Housing, Education, and Welfare (HEW) stalled in approving the regulations required to enforce it. Frustrated by the delayed regulations for the implementation of section 504 as well as the Education for Handicapped Children Act (EHCA; 1975), disability activists responded with organized protests and sit-ins across the nation—the longest of which was the
occupation of HEW offices which lasted for 25 days (Shapiro, 1994). Regulations for the Rehabilitation Act were finally signed in 1977.

Legal challenges to the exclusion of individuals with disabilities were also being made within the education system. The rulings in Mills v. Board of Education (1972) and Pennsylvania Association for Retarded Children v. Commonwealth of Pennsylvania (1972) struck down laws permitting the exclusion of children with disabilities from public schools while prioritizing inclusion and the right to due process by parents. The passage of the Education for Handicapped Children Act (1975)—now referred to as the Individuals with Disabilities Education Act (IDEA; 2004)—mandated that public schools provide a free and appropriate public education (FAPE) to all children with disabilities in the least restrictive environment (LRE) and committed funding to provide educational supports and accommodations to special education students. The implementation of the EHCA was not without conflict, and its mandates often went unenforced (Nielsen, 2012). The legal system became the primary arena for enforcing state compliance with the law. Mississippi fought the implementation of the EHCA for four years. During this period the class action lawsuit Mattie T. v. Johnston (1976) was brought on behalf of all students with disabilities within the state. The ruling for the plaintiff in 1979 resulted in a consent decree that forced the state to provide educational access to students with disabilities (Zames-Fleischer & Zames, 2011).

The 1970s produced great gains in providing accessibility to community spaces for individuals with disabilities as disability activists and allies worked to protest discriminatory treatment and unequal access to public services such as transportation and education. Unfortunately, the social stigma of disability continued to hinder attempts to develop inclusive communities. In 1979 the Center on Human Policy at Syracuse University published a
declaration titled *The Community Imperative* in part as a response to the *Wyatt v. Stickney* (1974) ruling (Schalock & Wehmeyer, 2013). Focused on establishing the right to live in one’s community, *The Community Imperative* emphasized that “all people have fundamental moral and constitutional rights” (p. 2). Outlining a series of assertions in the domains of human rights, educational programing, and human services, the declaration went on to state, “All people, as human beings, are inherently valuable. All people can grow and develop. All people are entitled to conditions which foster their development. Such conditions are optimally provided in community settings” (p. 2).

**1980s: Cross-categorical collaboration and disability rights.** While the closure of institutions gave rise to early efforts for normalization policy established by Swedish law, the stigma against IDD continued to frame the interpretation of beliefs ascribed to people carrying this label. The release of residents from the institutions into communities was controversial, and there were efforts to ban group homes for individuals with IDD through zoning laws. In 1985, the Supreme Court ruled in the *City of Cleburne v. Cleburne Living Center* (1985) that these zoning law were unconstitutional as they only applied to group homes whose residents had IDD. As more individuals with disabilities grew up in their homes and within their communities, there were concerted efforts to gain access to spaces and positions that remained closed to individuals with disabilities. Pioneering self-advocates who had managed to develop the skills and support systems needed to live independently within their communities following release from institutions shared their knowledge within the burgeoning disability community. Gaining the

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1 In the 1960s Sweden became the first nation to pass a series of groundbreaking measures in accordance with the principles of normalization establishing that all individuals with intellectual disabilities had the same rights and privileges as typical citizens as well as the right to accommodations and the supports required to employ them. This concept was brought to the U.S. by Swedish disability scholar Bengt Nirje and adopted by disability rights activists (Shapiro, 1994).
right to access institutions of higher education, inaccessible civic buildings, and inaccessible transportation systems became the focus of the increasingly organized disability rights activists (Pelka, 2012; Zames-Fleischer & Zames, 2011).

During this period, several prominent national organizations headed by self-advocates arose. Legal organizations such as the Disability Rights Education & Defense Fund (DREDF) worked to address national civil rights law and disability policy (Zames-Fleischer & Zames, 2011). American Disabled for Accessible Public Transit (ADAPT—now known as American Disabled for Attendant Programs Today) became known for their peaceful public demonstrations, civil disobedience, and direct action while protesting inaccessible public transportation (Pelka, 2012). The National Council on Independent Living (NCIL) started out as a grassroots organization that was run by and served individuals with disabilities. In addition to providing guidance and support for local Centers for Independent Living (CILs) around the country, they worked to lobby for increased representation of those with disabilities in Washington and against disability-based discrimination. Drawing on the legacy of the civil rights movement, these groups began to recognize the increased strength of collaboration among multiple disability categories (Ferguson, Ferguson, & Wehmeyer, 2013; Pelka, 2012).

The issue of human rights and personhood also became areas of contention within the medical community. Denied medical care resulted in a series of deaths of infants with disabilities such as Down syndrome and spina bifida in the 1980s. This raised ethical and legal debates around the ways in which interpretations of personhood and quality of life informed treatments decisions (Schalock & Wehmeyer, 2013). Disability advocate and ally Bruce Kappel (2009) asserted, “While the 1970s saw a decline in efforts to prevent people with disabilities from having children, the 1980s saw an increase in efforts to deny them the right to live” (p. 25). After
a series of court decisions established that these infants were not protected under section 504 of the Rehabilitation Act (1973), Congress passed the Child Abuse Amendments Act (1984). This amendment established the responsibility of states to intervene and advocate for infants who were suspected of being denied medical care due to IDD (Kappel, 2009).

During this period great strides were made in mobilizing individuals with disabilities to challenge barriers to community, employment, and transportation. Unfortunately, the stigma of disability remained, and its effects were particularly felt by individuals with IDD. However, the coordination and membership of disability rights organizations and their allies grew dramatically. Students with disabilities who had gained access to public education due to the Education for Handicapped Children Act (1975) began to graduate during this time and became vocal supporters of disability rights (Shapiro, 1994).

1990s: Self-advocacy and the Americans with Disabilities Act. Building upon the protections and rights to access enshrined in section 504 of the Rehabilitation Act (1973), EHCA (1975), and DD Act (1975), the ADA (1990) was to become one of the most significant pieces of legislation to protect the civil rights of individuals with disabilities and their families (Nielsen, 2012; Pelka, 2012; Shapiro, 1994). Drawing from the Civil Rights Act of 1964 and the concerted activism of the disability rights community, the ADA would challenge dominant conceptions of who should be afforded the fundamental right to engage in civic life. Originally introduced in Congress in 1988 by Representative Tony Coelho and into the Senate by Senator Lowell Weicker, there was a great deal of revision, guidance on the part of the National Council on Disability (NCD), and behind the scenes efforts on the part of activist and allies, such as Justin Dart, to gain commitments of support on the part of representatives. In garnering support from the Republican-led Congress, the ADA was primarily framed as a law that would remove
individuals with disability from public assistance by providing them access to employment (Heyer, 2015). Economic analysis by Acemoglu and Angrist (2001) in the years following the ADA’s implementation showed that this did not result in a decrease in individuals with disabilities seeking public assistance. It did however help to garner support and shift the perception that individuals with disabilities were simply seeking government handouts to those of Americans denied the opportunity to work (Pelka, 2012). Direct action organizations such as ADAPT took part in demonstrations and marches to demand passage of the ADA, including briefly occupying the Capitol rotunda and staging the Capitol Crawl in 1990 in which some demonstrators left their wheelchairs to drag themselves up the steps of the Capitol (Pelka, 2012).

After two years of concerted and relentless effort by the disability rights community in support of the ADA, President George H. W. Bush signed the ADA into law in a signing ceremony on July 26, 1990 that included many of the organizations and activists that had played a role in its passage.

The ADA mandates the gradual implementation of protection from discrimination in a broad range of areas impacting civic life, such as employment, transportation, access to public entities, and telecommunications. The ADA fundamentally differs from other civil rights laws in that it requires the presence of accommodations or supports in addition to access (Heyer, 2015). The language of the ADA was criticized for its vague mandates for “reasonable accommodations” to the extent that they would not cause “undue burden” for those implementing the changes required by the law (Shapiro, 1994). Many provisions of the ADA were left to the courts to clarify and were gradually weakened through a series of Supreme Court rulings that focused primarily on the definition of disability over the experience of disability discrimination (Zames-Fleischer & Zames, 2011). Following a public outcry and concerted
efforts on the part of disability rights organizations, Congress passed the ADA Amendments Act (2008) and restored the original intent of the protections (Heyer, 2015; Zames-Fleischer & Zames, 2011).

The first major challenge to the ADA was the case of *Olmstead v. L.C.* (1999). The case involved a woman named Louis Curtis, who had been diagnosed with intellectual disability and schizophrenia. After voluntarily committing herself in 1992, she was treated for a year and was considered by her medical team to be stable and able to return home with the support of community-based services. Unfortunately, she remained institutionalized for years later as community-based services were unavailable. The Supreme Court ruled on the case in 1999, stating that the denial of community-based services deemed appropriate by the medical team and desired by the individual constituted discrimination under the ADA.

**2000s–present: Victories and challenges.** Since 2000 there have been great gains in securing the educational rights of students with disabilities, the development of practical and effective assistive technologies, and the delivery of supports and therapies for young children with disabilities and their families through early intervention services. Ninety-five percent of students with disabilities are being educated in their neighborhood schools and continual progress has been made on increasing reading proficiency. Additionally, the rate of graduating students who are enrolling in college increased 17.3% between 1987 and 2005, and more young adults with disabilities are securing employment (U.S. Department of Education, 2010). In many ways, the overall condition of the population with disabilities is better than it has ever been in the United States. However, significant challenges remain in the struggle for equity, accessibility, and supports. Students with disabilities have lower graduation rates than the national average. The U.S. Department of Education reported that the national average for graduation rates in
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Public high schools was 79% in the 2010–2011 school year, while an average of 59% of students with disabilities graduated (Stetser & Stillwell, 2014). In many ways, the stigma against IDD continues to frame these individuals as helpless, irresponsible, and unaware of the world around them. The marginalization of and discrimination against individuals with IDD remains a difficult and persistent challenge, especially once these individuals leave school and become adults (Novak-Amado et al., 2013). The passage of the ADA has done a great deal to create opportunities and access, yet in many ways it has been inadequately supervised and poorly enforced (National Council on Disability, 2000).

Since the passage of the No Child Left Behind Act (NCLB; 2002), complications have arisen as schools and educators attempted to meet the learning needs of all students while abiding by strict requirements for accountability and demonstrating adequate yearly growth in student academic performance. NCLB requirements resulted in some schools being unable to bring their special education students up to grade level and therefore failing to meet adequate yearly progress (AYP) standards (Eckes & Swando, 2009). Schools have also struggled to manage the legal complexities and sometimes direct contradictions between NCLB and IDEA. Arguing that the policies enacted through NCLB failed to adequately address and meet the needs of students labeled with disabilities, Eckes and Swando (2009) highlighted the inequity that results from mandating standardized grade level proficiency from a population of students with a wide range of learning needs.

The disconnect between the rights and protections afforded by IDEA and the accountability demands focusing on standardized achievement by NCLB is, in part, due to the shift in the educational ideals of a well-informed and engaged citizenry in a democracy to efficient and effective workers in a market economy (Anyon, 2005). This shift is perhaps
reflected in the final statement in a report by the U.S. Department of Education (2010) on the progress and potential of IDEA: “Every child is a precious resource whose full potential must be tapped” (p. 12). This instrumentalizing language that frames students as resources is indicative of an approach to education that denies the inherent value and potential capabilities of human beings as rights holders. In the United States there are no specific anti-discrimination laws for children with disabilities outside of the school setting. IDEA contains no provision for confronting and breaking down the social stigma around disability. Perhaps most important is the disparity in how the education of students is conceived. In Board of Education of the Hendrick Hudson Central School District vs. Rowley (1982), the Supreme Court ruled that IDEA requires instruction be provided to students with disabilities that offers some educational benefit, but that does not need to be equal to their general education peers, nor is there a requirement to help students develop their talents and abilities to their maximum potential (National Council on Disability, 2008).

In addition to educational challenges, the United States is also facing difficulties in mediating the rights of individuals with IDD with the responsibilities of citizenship. The issue of guardianship has been particularly messy in both the denial of rights and the potential for abuse or neglect for the individual who has been deemed incompetent in the eyes of the law. While many states have implemented partial guardianship designations that assign guardianship over property or finances rather than the individual, the traditional form of guardianship continues to be prevalent (Carey, 2009; Power et al., 2013). The United States has begun to address the difficult issue of subminimum wage and the denial of organ transplants for individuals with
intellectual disabilities, yet progress is slow and there are areas in which the application of disability law remains unclear (Heyer, 2015).

United States civil rights laws are grounded within a framework of negative rights (or freedom from interference). The ADA departs from other civil rights legislation in that it mandates reasonable accommodations and access, which reflects a positive rights (or freedom to an entitlement) perspective. This small legal precedent can perhaps offer hope for more comprehensive protections, but there is a great deal of work to be done before individuals with IDD are afforded the protections, rights, and supports necessary to engage with their communities as valued citizens entitled to support and inclusion.

**Disability and Rights in the International Context**

Disability policy under United Nations’ international treaties was primarily framed within a social welfare framework in the 1950s. In the 1970s this focus gradually shifted to situate disability policy within a human rights framework (United Nations Enable, 2002). This section traces the evolution of disability policy to its present interpretation as firmly grounded in positive rights and the inherent value of all people.

**United Nations declarations.** Drawing on the precedents set by the Geneva Declaration of the Rights of the Child (1924), the Declaration of the Rights of the Child (1959), the Convention on the Rights of the Child (1989) as well as the Universal Declaration of Human Rights (1948) and the International Covenants on Human Rights (1966), the General Assembly adopted two prominent declarations in the 1970s. The Declaration on the Rights of Mentally Retarded Persons (1971) was a nonbinding resolution to establish and protect human rights

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2 Organ transplants have historically been denied to individuals with IDD due to concerns over their ability to appropriately manage their postoperative care (Ne’eman, Kapp, & Narby, 2013). The International Heart and Lung association has previously stated, “Mental retardation or dementia may be regarded as a relative contraindication to transplantation” (as quoted in Ne’eman et al., 2013, p. 3).
ranging from healthcare and assistance to economic security and legal safeguards. Four years later the Declaration on the Rights of Disabled Persons (1975) was also adopted. It was a nonbinding resolution of 13 objectives that reinforced and provided additional protections to the Declaration on the Rights of Mentally Retarded Persons, including respect for human dignity, prioritizing self-reliance, consideration in economic and social planning, protection from exploitation, and consultation with organizations of self-advocates.

The General Assembly proclaimed the year 1981 as the International Year of Disabled Persons (IYDP). This entailed the organization of international conferences and symposia throughout the year that focused on the themes of full participation and equality (United Nations Division for Social Policy and Development, 2015). At the end of the year the General Assembly adopted the World Programme of Action Concerning Disabled Persons (WPA), which was derived from the research and reports presented during the IYDP. The WPA focused on a global strategy for preventing disability, providing rehabilitation, and equalizing opportunities for individuals with disabilities (United Nations, 1982). The adoption of the WPA led to a proclamation of the International Decade of Disabled Persons (1983–1993) to encourage implementation of WPA. A review of the implementation of the WPA by the United Nations General Assembly (1987) led to further recommendations, including the development of an international convention on the elimination of discrimination against individuals with disabilities.

Leandro Despouy was appointed Special Rapporteur of the Sub-Commission on Prevention of Discrimination and Protection of Minorities in 1984 and in 1988 published a report titled Human Rights and Disabled Persons (Despouy, 1988). This report provided an examination of the daily experience of disability with a specific focus on the comparison with
typical lives within the broader community. Despouy noted individuals with intellectual disabilities were most vulnerable to discrimination. In 1989 the General Assembly adopted the Tallinn Guidelines in addressing disability rights. The Tallinn Guidelines were drafted at the International Meeting on Human Resources in the Field of Disability in Tallinn, Union of Soviet Socialist Republics, and asserted that individuals with disabilities were agents of their own destiny and that economic participation should be an exercise of human rights. It also emphasized the need for training and employment opportunities (United Nations, 1989). The General Assembly (1993) later offered further guidelines in the form of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities. Derived from the World Programme of Action Concerning Disabled Persons, it outlined 22 nonbinding rules that focused on access to social supports, community life as well as implementation and monitoring protocols. These rules were also notable in that they addressed preconditions necessary for equal opportunity of individuals with disabilities.

*Convention on the Rights of Persons with Disabilities*. In 2001 representatives of Mexico proposed to the General Assembly that an Ad Hoc committee draft a Convention on the Rights of Persons with Disabilities (CRPD). Meeting eight times between 2002 and 2006, the Ad Hoc committee drafted the CRPD and optional protocols. The CRPD was adopted by the General Assembly in 2006 and implemented in 2008. The Convention established the Committee on the Rights of Persons with Disabilities (made up of 18 independent experts elected at the Conference of the State Parties and offered four year terms). At the close of 2016, 172 nations have signed the convention and 160 nations have ratified the CRPD. The United States signed the convention in 2009 but has yet to ratify it. After ratifying the CRPD, states are required to submit regular reports on progress to the committee, the first within the first two years from
ratification and then every four years after that. *The World Report on Disability* (World Health Organization, 2011) was published five years after the adoption of the CRPD and utilized research from around the world to present the global state of disability as well as recommendations for policy and CRPD implementation.

The CRPD (2006) works to address the many intersecting factors that impact the experience of living with a disability. The CRPD outlines a broad array of positive protections and rights over a preamble and 30 articles that recognize and address distinct aspects of the disability experience. For example, article seven addresses the rights of children with disabilities and commits to the right of children with disabilities to have their voices respected and human rights protected. Article 16 guarantees freedom from exploitation, violence, and abuse. Article 17 provides direct protections for the integrity of the individual, stating, “Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others” (United Nations, 2006).

Article 24 of the convention specifically focuses on education and frames the commitment of state parties to protect the right to an inclusive education aimed at realizing the full potential of students in recognition of their inherent value as human beings. It also includes a commitment to uphold a student’s sense of dignity, self-worth, and freedom. The right to participate in a free society and to develop as social, emotional, and physical beings is also protected. Under the protections of this article, individuals with disabilities cannot be excluded from education, are entitled to appropriate accommodations, and are guaranteed instruction by qualified staff to support language and communication in order to fully participate as members of their community. Additionally, individuals with disabilities are assured access to post-secondary
education, vocational training, and lifelong learning on an equal basis to those without disabilities.

In 2008 the National Council on Disability (NCD) published a report that provided a comparative analysis of disability laws in the United States with the protections afforded by the CRPD and conducted an article-by-article breakdown of where gaps appear in U.S. law. They found that for the most part the Convention was in accordance with U.S. law and the U.S. had the potential to reach the level of convention mandates through stronger enforcement of current law and action by Congress to address rights currently outside the realm of U.S. law. A potential barrier to the ratification of the CRPD is the current collective approach to U.S. disability law that has provisions for disability rights essentially sprinkled throughout multiple pieces of federal legislation, such as the ADA, the Rehabilitation Act, and IDEA. Additionally, the federalist legal system of this country results in potential conflict between state and federal laws. Perhaps most importantly, the United States affords no protection under current law for vital components of the CRPD. The NCD (2008) lists these as, “Respect, dignity, equal worth, the full enjoyment of all rights, equality of opportunity…the use of special measures as well as other economic and social rights, and duties relating to the proactive alteration of the social understanding of disability” (p. 9). Out of the 30 articles directly addressing protections for individuals with disabilities, the United States is in compliance with 11 (National Council on Disability, 2008). In the United States there are no protections for respect, dignity, or equality as human rights.

The Stigma of Disability

The social stigma of disability manifests in many forms and is grounded in a specific cultural context that frames the ways in which it is interpreted and enacted (Ingstad & Reynolds-Whyte, 1995, 2007). For the purposes of this research, the concept of social stigma associated
with disability draws from the work of two scholars to explore the complex and interdependent nature of two constructs: Erving Goffman and Eva Feder-Kittay.

**Erving Goffman.** Sociologist Erving Goffman (1961, 1963, 1971) conducted research in the areas of stigma, deviance, and social relationships. Goffman studied the ways in which normative expectations are constructed and act to regulate behavior, highlighting stigma as a mediating force that polices behavior and serves to marginalize or exclude individuals who do not or cannot conform to expected norms. Examining the experiences of those living in or having lived in institutions, mental hospitals, prisons, as well as the perspectives of those living with disabilities, addictions, and other stigmatized conditions, Goffman (1961, 1963) presented the ways in which values and assumptions embedded in culturally-rooted expectations of personhood result in the interpretation of difference as bad, weak, dangerous, or deviant. Noting the ways in which stigma can be internalized and reproduced, Goffman stated:

> The stigmatized individual exhibits a tendency to stratify his “own” according to the degree to which their stigma is apparent and obtrusive. He can then take up in regard to those who are more evidently stigmatized than himself the attitudes the normal take to him. (1963, p. 107)

Goffman’s conceptualization of stigma is helpful in highlighting the unstable boundary delineating normalcy and deviance as well as the often invisible pressures to fit in, be normal, and behave in expected ways.

**Eva Feder-Kittay.** Eva Feder-Kittay (1999, 2008, 2009, 2015) is a feminist philosopher who challenged traditional conceptions of personhood and the vilification of dependency. She is the mother of an adult daughter, Sesha, who has severe physical and intellectual disabilities. Feder-Kittay focused on the ways in which traditional ideals of rationalism, individualism, and
independence work to shape expectations of what it means to be fully human. She framed personhood as marking “the moral threshold above which equal respect for the intrinsic value of an individual’s life is required and the requirements of justice are operative and below which only relative interest has moral weight” (Feder-Kittay, 2008, p. 139). Challenging reason as the defining human characteristic, Feder-Kittay took this premise to its logical conclusion, illustrating the “reasonable” consequences of eugenics and genocide. She argued for a form of prosocial intelligence, citing the human need for shared trust, joy, and connection. Feder-Kittay described her experiences of Sesha and the ways in which she would fail to meet the criteria for moral personhood, but nevertheless offer her own kind of contribution to the world:

She lacks speech but… has the capacity to enjoy life, to share her joy through her smiles and laughter, to embrace those who show her love and care, and to bring joy to all whose lives she touches—an individual who, through her warmth, her serene and harmonious spirit, and her infectious love of life enriches the lives of others and who has never acted maliciously or tried to harm anyone. Whether or not she would know what it means to determine her own good may be in doubt, but the good she brings into the world is not. (Feder-Kittay, 2008, p. 151)

Feder-Kittay (2008) asserted that there is a need to recognize and value different kinds of minds and forms of communication. She called for the cultivation of an awareness of the ways in which one’s cultural context privileges some ways of perceiving and interacting with the world over others and the ways in which these contexts can obscure the talents of those considered less than fully human. Citing the inevitable nature of dependency and the inherent interdependence of all humans, Feder-Kittay (2015) called for a more inclusive theory of justice that recognizes the inherent value of all.
Disability and Voice

It is through the interactive communication process that meaning is created, mediated, and assigned within social groups. This process requires the capacity to give an account of one’s experience in a context where this account is valued and recognized by others as meaningful. Given the essential role of voice in mediating relationships, conventions regulating access to and development of voice have powerful implications for broader discourses informing notions of personhood (Couldry, 2010; Feder-Kittay, 2008). In neoliberal society, interpretations of voice have weakened community engagement, furthered the commodification of communication, and regulated notions of personhood in the unequal access to and fostering of voice (Couldry, 2010; van Dijk, 2008). This inequitable access—and the values that inform and justify it—deeply affects the loss of voice for marginalized individuals and oppressed communities.

The denial of personhood—and the rights and privileges that accompany it—has a long and complex relationship with constructions of voice, especially in terms of establishing whose voice is valued and should be heard (Bauman, 2000; Trent, 1994). Self-advocates and allies of the disability rights movement have been engaged in the struggle for voice and access to inclusive communities for over 60 years (Nielsen, 2012; Zames-Fleischer & Zames, 2011). Individuals labeled with a disability—especially those labeled with intellectual disabilities or developmental disabilities—are often conceived of as incapable of full participation in society, unable to exercise voice and agency, and undeserving of full rights of citizenship (Wolbring, 2008). As a marginalized status, dominant interpretations of disability denote an inability to conform to expectations of self-sufficiency and productivity. This perceived deviance operates as a justification for the denial of voice and naturalizes the oppression and marginalization experienced by individuals assigned to this classification.
The ways in which an individual experiences disability is framed by the dominant values, beliefs, and practices operating within his or her socioeconomic, political, and cultural context. Individuals existing at the intersections of race, ability, and class often face compounding oppression and marginalization as they attempt to navigate and mediate the realities of what it means to be considered a minority, poor, and disabled (Connor, 2008). The denial of voice is often a regular and widespread occurrence for individuals experiencing life at these intersections (Blanchett, Klingner, & Harry, 2009; Erevelles & Minear, 2010).

Drawing from the critical articulations of his participants and contextualizing literature, Connor (2009) linked difference from the norm with perceptions of deviance and pathology. This interpretation of difference reproduces and reinforces dominant assumptions justifying educational segregation and social isolation as well as rationalizing external supervision and control by institutions of authority. Framed by dominant notions of truth, power, and knowledge, disabilities are interpreted with an assumption of incompetence, and this in turn acts to justify the denial of voice as well as increased external supervision and control (Roets, Reinaart, Adams, & Van Hove, 2008).

**Personhood and voice.** Constructions of personhood as a measure of human potential, value, and ability have a profound impact on one’s ability to utilize voice. The privileging of voice for some at the expense—or denial—of others contributes to a culture of inequity and exploitation informed by the dominant values of a neoliberal society. Zygmunt Bauman (2001) examined the ways in which the dominant values of neoliberal society predispose and at times actively encourage the dehumanization—or denial of personhood—and exploitation of marginalized populations. Efficiency, production, and profit take priority—partially through the
denial of voice—over the well-being of the individual and community. In this context destruction is disguised as progress and market fundamentalism dominates over conceptions of voice.

In *Modernity and the Holocaust*, Bauman (2001) characterized dehumanization as symptomatic of modernity. Situating his analysis as a direct critique of the modern culture’s contribution to the atrocities perpetrated against the victims of the Holocaust, Bauman extended his examination to include the many contributing factors that remain embedded within our culture and continue to frame values, perceptions, and behaviors in contemporary society. Within neoliberal society, destruction and domination continue to be framed and interpreted as rational and natural. Within this framework humans are interpreted and expected to function as units, autonomous individuals that are either inherently defective or whole. Efficiency is valued over equity and the concepts of rationality and productivity come to be seen as essential to the functioning of an organized community. Bauman stated, “Dehumanized objects cannot possibly possess a ‘cause,’ much less a ‘just’ one; they have no ‘interests’ to be considered, indeed no claim to subjectivity” (p. 104). Many individuals labeled with disabilities experience their voices as denied or negated through the social production of distance (Goffman, 1963). Language plays a powerful role in maintaining the stigma and isolation of marginalized populations. As described by Bauman, language “defines its objects while pretending to describe them” (p. 213). Language in modern culture works through the creation of composite traits rather than the unified qualities of the individual, suspending moral responsibility and reducing those who do not conform to dominant notions of productive consumers to defective units.

**Conclusion**

These diverse bodies of literature speak to the shifting representation of disability and personhood as context-dependent, historically-referenced, and culturally-rooted. Disability, and
IDD in particular, is a stigmatized and marginalized status that is often presumed to denote a deficiency, inherent deviance, and the need for supervision. This is a population that has often been hidden away, silenced, and disempowered. While there has been progress in relation to policies that protect the rights of individuals with disabilities, this does not always translate to the social context to which these policies are intended to apply. Persistent exclusion and denied personhood and humanity continue to decrease the opportunities and capabilities of many individuals with disabilities.
Chapter 3: Methodology

This chapter presents the research methods that guided this dissertation research. The study employed a qualitative research approach using a phenomenological lens to examine the lives of individuals with intellectual and developmental disabilities (IDD) emphasizing their voices and their experiences as well as the perspectives of their primary family members. By pushing beyond quantitative representations of disability, this study sought to explore how the participants of this study experienced and interpreted disability, community, and the ways in which these concepts informed their lived experiences. This chapter also addresses research considerations, data collection, security and safety measures, researcher positionality, and data analysis procedures.

Qualitative Inquiry

Qualitative research entails a distinctive environmental and conceptual positioning of the researcher in relation to the phenomenon, people, and places she is investigating. Although there are many contextual, political, and historical factors that frame interpretations of this research approach, qualitative research is an interpretive act that strives to understand the perspectives, actions, and lives of people within their cultural context (Denzin & Lincoln, 2011; Glesne & Peshkin, 1992; Seidman, 2006). Committed to the distinctive, *emic* experience—grounded in individual perceptions and interpretations—the qualitative research process is flexible, inductive, and generative. According to educational scholar J. Amos Hatch (2002), qualitative research takes place in the natural setting in order to better understand participant perspectives as they make sense of the world around them in their everyday lives. He framed meaning as central to qualitative research, which seeks to both understand the construction of subjective meaning as well as the factors that interact to inform or complicate meaning within each unique, irreducible
context. The qualitative researcher follows the concrete principle to capture sensory and aesthetic details from the environment and exemplaric verbatim from the narratives of participants in order to construct an analysis that attempts to capture both the related experience of the participant and the broader cultural factors that frame it (Geertz, 1973; Hatch, 2002; Spradley, 1980). Informed by the stance that meaning and truth are constructed within and deeply influenced by the cultural context, qualitative research involves careful attention to the research process and the role of the researcher as the primary instrument of the investigation.

As the primary instrument of the study, qualitative researchers must be mindful of their own subjectivity and positionality as framing the ways in which they interpret and construct meaning in relation to the world. Practicing critical reflexivity, the qualitative researcher carefully monitors his or her personal responses, interpretations, and thoughts during the entire research process in order to uncover the influences and experiences one brings to an understanding of the phenomenon being studied (Hollway, 2009; Watt, 2007). This critical reflexivity also serves to help bracket personal biases, assumptions, and preconceived notions that may impede a clear understanding of participant perspectives. Through the use of a research journal, qualitative researchers monitor their perspectives and responses to the design of the study, issues regarding participants, data collection, and analysis (Munhall, 2007; Spradley, 1980; Watt, 2007). In addition to the practical nature of critical reflexivity in protecting and honoring the voices, meanings, and experiences of participants, this reflective process can also serve to help researchers to perceive connections between theory and practice, inform the emergent design of the study, and help to illuminate the positionality of the researcher in relation to the phenomenon or dynamic being examined (Munhall, 2007; Watt, 2007).
The qualitative approach helps the researcher to remain mindful of the ways in which social interactions and cultural expectations gain greater personal significance as they are internalized—influencing and framing perception and a sense of self. Nakkula and Toshalis (2006) described the complex and contextual nature of identity as gradually constructed through interaction with the surrounding environment. Drawing on the example of a student entering a classroom, they stated, “What she presents to you as ‘me’ is the most recent iteration of her internalized life experiences, a representation contingent on her context at the moment” (p. 120). The qualitative researcher must take care to recognize the ways in which these multi-faceted and layered identities respond to people and places—specifically to the ways in which the self engages in constant interaction with the environment and the people within it.

Seeking to understand how adults with IDD and their families perceive and interpret their experiences relating to disability, this research was sparked by questions such as the following: How do individuals with disabilities experience inclusion or exclusion within their communities? How are social relationships between adults with IDD and their families interpreted? How does disability inform one’s relationships and daily activities? Phenomenology offers a method of exploring these questions and examining the ways in which the emic meanings are informed by the individual’s relationships, history, context, and personal capabilities.

**Phenomenology**

The process of attempting to capture—as authentically as possible—the perspective of another is painstaking and intensive (Creswell, 2013; Munhall, 2007). It can be even more so for an individual who displays unfamiliar mannerisms and expressions, has difficulty communicating clearly, or struggles with processing or recalling information. The phenomenological mode of research entails the use of interviews to investigate the experiences
of participants while also being highly attentive to the ways in which participants speak and taking into account tone, expression, and body language (Munhall, 2007; Seidman, 2006). This approach is also attentive to the many factors that frame one’s experiences, such as social context and environment. Additionally phenomenology employs careful analysis and coding to tease out themes and generate interpretive conclusions or further avenues of inquiry (Munhall, 2007; Seidman, 2006). This in-depth and comprehensive research approach allows for a rich representation of the participant’s lifeworld and a deep investigation into the ways in which he or she constructs meaning in response to the surrounding world (Hatch, 2002; Munhall, 2007; Schutz & Luckmann, 1973). Interpretations are tentative and rely upon a rich set of data in order to share the lived experience of another.

This comprehensive and flexible approach is the ideal mode of research for individuals whose internal logic is not easily recognized, such as when individuals exhibit differences in the ways they communicate, behave, or process information. The lifeworlds—or Lebenswelten—of participants are deeply informed by the emotional, social, and cultural realities within which they exist. In developing an understanding of the lifeworlds of participants, the researcher is better able to examine the ways in which participants interpret their experiences and construct meanings within their personal contexts (Munhall, 2007; Schutz & Luckmann, 1973). The phenomenological approach emphasizes the intentionality and internal logic of consciousness as one acts, interprets, and constructs meanings through his or her interactions with the world (Merleau-Ponty, 1945/2012; Roche, 1973; Schutz & Luckmann, 1973).

**Existential phenomenology.** The phenomenological approach has developed through a specific theoretical lineage that is grounded in philosophical inquiry seeking to understand human consciousness, intentionality, the lifeworld, and the ways we make meaning within it
(Roche, 1973). Existential phenomenology emphasizes the intentionality and internal logic of consciousness as one senses, interprets, and constructs meanings through an embodied perception of the world (Merleau-Ponty, 1945/2012). Existential phenomenology developed from and in response to transcendental or pure phenomenology, a theory advanced by philosopher and mathematician Edmund Husserl. Husserl was a pupil of Franz Brentano—considered to be the father of phenomenology—and focused on developing a precise understanding of pure consciousness. Husserl coined the term *epoché* to refer to a manner of bracketing away one’s natural attitude—or taken-for-granted personal and cultural assumptions—in order to perceive the pure or inherent essence of a phenomenon or object (Roche, 1973). While transcendental phenomenology focuses on isolating and understanding the essence of pure consciousness, existential phenomenology examines the subjective nature of meaning derived from the lived experience.

**Embodied perception.** In *Phenomenology of Perception*, philosopher Maurice Merleau-Ponty (1945/2012) presented an exploration of human meaning and intentionality—or the nature of consciousness as directed—grounded in the complex interplay of the mind, body, and context. Situating these layers of perception and meaning in time and place, Merleau-Ponty focused on the nature of experience as enacted through sensory perception and bodily reactions. While meaning is contextualized by the mind and framed by language, it relies upon the body to act as both the background and the foundation upon which it is constructed. One perceives the world while bodily anchored within it, wherein significance is embedded in direct experience that becomes refined or transformed when articulated, abstracted, or recalled.

Merleau-Ponty (1945/2012) described the coordination of sensory experiences as contributing to a constantly evolving sense of self, others, and the world that in turn informs the
ways in which one attends to and translates sensory information. In this manner, sensory stimuli informs one’s understanding of the world and the knowledge that is derived from this understanding informs or evokes one’s expectation of sensory experiences. He described perception as guided by familiarity or the truths that frame the world. Merleau-Ponty (1945/2012) maintained that we do not perceive the world, rather “the world is what we perceive” (p. xxx). One’s sense of the world arises from the intersection of one’s lived experience and the translated experiences of others. Phenomenological researchers attempt to capture the lived experience through the practice of intersubjectivity (Munhall, 2007; Seidman, 2006). Intersubjectivity—the idea that the one can deeply empathize and imagine themselves in the place of another—allows for experiences and perceptions within a particular context to be shared between the researcher and the participant (Merleau-Ponty, 1945/2012; Schutz, 1967; Schutz & Luckmann, 1973). Within phenomenological inquiry, the researcher further relies upon intersubjectivity to help the reader connect the stories of participants in a research study (Munhall, 2007; Seidman, 2006).

Merleau-Ponty’s (1945/2012) foundational work deeply informs phenomenological research that strives to articulate the unique lived experience of the individual. The researcher must seek to gain an understanding of the ways in which an individual creates his or her world in response to sensory perception, direct experience, and socially-embedded knowledge. According to Merleau-Ponty, this understanding is inevitably a translation that draws on the experiences and sensory perception of the researcher to craft the story of the participant. It becomes vital for the researcher to recognize the subjectivity of perception and strive to distinguish and decenter or bracket away personal modes of being to keep from imposing personal assumptions on the meanings of participants (Munhall, 2007). This can be especially challenging when attempting to
understand the world of an individual with an IDD. For example, if an individual experiences disruption in regards to temporal awareness, his or her perception of time will likely be very different from that of the researcher and shape a different embodied perception of the world. These perceptual differences greatly inform the meanings constructed in response to the environment and must be taken into consideration when striving to understand the lifeworld of another.

_The lifeworld._ In *The Structures of the Life-World (Vol. I)*, Schutz and Luckmann (1973) examined meaning, perception, and social relationships grounded in the natural attitude and lifeworld. Presenting a complex analysis of dynamics informing the lifeworld, the authors highlighted the interplay between experience and perceptions of space, time, and social organization. Schutz and Luckmann described the ways in which “every man stands in mutual relations to other men” (p. 18), wherein the social world frames and constrains perceptions of normalcy, order, and freedom. The everyday lifeworld is described as the realm of common sense where the daily actions of life occur. The natural attitude is defined as the often unexamined and unconscious perceptual framework that is constructed through the accumulation of experience and informed by the experiences of others.

Within the natural attitude, one is able to make sense of the lifeworld. Within this realm knowledge is practical, taken-for-granted, and self-evident. One behaves in ways that are meaningful and purposeful, and one can translate the behaviors and actions of others as this framework is social and intersubjective by nature. One assumes a shared understanding with the people in the lifeworld as they function within a “common frame of interpretation” (p. 4). The authors described perception as filtered, categorized, and assigned explanations by one’s internal schema, or stock of knowledge. It is grounded by relevance and guided by familiarity or need.
New meaning is created when stock experience ceases to match lived experiences. Munhall (2007) described the interconnectedness of four overlapping existential lifeworlds: the spatial, the corporeal, the temporal, and the relational. Spatiality refers to the physical space and environment within which the experience is situated and the meanings that are created in response to it. Corporeality—or embodiment—represents the meaning making that occurs within the body as a result of external and internal stimuli. Temporality relates the perception of time in connection to the meaning of the phenomenon. Relationality denotes the connection experienced with oneself and others within the lifeworld.

Responsive to the unique and contextual lived experience and the meanings created in response to it, phenomenology allows insight into the interpretations of meaning that arise from the spatial, corporeal, temporal, and relational lifeworlds. A focus on the ways in which the lifeworld of an individual informs his or her experiences is an essential consideration for phenomenological research. A focus on the ways in which an individual functions within his or her lifeworld helps to highlight the internal logic of behaviors or speech that may otherwise appear meaningless or random. For example, an individual with autism may employ idiosyncratic phrases or speech that initially appear to make no sense until one understands the ways in which the individual has come to use a phrase over time and in specific situations to communicate with others.

Relationships. Martin Buber (1923/1996) examined the nature of relationships, perception, and meaning in I and Thou. In distinguishing two modes of interaction, I-It and I-Thou, Buber presented two very different ways of perceiving and interacting with the surrounding world. The I-It relationship represents a dualism in which the I is foregrounded and the It is experienced. The I-Thou relationship is described as an exclusive and reciprocal
relationship wherein one perceives and engages with the entirety of the Thou with one’s whole self. Both of these modes of interaction are grounded in perception. Buber made clear that one’s self is deeply informed by these interactions. Within this framework, the self—or the I one experiences as the partner of It or Thou—is constructed in response to these two kinds of relationships.

Buber (1923/1996) maintained that when one utilizes someone or something, he or she cannot wholly engage with them but rather only recognize distinct qualities or facets that make up the entity; the meaning that results from this interaction is grounded in and informed by past experiences. Within this realm of I-It relationships resides analysis, categorization, and reflection. These are the purposeful or detached relationships that dominate much of the human experience, framed by place and time, expressed through words, and informed by memory. Analytic and objectifying forms of language are also of the I-It world, wherein words create distance as representations of the object world. Buber made clear that I-It relationships are habitual and vital for human existence and engaging in the many tasks necessary for daily survival.

In perceiving the Thou and fully engaging another with one’s whole self, one must relinquish one’s perspective framed by past experience. There can only be the present. Buber (1923/1996) stated, “Whoever says Thou does not have something; he has nothing. But he stands in relation” (p. 55)—or perceives the other as a whole being or entity. Within the I-Thou relationship, one’s interaction with another being so fills one’s perspective that the rest of the world becomes informed and saturated by it. Within the I-Thou relationship there is a recognition of the whole self, an awareness that goes beyond words. It is not something that can be created, only entered into. Here there is no purpose, no past, and no appropriation. It is an
exclusive and reciprocal lived relationship, though it is always fleeting. One’s Thou will inevitably become an It, perhaps repeatedly. Buber described these interactions as unattainable (in that one cannot go in search of and find them), one can only be ready to actualize them. In aspiring to perceive the Thou in another, one strives to recognize the other more fully, and one in turn becomes more fully human, or more truly him- or herself.

While it may not be possible for the researcher to fully enter into the I-Thou relationship to the extent described by Buber (1923/1996), his work emphasized elements of relationships that carry important considerations for the researcher. One of these considerations speaks to the complexity of the researcher-participant relationship and the sensitivity, care, and respect required to strive to perceive the world from that participant’s perspective. Buber’s work also highlights ethical considerations for the researcher, such as the need to monitor and bracket one’s own expectations and purposes during the research process. Further, Buber’s description of the ways in which the I-It relationship reduces or objectifies the other speaks to the need for the researcher to guard against imposing meanings onto the experiences of the participant and to strive to understand the world from the participant’s point of view. The phenomenological approach provides a powerful and rigorous method of investigating the perceptions of individuals with IDD and their families.

**Intersections of phenomenology, critical disability theory, and the human rights framework.** The phenomenological approach complements CDT and the human rights framework through the attention to language and the ways in which it frames and foregrounds personal meaning and perception. The research mode of phenomenology allows for the examination of the internal experience of disability as embedded in the social context, and CDT offers a framework for the analysis of the individual experience within the broader cultural and
sociopolitical context. The rights-based approach provides a focus on the inherent dignity, human rights, and agency of individuals within their given context. Gaining insight into the lived experience and perceptions of individuals with IDD and their families within their specific contexts through the phenomenological approach, this research analyzes, situates, and examines the ways in which the personal experiences of participants are informed by broader policies and social discourses around disability and personhood.

**Life Histories and Case Studies**

A life history is a chronological narrative of memories that foreground the individual’s experiences and meaning inherent in the lived world (Tierney, 2000). The recording of life history is an integral aspect of the phenomenological approach as the researcher seeks to understand the collections of past experiences and meanings that inform the perceptions of participants in the present. Tierney (2000) emphasized, “Ideology and social and cultural frames help define how we see the past and construct its stories” (p. 550). He described life histories as a form of storytelling that draws the reader in to experience the vulnerability and truths of the narrator. Lewis (2008) described life histories as recounted experiences that are produced through the interaction of the storyteller and the listener. He highlighted the strengths of the life history approach in its potential to offer historical depth and detail of recalled events, as well as its role in capturing personal interpretations that can challenge broader, simplified understandings of events or contexts. However, Lewis also asserted that it was important to be mindful of its weaknesses, such as the fact that these accounts must rely on fallible memory and how the reader will only be able to see the author’s representation of the storyteller’s narrative.

The researcher must be the one to decide what should be included from the narratives and what should be left out. This puts a great responsibility on the researcher to strive to capture the
personal interpretations and meanings embedded in the narratives and represent them to the best of his or her ability (Behar, 1996, 2003). Errante (2000) emphasized that the researcher’s voice must be minimized in an effort to foreground those of participants. She asserted that the researcher must be cautious of the ways in which his or her personal response may color interpretations of participant narratives and to strive to understand the stories and their contexts from the perspective of participants. Errante also pointed to the strength of multiple perspectives and the ways in which memories and stories develop meaning through interaction with others: “If what we remember and tell, and the ways in which we do so, are expressions of local constructions of personhood and voice, then some memories shared by specific communities may require a group-sharing experience to remember and tell” (p. 26).

This research creates case studies from life histories to represent and portray the unique experiences of each participant (Baxter & Jack, 2008; Creswell, 2013). Stake (1978, 2000) described case studies as a method of conducting qualitative inquiry that focuses on distinct or individual phenomena. Stake distinguished three general types of case studies: intrinsic, instrumental, and collective. The intrinsic case study highlights that the case itself and the meanings within it are what is of interest, while the instrumental case study is used to facilitate or speak to an understanding of the phenomenon in its broader context. Stake also described the collective case study, which is essentially a collection of instrumental case studies that is intended to build an understanding of the phenomenon or phenomena being studied through multiple perspectives and contexts. Stake highlighted the nature of case studies as bounded systems—areas of inquiry that maintain a tight focus on an individual, event, or phenomenon that also address the complex interconnected and interdependent factors informing meaning-making and patterns of behavior. Stake (1978) explained, “It is distinctive in the first place by giving
great prominence to what is and what is not ‘the case’—the boundaries are kept in focus. What is happening and deemed important within those boundaries” (p. 7). This research study draws from all of these categories to some extent. Each of the presented cases are of intrinsic interest while also of instrumental value to facilitate a broader understanding of life with disability. Taken together, the three case studies presented in Chapters 4, 5, and 6 speak to the diverse ways of experiencing and interpreting disability as well as the many complex factors that come to inform how it is perceived.

**Research Considerations**

**Access.** The issue of access was an important consideration in this research. It is necessary to address the role of gatekeepers regarding issues of formal and informal access (Creswell, 2013; Hatch, 2002; Seidman, 2006). Seidman recommended that researchers attempt to contact potential research participants directly unless access to these participants is restricted by gatekeepers, in which case efforts must be made to gain access via their authority. Urging the researcher to make contact in person, Seidman emphasized the importance of communicating to potential participants that they are important, respected, and to be taken seriously. This is a particular concern when seeking to recruit participants who may be hesitant to participate given the social stigma of disability and the blame that has been historically attributed to parents (Nielsen, 2012; Silberman, 2015). **Rapport and trust.** While expertise and experience working with individuals with IDD and their families can provide a certain amount of insider knowledge, rapport and trust can only be developed over time and with particular sensitivity to the individual participant (Creswell, 2013; Seidman, 2006). Drawing from Seidman’s (2006) three-interview structure for phenomenological interviewing, the life history focus of the first interview allowed for the contextualization of the participant’s experiences and provided an opportunity to foster
trust and rapport to grow over the course of the three interviews. I conducted interviews by attempting to clearly situate myself as a learner and the participant as the expert on his or her life. Issues of power and authority were also a concern as many individuals with IDD are encouraged to be compliant and might not feel comfortable advocating for themselves. Parry (2004) warned that the issue of acquiescence—or the tendency to respond in the affirmative when asked a question—can be problematic when interviewing individuals with intellectual disabilities as they may respond in a positive manner so as not to be perceived as disagreeable. This required that I be sensitive to when a participant may be attempting to tell me what he or she thinks I wanted to hear and to take care to avoid inadvertently reinforcing the responses of the participant during the interview. Participants were reminded before every interview that they did not have to answer any questions that they would prefer not to answer.

**Inclusive interview considerations.** There were several issues that were addressed in order to conduct the interviews within this study in a manner that was supportive and attentive to the needs of the participants. It is important to note that the population of adults with IDD is very diverse, and this was reflected in the study. Participants with disabilities displayed a great deal of variation in terms of processing strengths and weakness, expressive and receptive communication skills, and the capacity to focus and plan out thoughts. While interviewing family members before interviewing individuals with IDD provided some insight into individual processing strengths and effective supports, some universal supports were arranged prior to the interviews.

Caldwell (2010, 2011) reported successful use of a semi-structured interview guide that was provided to participants with IDD before the interview in order to give them more opportunity to consider and ask clarifying questions. He also found that requesting participants
bring an artifact along to the interview—such as a photograph, poem, or souvenir—in order to draw out topics of interest and to help them to focus was quite effective. Other researchers have found the use of initial prompts that fade back to open-ended questions during the course of the interview work well in terms of keeping participants with IDD focused and engaged (Frawley & Bigby, 2015; Mayes, Llewellyn, & McConnell, 2008).

Perry (2004) explained that the researcher must take care to communicate information in a simple and straightforward manner. He also recommended that researchers prepare for interviews by attempting to gain a level of understanding regarding a participant's processing strengths and weaknesses, and areas of competence, such as literacy. Perry encouraged researchers to make it clear that participants should feel free to ask questions of the researcher and be particularly sensitive is signals of anxiety or stress. Perry listed four primary areas for consideration during the interview process with individuals with intellectual disabilities: venue, opening the interview, questioning style, and questioning format.

Given the difficulty many individuals with IDD have regarding transportation, Perry (2004) emphasized the need to select a convenient location for an interview while making all attempts to ensure that it was secluded enough to protect the participant’s confidentiality and quiet enough to minimize distractions. Perry recommended opening the interview with a few minutes of chatting about a neutral topic and then taking the time to review the consent agreement and the focus of the interview (with the understanding that the participant has already signed the consent form and clearly informed of its contents previously). Perry warned that participants may be fearful that what they say could jeopardize their support services and that the researcher should be extremely clear about the confidential nature of the research and the motivations of the researcher. He also recommended assuring participants that there were no
wrong answers and to feel free to communicate when they needed to take a break or stop the interview. Perry stated that questions directed at the participant must always be short, simple, and clear. He drew on the work of Prosser and Bromley (1998) to offer guidance for simplifying questions, such as avoiding jargon, using positive phrasing, and short, clear sentences. Another important consideration was the need for wait time following a question in order to allow the participant time to process and formulate his or her response. Perry warned that care must be taken to ensure that the participant understands the question, and so wait time should be balanced with checking that the question was clear and understood. Lastly, Perry addressed the issue of question format. Noting that open-ended questions could be more time consuming and difficult to analyze, Perry urged researchers to conduct third party checks to cross-check responses and to clarify the meanings of responses with participants.

Drawing from the recommendations of disability researchers, an interview guide of general topics was made available to the participants in the study five days prior to each interview (see Appendix A). Four participants opted to receive them. I also encouraged participants to bring a meaningful artifact that they wanted to share and talk about. In addition to providing a comfortable topic of conversation, this was also intended to help participants to focus and engage in the interview. Lastly visual supports (see Appendix B) were made available to all participants with disabilities, though only one opted to use them.

Data Collection

Study population. The purpose of this study was to examine the perspectives of adults with IDD and their family members with a diverse range of circumstances, backgrounds, and resources. Participants enrolled as a pair (made up of one individual with a disability and one family member), except for the fifth participant who enrolled alone. A total of two males and one
female with IDD and two mothers participated in the study. All participants were living in urban and suburban areas of southeast Michigan.

While this dissertation sought to portray the lives of the individuals with disabilities who participated in this study beyond the confines of their disability labels, these classifications can further our understanding of the specific disability-related factors that have a very real impact on the experiences of these participants and the ways in which they interpret and interact with the world. The participants in this study were not required to provide documentation of their disabilities and their disabilities labels were either self-identified or communicated by the family member who participated with the individual with a disability. The three participants with disabilities in this study identified or were identified as having three different disabilities: autism spectrum disorder (ASD), traumatic brain injury (TBI) resulting in developmental disability, and intellectual disability (ID). These disabilities all fall under—or in case of TBI result in—the broader classification of developmental disability (Centers for Disease Control and Prevention, 2016a). The Developmental Disabilities Assistance and Bill Of Rights Act (DD Act) of 2000 provides the federal definition for developmental disability, which is characterized as a severe and chronic mental and/or physical impairment that manifests before the age of 22. Further, this condition must substantially limit functioning in three or more life activities that fall into the following categories: self-care, communication, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency.

ASD refers to a neurological lifelong condition that can impact an individual’s cognition, sensory experiences, expressive and receptive communication, and ability to understand and relate to others. It is also characterized by repetitive body movements or behaviors, a need for sameness or routine, and restricted interests (American Psychiatric Association, 2016). Some
individuals within this population are at greater risk of conditions such as seizure disorders and problems with sleep (American Psychiatric Association, 2016). TBI is the result of an acquired injury to the brain through traumatic force. Depending on the severity of the TBI, effects on survivors can be minor and temporary or result in life-long TBI-related disabilities impacting cognitive and motor functioning, emotional regulation, and sensory processing (Centers for Disease Control and Prevention, 2016b). Intellectual disability is characterized by the American Association of IDD (AAIDD; 2010) as significant limitations in intellectual functioning (such as reasoning, memory, and learning) and adaptive behavior (such as social and practical skills) that manifest before the age of 18. Please see Table 1 for participant demographic information.

*Table 1*

Participant Demographics

<table>
<thead>
<tr>
<th>Group 1</th>
<th>Age</th>
<th>Gender</th>
<th>Education</th>
<th>Disability</th>
<th>Race/Ethnicity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hanna</td>
<td>62</td>
<td>F</td>
<td>MSW</td>
<td>N.A.</td>
<td>African American</td>
</tr>
<tr>
<td>Chinedu</td>
<td>30</td>
<td>M</td>
<td>Certificate of completion</td>
<td>ASD</td>
<td>African American</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Group 2</th>
<th>Age</th>
<th>Gender</th>
<th>Education</th>
<th>Disability</th>
<th>Race/Ethnicity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sarah</td>
<td>50s</td>
<td>F</td>
<td>Ph.D.</td>
<td>N.A.</td>
<td>Caucasian</td>
</tr>
<tr>
<td>PMC</td>
<td>21</td>
<td>M</td>
<td>High school diploma</td>
<td>TBI</td>
<td>Caucasian</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Group 3</th>
<th>Age</th>
<th>Gender</th>
<th>Education</th>
<th>Disability</th>
<th>Race/Ethnicity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tracy</td>
<td>43</td>
<td>F</td>
<td>Dropped out of high school</td>
<td>ID</td>
<td>African American</td>
</tr>
</tbody>
</table>

**Recruitment.** Recruitment for the study began in the spring of 2016. I employed criterion, convenience, and snowball sampling. Selection criteria specified that participants must be adults with IDD, ages 18–64, who retained self-guardianship status with an established capacity for communication (via speech or augmentative and alternative communication device).
The inclusion criteria for family members required that they be adults, ages 18–64, who maintain regular contact with their family member with a disability.

Seeking to interview adults with IDD and their family members from a range of settings and levels of support, I contacted adult service providers, adult care facilities, and faith-based organizations that work with adults with IDD. After identifying a contact willing to speak in the organization, a meeting was arranged with him or her to explain the research study and request access to potential participants. I also sought out participants through professional and personal contacts, recruitment flyer (see Appendix C) postings in community locations (such as bowling alleys and libraries), and online posts. Study participants also referred friends with family members with IDD who might be interested in participation in the study. Potential participants were informed that they would receive a $25.00 gift card to Amazon or Target to help compensate them for their time following the final interview. A total of 11 individuals expressed interest in participation, but due to a variety of reasons (such as no longer responding to emails and phone calls, not wanting to meet in person, and not wanting their family member to know that they had a disability), a total of three adults with IDD and two mothers were successfully recruited and participated in the study.

**Study protocols.** Potential participants came to an initial meeting at a location of their choice (such as their home, coffee shop, or community center) to discuss the purpose of the study and what it entailed in greater detail prior to the first interview. During this meeting potential participants read through the consent agreement and consent form (see Appendix D: Consent Forms) and time was provided for participants to ask questions or seek clarification. Participants were informed of the measures taken to protect the identities of participants and the confidentiality of the content of the interviews and the nature of the questions. Participants were
also assured that they had the right not to answer questions or to withdraw from the study at any time without penalty. It was clarified that the consent form and their agreement were valid for follow-up interviews as well. The consent agreement and consent form were read aloud to the participant upon request. Participants signed the consent form prior to the first interview. Two copies of the informed consent form for the study were provided for participants to sign. I retained one of these forms and the other was provided to the participant to keep for his or her personal records.

This initial meeting also allowed participants to communicate preferred supports or accommodations (for example, font size on interview guides, visual supports, or phone calls before the interview to remind them of the time) and be provided with an optional interview guide to help them to prepare for the first interview. Two of the families had their initial meeting a week prior to their first interviews. The final participant’s initial meeting took place immediately before her first interview, though several phone calls were made prior to this meeting to establish contact, answer questions, and identify preferred accommodations.

**Interviews.** Data-gathering procedures occurred in two stages (parent interviews and participants with IDD interviews) and employed Seidman’s (2006) three-stage interview method. The interviews ranged from about 45 minutes to 90 minutes. Interviews took place in a comfortable and familiar setting selected by the participant. Interviews were recorded with a digital recorder and additional data was collected in the form of observational notes taken during the interviews. Family members were interviewed prior to the interviews with participants with IDD. This arrangement allowed the gathering of information regarding the processing strengths of participants with disabilities, their preferred modes of communication, and insights into the level of preparation they may prefer prior to their interviews. Interviews consisted of semi-
structured questions that focused on experiences of social relationships, community, and inclusion. There was a gap of at least one week between the interviews, which was intended to provide participants with an opportunity to reflect upon experiences and provide me with an opportunity to reflect upon and clarify information disclosed in the previous interview.

Participants with IDD were interviewed after their parents (except for the final participant who did not join the study with a family member). Participants with IDD were offered accommodations such as selecting font size for research questions, the optional use of visual supports, and being read interview questions aloud. All participants selected their own pseudonyms as well as those of family members who were referred to but not interviewed.

**Measures to Ensure Safety, Anonymity, and Confidentiality**

Following approval from the Institutional Review Board (IRB) at Eastern Michigan University for the protection of human subjects (see Appendix E), I began recruitment. Potential participants were provided with the consent agreement and consent form that informed them of their rights in the study and measures taken to protect their anonymity and confidentiality. Signed consent forms were kept in a locked filing cabinet in my home and were not accessible to anyone else. No other hard copies of documents containing identifying information were retained and all electronic files (such as emails) were kept on a password protected computer. All participants selected a pseudonym with which they would be identified on documents and within the dissertation and no identifying information was used. The names of organizations, towns, and friends were changed. I transcribed all of the audio recordings of the interviews and saved them in password protected documents. All participants were provided an opportunity to review their transcription and request portions be removed or changed. None of the participants chose to remove or modify the contents of the transcription upon review.
While there were no foreseeable risks to participating in the study, efforts were made to ensure that participants felt safe and comfortable by asking them to select sites for interviews that were familiar and comfortable to them. Further, due to the potential of distress of participants recollecting painful or distressing memories, Dr. Derrick Fries—my committee member with expertise in the areas of disability, education, and policy—agreed to be available for consultation if I was unable to provide adequate support for participants who became distraught or anxious as a result of sharing their memories during the interview process.

Data Analysis

The data analysis stage of this research began with transcribing the audio files of interviews. I chose to transcribe the interviews myself in part to stay immersed in the data, but also because some of the audio was difficult to make out and I was familiar enough with the speech of participants that I could understand the words being said even when they were not clearly articulated. This transcription took place during the data collection phase. After transcriptions were initially typed, they were compared with the recorded audio to ensure that missing or misspelled words were corrected and that intonation and expressions such as laughter were documented. Upon completion of the interview transcription, a brief profile was written up of each participant outlining my impressions of their prominent experiences, mannerisms, and relationships. This was followed by careful coding and thematic analysis to note emerging themes and recurrent phrases or references. The transcriptions were analyzed in conjunction with observational notes utilizing phenomenological coding and thematic analysis (Creswell, 2013; Glesne & Peshkin, 1992; Munhall, 2007). These themes were analyzed in relation to the personal experience of individual participants, situated within broader context of CDT, and examined in relation to disability policy and human rights.
Conclusion

This chapter presented the reasoning for the selection of qualitative methods in this research as well as the phenomenological approach that was used to construct the life histories and case studies of participants. Research considerations were detailed as well as methods of data collection, measures to ensure safety of participants, positionality, and data analysis. The following Chapters 4–6 present each of the three case studies: Hanna and Chinedu, Sarah and PMC, and Tracy.
Chapter 4: Hanna and Chinedu

This chapter examines the lives of Hanna and her son Chinedu. Hanna and her husband, Udo, live on a quiet cul-de-sac in the suburbs of a mid-sized city in southeast Michigan. Hanna is a warm and genial African American woman in her 60s. She is employed as a social worker with an organization that provides information and resources to families who have children with disabilities. Hanna has a daughter who is 32 named Nneka, who lives on the west coast and works as a doctor specializing in family medicine. Chinedu is her gracious and gregarious son. He is 30 and has autism. Chinedu spends his days attending a day program for adults with developmental disabilities and working on his video projects at home in his office.

Hanna

The way that people with autism don’t make eye contact, that’s the way I became!... I learned in public not to make eye contact with people, because it was punishing. You know, the judgmental looks and the stares or the snickers, or whatever. So I changed in a lot of ways. When you become a parent, you become a different person. As a parent of a child with a disability, I became protective of my heart, and my space, and my child.

Hanna was born in the 1950s to a large family in an urban area of southeast Michigan. She was the sixth of ten children, four girls and six boys. Hanna’s parents were part of the migration of African Americans coming from the south to find work in the automobile factories in the 1950s. Her mother was a homemaker and her father worked at one of the plants. Hanna’s memories of her childhood are filled with feelings of warmth and happiness. Hanna states, “It was a community. Everybody knew each other…. people felt safe, people felt connected. People felt happy. It was a great time.” She recalls their close-knit neighborhood, the empty lot they called The Patch beside their tiny house where all the neighborhood kids could play baseball and
Hanna has vivid memories of school, church, and spending time on drives with her family. She shares, “I can remember every season had a feeling, every season had a feeling and had different joyfulness associated with it.” While Hanna’s family was quite poor, she did not realize this until she was older. She remembers hot summer nights when all of the children would sleep on the floor of the living room while a single vacillating fan moved air over them, the doors of the house opened wide to allow cool air to enter. While she missed out on things like going to the movies, everyone in her family learned to play the piano and one additional instrument. They would also make the 12-hour drive to Arkansas every summer to visit and spend time with family while the auto plants were closed for retooling.

Hanna did well in school and graduated from a nearby university with a degree in elementary education. However, she soon decided that teaching was not for her and returned to school to get her master’s degree in social work. Hanna shares that most of her family took on employment or volunteer work that was in the service of their communities. Hanna chuckles when she notes that she seems to have passed this tendency to her daughter: “She does family medicine with the underserved, and she has some tough [cases]. I’m afraid I’ve afflicted her with my [passion].” After receiving her degree, Hanna took a job as a perinatal social worker at a hospital. Hanna describes her love for this work but also the emotional toll it took:

Doing perinatal social work, it can be very joyous. But is it emotionally heavy—it can be.

There are a lot of happy stories, you know, little tiny preemies that go on and make it.

Some babies would go on to live in the unit for months. Many of them would die. There were birth defects, what have you, and I put my heart into that.

Hanna continued to work after her marriage and the birth of her two children, Chinedu and Nneka, his older sister. However, she soon noticed that Chinedu was not meeting developmental
milestones. He would often not respond to his name and his parents became concerned that his hearing was impaired.

When Chinedu was around two years old, Hanna attended an infant mental health conference and sat in on a session in which a mother was describing her experiences with her child with autism. Hanna recalls realizing that the child’s behavior sounded very much like her son’s:

The sort of a restlessness, a hyperactivity, a not relating to us the way you would expect a toddler to—almost treating us more as objects, you know, taking your hand and taking you to something. Just a whole lot of what she was describing just nailed him. And at that moment I got the realization that he had autism.

Hanna was referred to a child psychologist, who conducted an evaluation of her son. Two weeks later she returned to the psychologist’s office to hear the results. Hanna relates what she was told: “At that time they called him PDD, they said he had pervasive developmental disorder. And they gave an IQ score.” Her voice lowers, “And they used the ‘R’ word. And that was devastating.” The psychologist spoke to Hanna about Chinedu’s future capabilities, telling her, “He won’t talk. If he doesn’t talk by the time he’s five, he’ll never talk.” He went on to explain that her son “couldn’t be educated. There’s no cure. It wouldn’t change. He could be trained.” He encouraged Hanna to enroll her son in his program on a university campus. As Udo had been unable to attend the consultation, Hanna drove home alone with her son, trying to come to terms with this overwhelming diagnosis. She shares:

I remember having to talk to myself, to sort of coach myself to drive. I was not aware of him in the back of the car kind of babbling and talking. It was all I could do to concentrate and keep my hands on the wheel and drive.
Terrified for the future of her child, Hanna struggled to reconcile this new perception of her son:

It was devastating, you know, it’s your child. And I don’t care who says they don’t, I think all parents, from the moment you find out you’re pregnant, you think, “Oh, is he or she going to look like this or that?” Or you wonder what talents they’re going to have. You imagine yourself playing some of the games you used to play. You do. You have dreams. You have hopes.

While Hanna does not blame the psychologist for his harsh depiction of her son’s future—accepting his interpretation as a product of prevailing beliefs of that time—his words left her without hope. All she knew about autism was that her son would be terribly impaired and never be able to live a normal life.

As a social worker, Hanna had worked with parents to come to terms with the “shattered dream”—the realization that one’s hopes and dreams for one’s child may never come to be. She reflects:

Nine years prior to my son’s diagnosis, I had worked with families who were living that shattered dream. You know the baby that’s premature, the baby with a birth defect, sometimes fatal…. But you know what? Had it not been for that job, I think that I would have crashed even worse. It prepared me.

Soon after her son’s diagnosis, Hanna began to struggle with anxiety under the double burden of her fears for her son’s future and the immense emotional toll of her work at the perinatal ward. She also grew distant from much of her family following some painful experiences witnessing the children of other family members:

It was hard for me to go to family gatherings. I have a large family with a ton of nieces and nephews…. it was—it hurt to see them reaching milestones. Reaching milestones and
doing things that he wasn’t…. So I kind of, you know, withdrew in the sense of I didn’t, I just didn’t go to family gatherings a lot.

A few months after the news of the diagnosis, Hanna moved to half-time at work following an emotional crisis while on the job. She relates a memory from that period, a night during her struggle with an increasing anxiety that left her feeling fearful, panicked, and weak:

I got up from the bed because I was crying and I didn’t want to disturb my husband. And I went to the spare bedroom. And I lay there and I just cried…. I felt like I was going to just fly apart in pieces. And I remember that I prayed and I asked God if he would just keep me from losing my mind. If he would spare my sanity, that I would work for families who had disabilities.

Hanna credits her faith, her husband, and her time with a therapist for helping her come to terms with the stress and anxiety of this period. She ended up quitting her job and began working at her current organization, an informational hub for parents of children with disabilities.

Chinedu initially received services at home. In addition to his autism diagnosis, he was also identified as having a mild hearing impairment and a seizure disorder. When he turned three, he was enrolled in a half-day preprimary impaired (PPI) program for four days a week.

Hanna becomes emotional and speaks through tears when she describes going to pick him up one day:

I went to go pick him up and his teacher came running out and she was just so excited. And I said, “What’s going on?” And she said, “He spelled Pluto!”… He had taken scrabble letters and spelled Pluto…. Oh my God! I knew he was in there…. I knew he was intelligent. I knew he was smart…. That’s our favorite memory. Because we had not taught him how to read. We had not taught him ABCs.
The realization that her son was capable of thinking and learning created a profound shift in the way in which Hanna perceived her child. She began to recognize how the heavy shroud of the diagnosis had impeded the ways in which she understood and related to Chinedu. She shares:

It is really from that point that I decided that I had to get to know him…. that I had to get to know him beyond that diagnosis. And outside of it, beyond it, behind it, however you want to—that I had to get to know him.

As Chinedu grew older, he became the first child with autism to be included in general education classrooms in his school district. Reflecting on her role in supporting her son’s education, Hanna states, “Some things did not happen the way I would like them to have, but overall I was a collaborative parent. I interacted with them, I worked with them. I believe I advocated for him the best that I could.” Hanna recalls that there were some wonderful educators in the district that truly included her son in the classroom while keeping their academic expectations high. However, other teachers were less willing to accept a student with a disability in their classrooms and were much less cooperative. Hanna remembers one music teacher in particular who refused to speak with her:

I wanted to talk with the music teacher. I just wanted to meet with the music teacher to… talk about her plan for the school year, you know what things are the kids going to be doing, so I could work with him at home and maybe one of his uncles could help him out. Long story short, she refused to meet with me. I never met with her. I kept calling her and calling her. She never answered. I left a note. And then I found out from one of the other teachers… that she had said, “She’s not gonna tell me how to run my classroom.”

When Chinedu was 11, his family moved to another school district where he attended middle school and high school with his typical peers. For the most part the new district was a
positive experience due to the efforts of Hanna and her husband to actively advocate for their son and some wonderful teachers who supported these goals. There were also disappointments. One day after Chinedu returned home from high school Hanna checked his backpack for homework. She recalls, “I found some coloring [sheets] in Chinedu’s backpack. And I just broke down crying. I did not expect that, that they were coloring…. This was some kiddie workbook page.” Disheartened by the constant struggle to secure a quality education for her son, Hanna found herself wondering if her expectations and aspirations were simply incompatible with the opportunities available to Chinedu:

I was always there, participating and negotiating with them on the goals and all of that. There got to be one point where I said, “You know what? He’s getting out of the house, he’s having some activities. It’s not costing me anything beyond my tax dollars and I’m getting a chance to be able to work. Maybe this is as good as it gets.”

However, there were also some wonderful experiences where Hanna was able to see Chinedu included and accepted among his peers. He enjoyed his drama and computer courses. He sang in the men’s glee club and delighted in giving performances with them. Hanna recalls, “That first show, when he sang in Latin I think, in a tuxedo…. It was just marvelous. We always felt good there. He was one of the guys singing! You know, just one of the dudes!”

In addition to his education in the public schools, Chinedu also spent time receiving speech, occupational, and music therapy outside of school. For a time he had a wonderful music therapist whom he appeared to really enjoy, but she married and moved away when Chinedu was 11 years old. Hanna began to seek out a new music therapist and was given a recommendation for one that worked with the son of a friend. Hanna describes her initial meeting with this
therapist at an autism society meeting that took place at her work and the cold response Hanna received upon meeting her:

I called her after several years of Chinedu not having music therapy and she was just so animated on the phone and we had a really good conversation…. but when I got up to the table and introduced myself, she just took one look at me and her face just fell. And the light went out of her eyes…. I don’t want to label that, I don’t know what was going on.

Hanna does not state that this hostile response was due to racism, though it does appear to be a factor in the music therapist’s reaction. Hanna did not return to another autism society meeting. This was not the only time that Hanna felt unwelcome and excluded by service providers. She also describes a time when she enrolled Chinedu in a combination speech/occupational therapy program. She received a phone call from the program when a new session was about to start telling her that they were full and enrollment was closed. Hanna maintains a pragmatic attitude towards these kind of rejections. She shares:

Those were disappointments but I had to develop an attitude, again out of my faith that whatever good God intends you to get, it will come to you and no one will stop it. No one can stop it. And so, about that music teacher, about that combo speech/occupational therapist, the music therapist, I was like, “If there was something in that, that was for Chinedu, he would have gotten that and nothing would have been able to stop it.”… I believe that. If you look at it with not as strong of a spiritual veneer, it is: if it was that they didn’t want to work with my son, would I want to work with them? Would I want to try?

After Chinedu aged out of educational services Hanna enrolled him in a nearby adult program. While he initially appeared to enjoy himself, he began to come home agitated,
sometimes in tears. He told Hanna that a staff member was yelling at him. She suspected that her son’s money was being stolen. She found that a report had been submitted by her son’s case coordinator regarding verbal abuse. However, the final straw was when she received a call from one of the staff members who had been filming a play that the program’s participants were putting on as part of a movie he was planning to make about them. He wanted her to sign a waiver after the fact. Hanna was furious that her son was being filmed without consent and called the director of the program who, at first, denied this was occurring and then denied there was an issue with it. Hanna pulled Chinedu from the program after having her lawyer put out an order to stop distribution of the film. She is grateful he is now in a program that respects him and that he enjoys. While there are certainly aspects that she would like to see improved, such as communication with parents regarding the activities, planning, and choices made available to clients, as well as more evidence of skill building, Hanna feels this is the best they can expect within their current circumstances.

As an adult, the severity and frequency of Chinedu’s seizures has decreased and he has become increasingly independent, but Hanna still worries about him injuring himself if he has one when he is alone:

I’m loath to say, go upstairs and take a nap and leave him down here on the floor alone. He has fallen before. So that vigilance, you know for his physical, mental, emotional health, yes, it has eased. It has eased. But…

Hanna works to stay physically active and fit for her own well-being but also to keep in good health so that she can be there for her son. She reflects, “I try to stay healthy for myself, but also for him…. This may well be the last house that I’ll live in. Which is fine with me. I’m trying to stay in shape so I can do the stairs.”
Hanna describes Chinedu’s father, Udo, as a warm and supportive presence in their lives. He accompanied Hanna to individualized education plan (IEP) meetings when he could get the time off work. Hanna shares that when Chinedu was younger she was the one who dealt with his more challenging behaviors while Chinedu rarely misbehaved when he was with Udo. Chinedu’s sister, Nneka, no longer lives in the home and is practicing medicine on the west coast. Hanna does not discuss Chinedu and Nneka’s relationship, but she does share a story about them when they were younger and Nneka was watching a Baby Huey cartoon:

He had an over-affective kind of, “dumb” voice…. And she was playing it, ‘cause she, you know, it’s a little dumb cartoon and she liked it. So she was playing it and Chinedu kind of got defensive. Got upset about it…. His sister noticed it also…. And yeah, he did, he got defensive over Baby Huey. And that’s the closest that I’ve come to him perceiving that he might be perceived differently by some people. That’s how I took it.

Hanna has never spoken to Chinedu about his disability or self-disclosure. She cherishes his high self-esteem and worries about the ways in which he would interpret and internalize the meanings associated with the label of autism. Hanna explains the difficulties with navigating this choice:

I’m loath to use that term because one, would he understand it? And two, I think he has good self-concept…. and I don’t want him to feel poorly about himself…. I don’t know a way to describe those terms to him that would not end up maybe hurting him and making him feel less. So then it’s like, why do I have to do that?

Hanna has made peace with the challenges her family has and will face. She is no longer tormented by intense anxiety, and while she maintains hopes for her family’s continued stability and well-being, she is content with the present for now.
Community experiences. When asked about her community, Hanna shares that her family does not really have one. While she has reconnected with her family, her siblings are now spread across the country. Her father died a couple of years ago, and her mother is now staying in a nursing home. Hanna used to go to her mother’s house every Sunday to relieve the attendants caring for her. She now makes a trip to the nursing home on Sundays to spend the day with her mother and help her to Skype with her siblings. While she knows her neighbors in nearby houses, she is not familiar with the families beyond them. Her family primarily spends their free time at home rather than going out, and Hanna refers to herself and her husband as homebodies. This is in part due the busy schedules that the three of them juggle, but it is also in part because of negative experiences Hanna’s family has had in the past.

When Chinedu was young people were often judgmental and angry about his behavior in public. He could become fixated on certain objects and refuse to leave them or see something he wanted and throw a tantrum. Hanna explains:

You go out and you have a child that’s not acting like other children, doing those things I said, not using words but loud vocalizations, zipping here and there, pulling you by the hand. When he was a little guy… I had to be on my toes, ‘cause you know, you had to go running after him. Not only to keep him safe, but from going places he wasn’t supposed to go…. like he might go in a store and might want to go behind a counter…. He might see something and just have a meltdown ‘cause he wants it…. You know people shoot daggers at you… “What’s the matter with her?” They stare.

Hanna ticks off the negative encounters that have stuck with her the most. She recalls going to an art fair and a vendor shouting at her son when he touched a woven basket. She talks about going to a clothing store and having a clerk yell at her son and demand he leave after he touched
a mirror. Another time they were walking at the recreation center and man shouted at Chinedu for looking at him. Once Chinedu approached a food stall and the two young men behind the counter burst into laughter when he spoke to make his order. Perhaps one of the most troubling events was when she and Chinedu, when he was a young man, went to see a Disney film (an activity Hanna loved to share with Chinedu after being unable to see them as a child) at a local movie theater. Chinedu was delighted by the film, laughing and enjoying himself. However, Hanna realized that an usher had come to stand beside their seats at the back of the room. The next time Chinedu laughed, the usher told her that they would have to leave if her son didn’t settle down. Hanna was livid. She describes her reaction:

I told him off real good and loud. You know, “Pardon me, I’m sorry that my child doesn’t laugh like your perfect children or whatever.” It was so out of place! It was a movie!... I don’t know if someone just decided his laugh sounded different. Or heard him maybe make a sound that other people don’t make and so they decided, he needs vigilance. He needs to be surveilled. That is absolutely not welcoming.

Hanna learned to keep her head down and ignore the people around her while trying to manage her son’s behavior. Now that he is an adult, Chinedu no longer runs around or has meltdowns in public and is in many ways indistinguishable from the people around him. However, Hanna still worries about his challenges with language and his vulnerability to being perceived as a threat as a tall African American male. She shares, “My concern also is, his behavior is more normal than it was, but… I don’t want him to encounter someone who doesn’t understand the way he presents himself and become threatened or frightened for whatever reason.” Hanna has also been working to reconcile her need to protect and nurture her son as a mother with her commitment to recognizing and valuing Chinedu’s autonomy and personhood:
It’s a balancing act. And it’s not over. You know, when we’re with him in public we try to be respectful and talk to him as an adult and what have you. And kind of keep an eye on him to make sure that somebody isn’t going to pick up on that innocence that his IDD can present, to exploit him. So we accept that that’s a challenge.

Most of Hanna’s social relationships are with her coworkers. As one of the requirements for the job is that one must have a family member with a disability, many of them can relate to her struggles and join her in celebrating successes. While many parents at her organization are pushing their children to move out and find independence, Hanna is happy to have her son stay at home for as long as she and her husband can care for him. This has made her feel like a bit of an outcast at work, but it is integral to her faith as a practicing Muslim that she cares for family. While she would support Chinedu’s decision if he expressed any desire to live independently, Hanna take comfort in being able to make sure his needs are met and his personhood is respected at home.

During the final interview, Hanna discusses her realization that she may have a role in what she perceives as a lack of community. She shares her recognition of the ways in which negative experiences in the past have framed her outlook and decisions in the present:

I’ve been thinking a lot about the concept of community since doing this and I tend to just think of the neighborhood. And, you know because we’re such homebodies, we go to work and then we come home. You know, he goes to his program and he comes home, and he goes to the rec center. I go to the nursing home on Sunday. Maybe people are better and know more about disabilities that I think?... I purposely chose to narrow my contact with my neighbors because I didn’t want to encounter any misunderstandings and unpleasant situations like those I described…. Yeah. I think I cut that off. I cut off any
chance of positive and negative interactions…. I haven’t given people a chance to be welcoming in that sense and I own that…. Maybe people have gotten better? You know? Retiring the R-word… I don’t know. Or it could be that we’ve pretty much now… got a routine down and have accepted the dimensions of our world and we’re happy living in it.

Concluding thoughts. Hanna is proud of her son and the man he has become. While she has in many ways become resigned to the limited opportunities that are available for him to display his strengths and be valued, she maintains aspirations for his future. Hanna explains:

I think he feels good about himself. And I want him to always feel that way. I thank God that he’s able to grow up in a safe environment, inside the home and outside the home, and within the family. He’s had those few little ugly things that happen, but they probably happen to all of us for some reason or another. Nothing scarring. I want that to continue. I want him to discover things within himself that he wants to explore. If that pleases him.

Hanna goes on to state:

I want his ability to be introspective and to find things within himself to grow, and I want him to feel that he can and he should explore those. And I want him to know he can always ask for help if he needs it, to explore those. If he were to decide that he wants to live with a roommate or something, or friend, that’s open to him. And I want him to feel free to say that.

Hanna and Udo are committed to supporting these opportunities for their son for as long as they are able to do so. When asked if there is anything she wished people knew about Chinedu, Hanna responds:
How persistent and intense he is … passionate, dedicated, serious. I remember when he was, he might have been nine or so, and his dad said, “Okay, you can go back and play on the computer.” “This is work.” [laughs] And you know… it’s his work. He loves it. How compassionate he is. You know they say that people with autism… that they’re emotionally dead or blank or what have you. No, that’s not the case. He’s concerned about others.

Hanna describes Chinedu’s passion for his projects and for teaching himself to use video editing software. Hanna shares, “I’d like them to know that he is intelligent. I mean he’s learned all those [video editing] programs himself and whatever it takes to do what he does, that’s a special intelligence.” Hanna also wants people to know that her son has value outside of economic interpretations of personhood: “What he does has value without a paycheck coming. ‘Cause I know really that’s our goal in this society.” In reference to developmental disabilities in particular, Hanna states, “I wish they knew that that doesn’t make the person not human. Not a person with emotions. That is still a person with dreams. Still a person deserving of respect and attention. Not to be pitied.”

**Chinedu**

I was thinking a lot like favorite characters, and there’s, there’s Micky and Minnie, Donald and Daisy Duck, like the two dogs, like Goofy and Pluto. Or the two courageous chipmunks, Chip and Dale. And Donald’s nephews are Huey, Dewey, and Luey are my newest inventions.

Chinedu is 30 years old, tall with a medium build and a gracious manner. He bows as he opens the door to welcome me into their home. Chinedu has an encyclopedic knowledge of Disney films and older animations. He grew up attending inclusive classrooms in school and
refers to his “learning adventures” throughout his descriptions of his education. Chinedu says he had many friends in school and shares his memories of twin brothers who were in his elementary school:

At Eastern Elementary School there’s Ben Jones and also Alan Jones, are the two Jones boys…. they’re two classmates. Teaching math and science!... They are learning. The part of learning adventures, just like my learning adventures…. I was playing with the Jones boys at recess.

Chinedu describes how he enjoyed playing in water and watching the Disney channel when he was a child. He also shares that he remembers playing with his sister, Nneka, in kindergarten and that he would play songs with her on a digital keyboard. When asked to recall a memory from his childhood when he had fun, Chinedu talks about going to visit someone’s house for what sounds like a party: “Going to Mrs. Mary’s house to visit…. With my friends…. To watch a Sesame Street Video, having water fun, and having a lunch!... Just a visit and a party time!”

Asked what he remembers of his teachers at high school, Chinedu describes one of them: “Mrs. Walker…. A real teacher…. Teaches, teaches about studying.” He goes on to talk about another teacher he enjoyed: “Other teachers like Lauren’s the teacher…. Lauren is the teacher in the world…. Math, science, and…and…and…and other ones like drawing. On the chalk board.”

Transitioning from our talk of the past, Chinedu changes the subject to one of his favorite topics, the short music videos he creates: “And in the future I was making the clips of the DTV music videos on it. And from youtube.com I was making it…. I was making from the audio CDs. There’s Capital Classics, Motown Classics, Disneyland Records, Atlantic, and other stuff like RCA Records.”
Chinedu spends his mornings attending a disability workshop group that advertises itself as an organization promoting vocational services and community integration skills training for adults with developmental disabilities. They pick him up at his home every weekday, and he spends time with other adults in the program and the staff doing recreational activities, workshop programming, and visiting places in the community. He is particularly fond of bowling, and his mother notes that he is quite good at it. Chinedu appears to enjoy going to his group and gets himself ready every morning to stand by the window and wait for the van to come pick him up.

Chinedu has a ready smile and a habit of dropping his chin down and looking up over his glasses when he listens. While he often employs echolalia (repeating words he has previously heard from people and films) in his language, Chinedu’s speech is formal and very expressive. His deep baritone carries the expressive range of a radio announcer, and it can at times be difficult to distinguish between his own statements and those recited from movies. Chinedu can struggle with receptive language and understanding what is being asked of him. While his nonverbal body language and facial expressions are animated and convey a great deal about how he is feeling and what he is thinking, he can have difficulty articulating himself through speech, especially when he is speaking about something new. Pronouns can also be difficult for him to assign correctly. Familiar phrases tend to flow easily, but when he is talking about something outside the range of his normal routine, his speech becomes more halting and hesitant. He may answer in single words or a brief sentence. When asked questions, he will sometimes hesitate with a small smile on his face as if confused and unsure how to answer; though if the question is reframed as a yes or no question, he answers readily.

Chinedu describes his typical day through collaborative story telling:
Chloe (the researcher): We could tell a story together. Let’s see, there once was a young man named…

Chinedu: Me.

Chloe: You? Chinedu. So there once was a young man named Chinedu and one day he decided to go to the…

Chinedu: Program.

Chloe: Program. So he got up in the morning and he got ready…

Chinedu: And I was brushing my teeth and was eating breakfast, when I was waiting in here and Alma picked me up in the morning, and they drove the van to the program.

Chloe: And you got to the program. And Chinedu waved hi to his friends. Did he say hi to the staff too?

Chinedu: Yes. Or hola to the staff and also their friends. And this morning. And they were having a good time and then they drove over to the—traveled to the community!

And after the community it was lunch time at 11:30.

Chloe: At 11:30 Chinedu decided to have lunch and for lunch he had some…

Chinedu: It was a sandwich.

Chloe: He had a sandwich.

Chinedu: And other foods. Like also fruits, like grapes and cherries. And all the food I ate. And after lunch, and I went to the park and this afternoon. And after park… and I was waiting to 2:30 to go home. Like Alma picks me up at 2:30…. But 3:30 I went home.

Chloe: Hmm. Nice. What about, what if in the story Chinedu goes bowling? Does he like to go bowling in the story?

Chinedu: [shakes head]
Chloe: No? Chinedu doesn’t like bowling? Or is it because it didn’t happen today?

Chinedu: It didn’t happen. It was happen at ACS [Adult Community Services].

When Chinedu arrives home in the afternoons, he goes to his office where he has a computer of his own to work on. The room holds shelves filled with DVDs and VHS tapes. This media is primarily focused on Disney and other forms of animation. They are arranged by theme, such as fall, Christmas, and fairytales. His mother tells me they have another room at the back of the house that is also filled with movies. Chinedu loves music and often hums and whistles along. He has boxes of music CDs that sit near his desk. Chinedu spends a lot of time watching YouTube videos at his computer when he is home. He wears headphones when he listens rather than using speakers. Chinedu works on projects he has designed when he is at home. These are compilations of music videos he creates using his favorite songs and animation clips from YouTube on a video editing program. He uses a computer with ease and has taught himself to use complex editing programs. When asked about how he learned to use these programs, Chinedu responds:

Chinedu: Learning adventures.

Chloe: Lots of learning adventures? What did you do to learn the computer? Did you read books or take classes? Or did you just figure it out?

Chinedu: Figure it out. Like thinking [points to temple], like using my thinking cap.

Chloe: So you would sit with Corel and figure it out?

Chinedu: Corel DVD Movie Factory is a new application.

Chloe: Do you know how to use that or are you still learning it now?

Chinedu: Learning.
Chinedu has created an immense library of animation clips. He painstakingly organizes the animation of the video clips to mesh perfectly with the musical arrangement and theme. They appear to approach professional quality in terms of the polished editing and audio/visual sync. Chinedu calls the music videos his “inventions,” which he burns onto DVDs. He has completed three volumes of these compilations and is currently working on the fourth. Chinedu’s passion for Disney films, as well as his musical aptitude, is shared by many members of his extended family.

Chinedu often communicates through references to animated films. It can be difficult to understand what he is trying to express if one is not familiar with the movies he describes. He also seems to enjoy listing names and descriptions of cartoons. While he sometimes stops to briefly answer questions about these animations, Chinedu will quickly return to his monologue:

Chinedu: And in this movie, this movie, the dwarves wants to rescue Snow White. But the dwarves was too late. The wicked queen tricked her and eating by a poison apple. And Snow White was falling fast asleep. And Snow White didn’t wake up for one hundred years!

Chloe: A hundred years? That’s a long time.

Chinedu: Yep, for one hundred years. The witch runs away and the dwarves get the witch!

Chloe: What happens then?

Chinedu: In the Sword in the Stone, they having a wizard’s duel. Like they change into all different animals. There all kinds of the wizard’s duel. Like a mice, the elephant, the crocodile! The tortoise, and other blue and pink animals.
When Chinedu shares his yearbooks from school, he points out his own picture as well as his friends and sister who was two grades ahead. One of his teachers worked with him to make an “A-Z, All About Me” book that is filled with pictures of family members, vacation trips, hobbies, and favorite foods. He is particularly excited to show his picture from the men’s glee club in his high school year book which he participated in for all of high school. Chinedu shows me the pictures and points himself out: “So that was me, I was wearing [a] black and white tuxedo.” Chinedu becomes animated as he describes how his glee club would sing on stage and his family came to watch:

I was singing at the choir on stage. And I was wearing a tuxedo!... songs is on the camera, because my father recorded a camera. ‘cause I just remembered, my father recorded on video to see me on stage…. I was singing on stage all through the years.

Chinedu also shares a picture from Special Olympics and his class photos, listing the full names of everyone he remembers. He also appears to have fond memories of his post-high school years attending a program at a local community college. Chinedu says he made friends there: “The friends is at Madison Community College…. I went to Madison Community College with my pals. There’s Annie, Seth Carter, Alan Morgan… and other friends!” When asked how he has changed since he was a child, Chinedu refers to the wall where a series of short horizontal lines and dates mark his growth in pencil over the years. He states:

Chinedu: When I was growing up into more years old. Look [points to pencil marks on wall showing growing height over time]. It was more than an inch. [moves to stand by wall]

Chloe: Oh yeah, I can see.

Chinedu: I was growing up.
Chloe: Getting taller and taller. And you marked where—every time you grew on the wall.

Chinedu: I was growing on the wall. After young adult, I’m not a teenager anymore. It all started when I was a teenager [marks on wall begin at approximately five feet high] and I was going to school. After a teenager I was an adult.

Chinedu works on his computer when he gets home from his day program. While sitting at his computer, Chinedu appears thoughtful and deliberate, carefully selecting and sorting video clips and images. His hand often roams across his face and scratches at the stubble on his cheeks. He punches in shortcut commands on his keyboard without looking away from the screen. He plays one of his favorite animated shows, Octonauts, while wearing his headphones. He recites the lines of the characters out loud when I tell him I cannot hear them. He has memorized the episode, and his words lip sync with the characters perfectly:

And the bagel went upside down. Soon they came by and saw something was gone! He said, “He went thataway.” [lowers voice] Sounds like vegimal talk. And the whole Octopod, they played table tennis [pause] and it bang on his head. “Urgh! Come and fight!” Bang, they broke the table tennis. You’re not—bang! Thataway! That’s a shrimp. Mantis shrimp wants to fight…they pull the vegimal out of here. They falling down…they heading closer and closer to the HQ… “Come on and fight!” They pulling the Octo-alert, like Mantis shrimp.

Chinedu’s passion and knowledge of animated movies and television shows provides him with a rich dialogue to express his ideas and opinions. However, this can result in misunderstandings and miscommunications for those unfamiliar with the background and references from which his vocabulary draws. Fortunately, his facial expressions and body language clearly communicate
when he is feeling confused, frustrated, happy, or upset. While this does not always clarify miscommunication, it does highlight when Chinedu does not understand what is being asked of him:

Chloe: Do you have neighbors here?
Chinedu: I have a few neighbors, like Mom, Dad, me and my sister.

Chloe: What about in the houses around here? Do you know any of the people around?
Chinedu: There are the neighbors in this houses.

Chloe: Uh huh. Do you know their names or do you just know that they’re your neighbors?
Chinedu: They’re our neighbors.

Chloe: Do you ever get to walk around outside?
Chinedu: I walk around outside.

[does not appear to be terribly pleased with my questions]
Chloe: What kinds of things do you look at when you walk around?
Chinedu: Like stores.

Chloe: Around here? Or when you walk in town?
Chinedu: In town! [His expression indicates that I have just asked a ridiculous question]

Chloe: Which town do you walk in?
Chinedu: Downtown.

When asked how he would like to be described, Chinedu responds, “I am 30 years old.” He continues when pressed:

Chloe: Do you want me to say anything else, like he’s good at using the computer, he’s nice, he’s funny?
Chinedu: I am nice.

Chloe: Okay.

Chinedu: Just like positive words.

Chloe: Yeah. What kinds of positive words should I use when I talk about you?

Chinedu: Nice to meet you.

Chloe: I’ll say it was nice to meet you?

Chinedu: Yes.

Chloe: And that you’re thirty. And that you’re nice.

Chinedu: And thirty.

When I speak to Chinedu, I find him to be polite and considerate. While he at times struggles to understand the people around him, he uses a variety of strategies to communicate and clarify the meanings of others. His mother shows me a couple of visual dictionaries in the dining room that offer concrete definitions of abstract words such as community and friendship, along with visuals to represent these terms in the human experience. Chinedu uses these books to clarify terms that he does not understand. His mother tells me about a time when they had a disagreement over something and Chinedu went to get the dictionary to clarify how their interpretations of a word differed.

Chinedu plays one of his “inventions” on the large television in the living room. Once the music starts, he immediately becomes more animated, moving with the music. He sings along, perfectly in tune. As the song goes on, he begins to sing counterpoint, weaving his words along with the music:

Drying and clean, at the beach, sailing, splash all over the place! They can’t be beat [spoken lyrics] and so mermaids too! Anyone see the water lions? Fishes underwater!
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BRRRR! It’s cold! All day, every day [spoken lyrics], they’re surfing all over the place!

And splash! [spoken lyric] They’re spinning with Mickie! And smile on his face!

[laughs]…. You’re soaked! Goofy is soaked! They’re wet! Now that’s the best part!

[Song ends] That’s enough. That’s one song.

Once the song ends, Chinedu removes the DVD and puts it safely back in the container. He bows to my applause.

Conclusion

When Hanna and Chinedu are together in the same room, they almost appear to move and interact in a kind of coordinated tandem. They seem to have developed a comfortable language beyond spoken words, and I cannot always keep up with these nonverbal exchanges. Hanna has warm memories of a safe and happy childhood, an experience that she strove to recreate and share with her two children. Chinedu’s diagnosis of ASD and the bleak prognosis by his doctor appeared to have cast this aspiration into doubt until Hanna heard that Chinedu had spelled Pluto, and she realized he was more than his assigned label. This proved to be a pivotal moment in Hanna’s relationship with Chinedu and her understanding of the ways in which he perceives and relates to the surrounding world.

In Hanna and Chinedu’s shared experiences of social rejection and hostile interactions in the community, it is not clear how Chinedu perceives these encounters. He does not appear to feel left out or isolated from his community, and Hanna works hard to maintain this perception. Hanna did her best to shield Chinedu as a child and perhaps continues these efforts to some extent today in the family’s relative isolation. It can be difficult to reach out and risk rejection, especially without knowing exactly what kind of community one is reaching out to and how it may impact one’s child. It is unclear if or to what extent Chinedu recognizes his disability and
the ways in which others perceive him; although given his response to the Baby Huey cartoon, he relates on some level to that representation of disability. Hanna is unsure of how to discuss ASD and disability in a way that Chinedu would understand and that would not damage how he feels about himself. She is placed in the difficult position of not wanting to risk Chinedu misunderstanding what it means to have ASD or having him see himself as deficient or broken while potentially leaving Chinedu to draw his own conclusions about the differences between himself and those around him.
Chapter 5: Sarah and PMC

This chapter focuses on the lives of Sarah and PMC (Pizza Mac & Cheese). Sarah lives with her husband Ben and their four children on the western outskirts of a mid-sized city in southeast Michigan. Sarah is a calm and confident Caucasian woman in her 50s. She spends her days working at her husband’s accounting firm and teaching online graduate courses for a state university. They have four sons, two of whom were adopted from Russia as infants. PMC is their second youngest son and is adopted. He is a determined young man with a very dry sense of humor. PMC is 21 years old and has TBI-related developmental disabilities. He is also a musician, a student at a local community college, and a part-time worker at a restaurant.

Sarah

I had complete and total confidence in my children. I also knew that they were going to move at their own pace. They heard me say it, I don’t know, possibly a million times growing up: “Life is not a race, we’ll get there when we get there. It doesn’t matter what anybody else is doing.” My children firmly believe that. They’re moving at their own pace. All of them.

Sarah grew up in a large urban area in Illinois, the eldest daughter of two working class Jewish parents. She smiles as she describes her parents: “My parents were very protective. You know, I was the first child, I was a girl…. I came home from college and I still had a curfew. So I was a city girl.” Sarah’s family moved around a great deal, and Sarah has vivid memories from her childhood of living in different parts of the city as her family moved from neighborhood to neighborhood. She wistfully recalls the small green lawn situated between her apartment building and another apartment building, fenced off and inaccessible to the children who lived there.
Sarah describes herself as an endlessly curious child who read voraciously and yearned for adventure; however, she often struggled to fit in with those around her. She believes this was due in part to her family’s frequent relocations. Sarah shares:

There was one point in my life where I was in a different school every year for seven years—you know, between elementary and middle, and high school. It just ended up being—I remember counting, seven years, seven schools.

Despite her diminished opportunities to maintain long-term friendships, Sarah was a social child who actively sought out connections with those around her. She made friends with the children in her neighborhood and at school. However, after Sarah started middle school, she became unable to shake the feeling that she did not quite belong. She recalls one day approaching her mother to confide this feeling:

I remember coming to her and telling her I didn’t fit in and I was very unhappy…. she basically told me, “Yes, you will fit in. Of course you’ll fit in. Make sure you fit in.” But that wasn’t who I was. And I don’t know why I knew that and I don’t know why I didn’t try to fit in. But I haven’t fit in since middle school. I just hadn’t fit anybody’s mold. It’s not like I’m not friendly and it’s not that I can’t have conversations or connect with people. I don’t know, I just haven’t fit.

Sarah also had asthma when she was young and was often ill. She shares that she was absent for two-thirds of her first grade school year due to illness and also missed part of her fifth grade year after being diagnosed with mono. She spent a great deal of her time reading and visiting the public library. Her favorite books were science fiction, but she also loved Anne of Green Gables and the Narnia series. Sarah relished the sense of adventure and exploration that books provided. She reflects, “I have a very curious mind. And I read really, really fast…. I’m always thinking
about new ideas and I just want things to think about. So that’s where I got ideas.” The library
also became a sanctuary of sorts in the face of social isolation:

When I was in eighth grade and I had no friends because the girls were all being mean to
me, I read the entire library…. I started with the As and moved all the way through. I
read every single book.

Sarah met her husband, Ben, while attending the same college in Michigan. She
graduated with a degree in education and after graduation they went on a bike tour across
Europe. They moved out to Los Angles, California, before embarking on another bike trip across
the United States in search of a place to settle down and raise a family. One morning they
realized they wanted to return to Michigan and moved into a house in a town near where they
had gone to college. In the early 1990s, Sarah gave birth to her first son. He was born 10 week
early. She describes:

Daniel was three pounds, six ounces when he was born…. He was in the hospital for
eight weeks. So all developmental milestones were off. He was nine pounds at nine
months because he had sleep apnea and they had to give him medicine and so he couldn’t
gain weight. And when they finally took him off that medicine at nine months, between
nine and twelve months he gained ten pounds.

Sarah’s second son was also premature, and she worked hard to research how she could help
them both with their developmental delays.

A couple years later, Sarah and Ben decided to adopt a child. They contacted an adoption
agency in Russia and were sent video clips of infants in their cribs that were each about a minute
and a half long. Sarah describes this experience as initially disturbing and intimidating:
We were sent a video with 10 babies on it. “Which one you want? How many would you like? Who are you interested in?” That’s how it worked. The first time they sent me a video, I felt like I was playing God and I thought, “I can’t do this.” Sarah eventually came to terms with the power she had been given to so profoundly change the life of one of these children. She decided, “My hands will be guided, my heart will be guided…. families are built in many ways, and clearly this is how my family’s going to be made.”

As soon as Sarah saw the video of PMC, she was certain that he was the one. Sarah describes:

He was in a crib, on his side, you know like propped up on his elbow…. so they had a videographer at the orphanage and a photographer. And he was taken by the camera—something about that camera—and he got up—you know pulled himself up because he couldn’t really stand very well. And he’s grabbing for that camera, he was so interested!

And his face was so alert. I said, “I want that one.” It was really clear. It was totally clear.

Sarah and Ben adopted PMC and another child, Ethan—though she does not explain what motivated them to adopted him as well—and flew home with these two infants who were less than a year old. However, it quickly became clear that PMC struggled with sensory issues as well as language and coordination: “PMC was not acting normal in any way, shape, or form…. It was very hard for him to be held, to be touched, to be looked at.” Sarah immediately set about trying to identify his condition and to secure services to support her son. She recalls:

Conventional medicine told me, “Well, he doesn’t have a tumor on his brain, we can’t do anything else for him.” I was like, “A tumor?” I didn’t even know that was an option. So conventional medicine couldn’t do anything for him. I mean, I knew something wasn’t right but I didn’t know what it was. And I started reading and that’s when I figured out,
“Oh, PMC has a closed head injury. He has all the symptoms of this.” And I talked to the
doctor, and the doctor said, “Oh, yeah. That’s what it sounds like.”

All of Sarah’s children face challenges with disability to some extent. She notes that her two
oldest sons, Daniel and Gavin, have learning disabilities, and while her youngest son, Ethan, is
one of the smartest people she’s ever known, he was unable to cope with school and dropped out.
Sarah states, “I have four special needs children…. they all have different learning issues.”

After PMC was identified as having a closed head injury, Sarah was frustrated to find
very few options available for treatment in conventional medicine. She began to seek out any
potential alternative treatment or therapy that might be able to help her son. She describes:

Within the first year of his life or something, he had been to so much therapy already…. He’s had biofeedback, he’s had integrative eye therapy…. He’s had cranial—he had cranial for years and years…. He had physical therapy, he had occupational therapy…. He had this other kind of occupational therapy that had to do with bouncing a ball and clapping with rhythm.

Sarah soon realized that some of these therapies could be helpful for her other sons as well and
began the challenging process of juggling and coordinating multiple appointments for her
children in addition to therapy work at home where Sarah would pair memory, speech, and
coordination activities with games:

We played crawling games, and rolling games and clapping games. Everything to try to
get the connections across the brain. And we would do eye exercises and every—I mean, it was three or four hours every single day. And the idea was that it had to be fun.”
Sarah scoured her library and the limited resources on the internet in search of potential therapies they could try. She spoke to anyone she could find about treatments that could potentially be helpful for their children. She was willing to try anything:

It was word of mouth. I would listen to people talk. When I would be in the waiting room of one place I would talk to the mom sitting there with their children and they would talk about other [treatments]…. It was completely hit or miss. There is no coordinated system for alternative healthcare. But, if it was out there, I considered it. If I heard of it, I considered it.

Sarah also relied on her own intuition when considering courses of treatment. She describes:

It’s not like I’m a religious person, but I am a spiritual person and I do believe that I have been given help in this path. I would just kind of focus on something and try to decide if it was a good thing to attempt. You know, is this going to help? Before I would act, I would just kind of sit with the idea for a while and try to see if I could get a message. And a lot of times I did. And so we would try it, and when it would stop working, we would stop.

When PMC was four, one of his eyes stopped moving in tandem with the other and visual perception became difficult. To this day his left eye faces forward, but his other eye points off to his right. Sarah notes, “He would tell you that he had two images. Like a deer. He could hold these two images in his head.” Sarah recalls the difficulty in working with him to learn numbers: “He wouldn’t have number constancy, so if you put five items down, this eye moved, then this eye moved—so how many were there? I mean he couldn’t tell. That was a nightmare.” His visual problems also made it difficult for PMC to learn to read.
Sarah homeschooled her children through much of their elementary years in addition to taking them to multiple therapy sessions throughout the week. They joined homeschooling co-ops, sports teams, cub scouts, and took music classes. PMC was talented in music and soon taught himself to play the drums and guitar, and he also learned to play the piano. When her sons got older, they decided they wanted to attend schools. For a time Sarah had to contend with managing the therapy and academic schedules of four boys, which left her with little opportunity to volunteer with and participate in school community activities. Sarah also began working again during this period, first as an assistant principal at a local Jewish school and later at her husband’s accounting firm.

When PMC decided he wanted to go to middle school, Sarah found a school with a reputation for their relaxed and welcoming approach to students with disabilities. Unfortunately, the transition to school was difficult, and Sarah struggled to advocate for her son in the face of low expectations. Sarah recalls when PMC was evaluated by the school psychologist:

He took all those tests, including the IQ test, and he tested very poorly because learning disabled people do not test well. It’s not valid for people with learning disabilities. But I will tell you that the people at the Madison schools do not believe that, they do not teach that to their support people. So, I mean, he got like a 70 IQ or something. And I said to the middle school person, I said, “Come on now. My son is obviously not a vegetable. Seventy would indicate a vegetative state. You’ve talked to him. He’s mobile. He’s—this is obviously incorrect.”

Sarah also had issues with the school teaching consultant (TC) providing supplemental support for PMC while in school. She shares, “The TC at the middle school was just horrible. Just horrible. She wasn’t mean or anything, but she had such low expectations for PMC.”
In addition to these challenges, PMC was bullied by the other children in school, and often by the daughter of one of the teachers, who would bite him. When bullied, PMC would lose his temper and get disciplined for his response, rather than the bullies. Sarah was often called to the school after incidents such as these, where she would confront the administration about their failure to keep her son safe. Despite their assurances that the issue was being handled, the bullying continued. One day, PMC lost his temper and punched someone in the face. Sarah was called to the school once more, this time facing threats of her son’s expulsion:

I said, “Damn straight he hit them.” I said, “What’s been going on for the last however many weeks?” I said, “What did you do to prevent this situation so my son didn’t get this upset?” I said, “Don’t you dare tell me he doesn’t belong in this school and that that behavior—that retaliation wasn’t acceptable.”

PMC managed to finish middle school and won a lottery spot in a local alternative high school with an excellent reputation as a caring community with good student support services. Sarah was relieved to see her son thrive in this space, and many of PMC’s teachers were wonderful and supportive. However, Sarah and PMC continued to contend with the lowered expectations she perceived on the part of many staff. She recalls meeting with his IEP team to argue for her son’s right to get a diploma rather than a certificate of completion:

They wanted to put him on the certificate track with the children who are nonverbal and non-mobile…. It’s nothing. It’s a worthless degree. But it’s essentially for those young people who need babysitting…. I remember saying to them, you know, I said, “My son will have a diploma, whether you give it to him or whether I pull him out of school and do it myself. He is well smart enough to earn a diploma.”
PMC did graduate with his high school diploma and now attends a local community college. Sarah is relieved that her son as grown to become a strong self-advocate who is comfortable asking for help and knowledgeable about his rights as a student with a disability.

Sarah’s experiences of exclusion as a child appear to have deeply influenced her commitment to protecting and fiercely advocating for her children. Recalling the isolation of a young man with IDD in her high school, Sarah asserts, “Nobody should be alone. Everybody should have a friend.” Sarah worked hard to make sure that her four sons could rely on the family and each other. Her protective nature appears to have rubbed off on her two oldest sons—especially Daniel who is very close to and protective of PMC. Sarah recognizes the role that disability plays in the lives of each of her sons. She is committed to supporting them and respects that sometimes this means disregarding traditional norms around adulthood and independence.

She reflects:

It just means that the rules are different. That there are no rules really. That it doesn’t matter what other people say. You know, when my children graduated high school they were not ready to move out of the house…. developmentally, they were not ready.”

Sarah’s sons are now all in their 20s, and Daniel, Gavin, and PMC still reside at home. Sarah describes her husband, Ben, as supportive but very busy with his work. She shares that Ben always excelled in athletics and was disappointed when his sons initially lacked the coordination to share this passion with him:

I think it was a lot harder for my husband when the boys were younger, because he was an athlete and his children couldn’t compete. You know, Ben was the youngest of nine with five brothers, so he played basketball possibly every day of his life growing up…. So it was much harder for Ben, you know, when the boys played T-ball, when we signed
them for soccer, and... it was just very, very hard for him to watch his children. Because he couldn’t brag about them, you know, this or that like all the other dads. Then Daniel got into swimming and he did really well. So suddenly Ben had something he could talk about, plus he had no expectations, ‘cause actually Ben can’t swim.

When PMC was 16 years old, he told Sarah he wanted to get his driver’s license. After being enrolled in a nearby program that assessed individuals recovering from TBI on focus, reaction time, and perception, PMC passed and completed Driver’s Ed. He now has his own car. Sarah’s sons work, take college classes, and continue to work toward independence. Sarah still cooks most meals and cleans the house in addition to her work. Sarah went back to school, earned her PhD in health and nutrition, and now teaches online graduate courses.

Sarah and Ben are still working to pay off the debts they have accrued to fund their children’s years of therapies and treatments. While they are fortunate to make enough money so they could just about afford to spend $40,000 a year on medical expenses, it required sacrifices and commitment. When asked if any of these treatments were covered by health insurance or if she received any funding assistance, Sarah responds, “None of this was covered by insurance…. My children were not disabled enough to get social security or disability.” Sarah describes the difficulty of having to weigh her children’s well-being against her and Ben’s financial stability:

Every time the two of us start getting anxious about that, I just remind him, eventually it will end and eventually we will pay it off. And we still have many more years of working life ahead of us…. I had multiple children doing multiple things, the numbers were enormous. And Ben would say to me, “Is it all necessary?” I would give him the same answer: “Okay, what can we afford not to do for these boys?”
Sarah shares how she has been able to witness the profound impact that some of these therapies have had for her sons. She becomes emotional talking about how Daniel is now getting biofeedback in conjunction with acupuncture and how it has changed his life:

He says, “I can remember things now.” He’s totally off his ADD medicine. He was on the maximum dose, taking it twice a day. And he gradually over a number of months worked his way off of it…. What a miracle. And then I said, “You tell her you need memory help.” And so now he will say things like—it makes me cry practically—“I can remember what I did yesterday now!” Can you imagine? So, I will keep paying for this.

You know, periodically I say to him, “Is it still helping?” And so far he’s said “Yes.” ‘Cause as soon as it stops helping, we will stop. But, how does one say no—how do you say no to your child when you know something is helping? Or when something could help? You can’t.

Since Sarah began working at her university, her family’s financial strain has eased a bit. They have been putting this money towards travel and going on trips as a family to places like the Caribbean.

Sarah has always been a firm advocate for her children. She has never doubted the capabilities of her sons in the face of authority telling her to expect less. Sarah trusts her own judgment and has done so for as long as she can remember. She recounts the time she confronted her Daniel’s principal about false assumptions the principal made about her child:

I had his principal tell me he was a lazy child. I was like, “No, he’s not. You have no idea how hard he’s working…. How can you possibly say that to me?” Yeah, she used the word lazy. I said, “You are dead wrong.” So we had many more problems, but again, I wasn’t afraid…. My degree’s in education…. and don’t get between a momma bear and
her cubs. I knew I knew my children better than any school official. I felt confident enough that I knew what I was doing…. ‘Cause I’ve never been afraid—but then I’ve never been afraid of people in authority.

Sarah has no qualms about being critical of professional educators and service providers and the ways in which their diminished expectations have framed her son’s experiences. She tells me about a saying that she often shares:

If I had a penny for every time… some professional person told me PMC wouldn’t be able to do something, we would be independently wealthy. Independently wealthy. They told me he would never learn to read…. He has a job no one ever thought he would—you know, these experts didn’t think he would graduate from high school or be able to hold a job. Go to college. Nothing. It’s like, what did you expect my child to do all day? Sit at home and watch television? Please!

Currently, Sarah continues to advocate from her children, but she has taken a step back from the more active role she once filled. Sarah describes talking to PMC about calling a music store that helps musicians find bandmates:

We’ve been talking about this for a couple of years now. “Go over there. Call them. Find out how it works. I can’t do this for you. I can’t call up and say, ‘Hi, my son is…’ I can’t do this!”

With a frustrated sigh Sarah explains that she is learning to accept that as adults her children must learn to advocate for themselves by making plans and following through on them. She shares, “I can’t do it for my kids. Not anymore. And they’re just not doing it for themselves.”

**Community.** Sarah states that she has been looking for community as long as she can remember. Since her children were born, Sarah has worked hard to find a place where their
family is accepted and valued. Sarah relates a story about how they used to live in a small town nearby. She recalls how happy she felt when she would drop Daniel off at school in first grade and hear his classmates greet him and call his name. However, she recalls how this changed on Daniel’s birthday:

We had a birthday party, he was six. And nobody from school came because at that point, Spring Hills was still very insular, Christian, and we were outsiders…. so luckily at that point we had other friends too and all of the other people came…. I think that had a huge impact on Daniel because he pulled in.

Sarah and her family moved away soon after this event. While she loves the diversity, youth, and green spaces in her city, Sarah does not feel they have been able to find a community here. Sarah shares:

We don’t live in a community really, we live in a neighborhood. We don’t have a community. We did for a while with our congregation. I don’t know if PMC mentioned it, but I worked really hard for a long time to try to fit us into a community. And then we had to leave.

Sarah had been the vice principal of her congregation’s school. After the principal had to go on leave, the rabbi took over. He met with Sarah, and she found him to be incredibly patronizing and disrespectful as well as entirely uninformed about how to run the school. Sarah left soon after once it became clear that she would likely be blamed for some of the decisions the rabbi made. Sarah continues:

So no, we don’t belong to any sort of community. It’s been very sad. I mean it was kind of my goal when my children were little to build community for them…. And none of them have ever stuck. I’ve worked hard in a number of places… and it never stuck.
Sarah speaks of the many failures and many rejections her children faced; however, they did find acceptance in Boy Scouts for a time. Her sons participated as Cub Scouts before joining a Boy Scout troop, and PMC and Daniel became Eagle Scouts. Some of Sarah’s favorite things about this community was their focus on wilderness activities, the way in which they welcomed her sons, and how they managed supports for PMC:

Boy scouts did a great job. They supported PMC. And it was in the background. It was like, alright, let him try. Let’s see what he needs and then they would step in, so they weren’t doing things for him…. PMC was accepted into that community…. the scout masters, all got it. And they made sure PMC was included. And that his differences were supported.

Sarah says that even after leaving the Boy Scouts, her sons have retained the friends they made there.

When Sarah considers the reason it has been so difficult for her to find a community, she thinks it may in part be due to a lack of experience in maintaining friendships as a child:

I wanted to be a part of a community since I was a small child. It’s just kind of one of those driving forces in my life. I’ve not been able to achieve it yet. Not at work. Not anywhere. I mean I think a part of it personally is… we moved a lot when I was growing up…. I wasn’t able to establish long-time friends. And that lack of practice means I’m always on the outside looking in. Or on the edge. I don’t have the skill set or the desire or the whatever to do whatever it is that other people do.

She also points to the fact that everyone in the family is extremely busy. She herself spends much of her time working in accounting in addition to teaching online and cooking and cleaning
for her family. Ben works a great deal, as do her sons, who are working in addition to taking college classes. Sarah concludes:

I’ve done what I can do for my children. I mean I didn’t have to totally fit [in]. But I wanted my family to fit. And there was no reason that my family couldn’t fit, but I think my children also don’t fit. And so, you know, six possible points of connection. Zero permanent connections. It just didn’t work. We were too different as a family and as individuals. Even within our religious community, you know, my boys went to all the youth group activities, they participated as much as you could participate…. the other kids just didn’t accept them… it just didn’t work. I haven’t given up, but I mean now we just kind of make our own little… you know, I’ve tried to make our family supportive, because that’s what we have.

While Sarah continues to strive to find a community, her experiences in her city have been mostly positive. She worked hard to make sure that her sons were well-behaved in public and that they understood acceptable behavior in places like stores and restaurants. She laughs as she states, “If anyone in the store could hear me, they’d hear my little mantra, you know: ‘Don’t touch with your hands, look with your eyes.’” Ethan was the only child who ever had tantrums, and those were rare. Sarah recalls:

There was the time that Ethan decided to throw the temper tantrum in the middle of floor…. I’d stand there and watch him. And say things like, “People are staring at you. This isn’t going to get you what you want. You’re going to hurt yourself. Don’t pull those things down on you” [said in calm, quiet voice]. And then eventually he would stop. People would stare, but people would have stared at me anyway. But having a child at
that age with a temper tantrum, people always looked at me with pity [laughs]..... we would all just sit there and wait.

Sarah also states that because of the visible nature of PMC’s disability evident in the shifted direction of his right eye, people were more understanding and less judgmental.

Concluding thoughts. When asked what she wishes people knew about disability, Sarah states:

I wish people would understand that disability is simply—that it’s okay. I think people get scared. I think there’s some kind of fear factor when they see disabilities, because life is hard as it is. And if you can’t do certain things it’s so much harder. And I think that scares people to the point where they simply can’t be open and accept there’s more than one way to live a life. So I wish people knew that it’s okay to have a disability. It’s not fun for the person, but they’re still people.

Sarah is critical of the ways in which disability is perceived and emphasizes that it is a condition that anyone can enter at any time. She continues her critique to include the ways in which American culture interprets notions of personhood:

The elderly are not respected or cared for from our culture either. You know, once you are no longer able to do a certain number of things or tasks—and it’s not like it’s clearly defined, then again, you become less than. In this throwaway culture, people are thrown away.

When asked what she would like people to know about PMC, Sarah responds:

I would like people to give him a chance.... Because there is so much more to him that meets the eye. I wish young ladies would give him a chance. Because he would be a wonderful boyfriend. A wonderful friend.... People do not give him a chance.... These
barriers prevent people from getting to know others. And people with disabilities become “that guy in the wheelchair” or “the person with the weird eyes,” instead of whatever their name is. They don’t ever get to the name. They’re objectified before anyone’s gotten to know who they are.

PMC

Everyone has something. You just have to find out what it is. And don’t let anyone tell you that you can’t do something, because I’ve achieved an awful lot that people said I wouldn’t be able to. I’m a good example of that. I want to spread the message through music.

PMC is a tall young man with a lean build and sandy blond hair. He is very earnest and looks directly into my eyes much of the time we are speaking. PMC comes to the first interview with a worn children’s book called *Tacky the Penguin*. He hands it to me and folds his arms over his chest. “That’s me,” he says, nodding to the book. Tacky is an eccentric penguin that is often ridiculed and rejected by the other typical penguins. However, Tacky’s odd behavior and difficulty reading social situations ends up saving all of the other penguins from danger as he confuses and defeats the predators that hunt them through his odd but effective behaviors. PMC states several times that he relates to this character and shares that his mom first started reading it to him when he was four or five years old. According to his mother, PMC’s closed head injury resulted in struggles with coordination and sensory integration issues. He also experienced delays in speech and issues with emotional regulation and impulse control. She relates that he tends to see the world in “black and white” (has difficulty perceiving nuance), struggles with planning and spatial awareness, and cannot understand sarcasm.
PMC has fond memories of being young and playing with friends. He shares, “I had very good friends when I was a kid. We’d laugh a lot, we’d play games. We’d go outside. You know, we weren’t the type of kids who were always in front of the screen.” PMC likes to run every morning and spent the summer training for a half-marathon. He also goes to the local Y every afternoon before work to lift weights. He has a black belt in Kung Fu. He is very conscientious about his health and is open in his disdain for junk food:

My rule is that if it’s not in nature, I’m not eating it. If it has chemicals that I cannot pronounce, I’m not eating it. Not eating it. No. It’ll cause problems…. The body is the most expensive machine you’ll own. That’s what my parents taught us. And you treat it as such.

PMC reports enjoying his time in the homeschooling co-ops when he was younger and the friends he made there. He admits that he struggled with social cues and did not necessarily notice when other people were being unwelcoming or unkind. He shares, “When I was younger… I was oblivious to these things honestly. When I was younger I’m still trying to figure myself out. You know? Still trying figure the world out, figure out how things work.” PMC’s favorite memories when he was younger are of visits to Sleeping Bear Dunes National Lakeshore for the first time when he was four and when he met his friend Jacob in middle school. PMC recalls:

We took math support together. I’m glad I met Jacob. He is a great friend. We still hang out. Still enjoy each other’s company…. It was awesome. We had so much in common, we could hang out together. I could be myself around him. He wasn’t judgmental…. He’s one of the friends who’s still friends with me ‘til this day. We’ve known each other like seven years, eight years now.
Jacob was a welcome bright spot in an otherwise sad and lonely experience. PMC shares that middle school is where he has felt the least welcome and is very critical of the ways in which his middle school treated their students. He states, “I was bullied a lot because I was different. I was annoying too. I admit, I was pretty annoying, but who isn’t? Kids are annoying, let’s be honest. That was hell. That was hell. Where I went was awful.” When asked if he believes the school is still like that or if it has changed, PMC responds:

I’m not going back to find out. I don’t care. Anyways that place was a living hell for me. And I don’t want to go back. I don’t want to get in any nose fights with anyone—break anyone’s noses, Ah, Gosh! I didn’t want it to come to that. I did not want it to come to that conclusion. ‘Cause I don’t think violence solves the answers about anything. It just makes the problem worse. I just still think the principal should have done her job and protect her students. They failed. Epically. They failed epically. But it’s okay, ‘cause I never have to go back. And if I have kids I’m not sending them there.

PMC contrasts this experience with how much he enjoyed his high school experience, where he found teachers to be more approachable and supportive. He shares:

They have an awesome support system, they’re very accommodating, very understanding. Very awesome teachers that you can be friends with. Be close with. Which makes it a lot better when you encounter them about a problem. It’s not as awkward. ‘Cause you don’t look at them as this power figure. You look at them as people you can talk to.

PMC is critical of traditional structures of authority in the public schools. He believes that educators should strive to teach all of their students and does not hesitate to stand up and
advocate for himself when he believes a teacher is not doing his or her job. He shares an experience of being in high school when he started taking music classes:

I was confused because they were moving so fast. And I was like, “Could you slow down?” And they were like, “No. I’m not going to slow down. You know this already.” I’m like, “Are you serious? How do I know this? If I’m asking for help, you’re supposed to help me! That’s your job!… You’re supposed to teach. And when the kid has a question or the student has a question, you’re supposed to assist that student and help them understand the problem, so that they can grow. How dare you tell me that crap?”

PMC ended up dropping this class but is happy with the decision because he was able to find a piano teacher who continues to work with him in the present. “He’s very excellent,” PMC states, “Very patient, very understanding. He’s teaching me things that I want to learn.”

Music is one of PMC’s greatest passions. He tends to practice three or four hours a day and would play more if he had the time. PMC shares:

I want to be an amazing musician, I wish I could, you know use my music to feed me…. ‘Cause I’d be full all the time. [laughs] I would. You could play your music all the time and quench your hunger. That’d be cool. That’d be cool to figure out how to actually do that. I would gladly do it…. I think it’d be awesome if I could play my music all the time.

While PMC got rid of his drum set while in high school, he still plays the guitar, piano, and bongos. He composes his own music and has a great fondness for music from the 1950s and 1960s as well as classical music, opera, and musicals. PMC enjoys music that he feels is “distinct,” like Frank Sinatra, the Rolling Stones, and Keith Jarrett. He is quite critical of contemporary music, stating, “I say a lot of music nowadays comes out of the butt. It is terrible. Taylor Swift sounds the same. Katy Perry sounds the same…. Ugh! I grew up with such garbage.
Such garbage.” He is equally critical of films from this period, though he does enjoy Pixar animation films like *Toy Story* and *Finding Nemo*.

PMC currently works at a burger restaurant, but he is looking for a new job. He has trouble getting along with co-workers, especially the young women who often tease him and call him by a nickname he does not like. PMC is also frustrated by what he perceives as them trying to get him to do their work for them. PMC says that while he is much more capable of managing his temper and impulse control than when he was younger, he finds that interactions with these coworkers often leave him livid. PMC shares his plan to stop one woman’s teasing:

I came to that realization after Mom explained it to me. That this girl keeps calling me a nickname that I don’t like. She’s just doing it to get a rise out of me. I’m not going to do it to her. That’s what children do! Not a real woman… That’s what children act like. Someone asks me to stop, I stop. I say, “I’m sorry,” and I stop. I don’t continue. Children don’t know when to stop. So I’m just going to ignore her and give her not what she wants. Then she’ll stop.

PMC likes to stay busy at work and hates to be bored or sit for too long. During one interview he shares that he is going to apply at a fitness store but will first meet with the manager to make sure there would be plenty of things to do so he would not have to sit around.

When considering his future, PMC states that his plan is to graduate with a degree in broadcast arts and communication in 2018. After that he would like to be a millionaire. His plan is to become a famous musician, own his own record label, and live near Sleeping Bear Dunes. PMC continues:
I want my future house to look like a giant glass piano, that’s honestly what I want. But I can settle for a log cabin. With fake wood, not real wood of course, ‘cause real wood gets termites. No thank you. Or if it was laminated that would be fine too.

PMC is also very fond of cars. After getting the chance to drive the Aston Martin from one of the James Bond films last year, PMC has decided he would like one as well. He notes: “A BMW would be… pretty much my everyday car to drive around, ‘cause BMWs are standard. And then every once in a while drive my Aston Martin. And have my McLaren too. I’ll have a garage.” When asked if there is anything he would like to do that he has not yet been able to do, PMC responds:

I’ve done a lot of cool things. I’m satisfied with what I’ve done. However, I long to try the Spire [musical venue] again, ‘cause I did my first debut, you know kind of thing. It wasn’t the best. I just wasn’t used to the stage up there. I needed to start with a slower song.

PMC continues to practice his music every day while working toward graduation and moving out of his parent’s house. He is worried about being perceived as overly-dependent on his family and strives to be as independent as possible. He has a great disdain for people he calls “mama’s boys.” He shares, “You have to get burned—or go through the fire is what you say—to learn stuff. Life is brutal sometimes. You have to accept that.”

Community. PMC likes the town he lives in and describes it as a “helpful” place. “Everyone around Madison is very helpful,” PMC states, “It’s not awkward to ask someone for help, like ask for directions.” When PMC is asked about communities that were accepting, he identifies his high school and his Boy Scout troop. He also enjoyed the way people in his town responded to him when he was in uniform:
They always seem to be welcoming. Especially with my Boy Scout uniform on, they all have respect for Boy Scouts. ‘Cause we do a lot for stuff…. We did a popcorn sale at Lowes and everyone was so friendly ‘cause we were asking people to buy popcorn. But they were friendly and warm. So, it was a good time.

When asked about his experiences left out, PMC responds:

It’s depressing. I told you about my middle school. No one really liked me. I didn’t fit in…. No one accepted me for who I was. They always picked on me… I think that would be feeling left out of your community. I’m just going to count my middle school experiences and leave it at that.

PMC shares how troubling and hurtful this experience was. For a time he contemplated suicide, but he says that he was able to make it through this time with the support of his family.

Considering the advice he would have given to his younger self, PMC states:

Don’t give up. I mean there were times when I thought about killing myself ‘cause it’s so brutal and dark you know? Those days were awful. I hated it. I even tried—attempted to kill myself, but I was like, what would that prove? I’ll get through this. I’m sure every person had the…thinking about killing themselves. It’s ridiculous. It’s the truth though.

He emphasizes the need to protect young people who are struggling and to accept them for who they are so that they can feel comfortable and welcome.

**Concluding thoughts.** PMC reflects upon the ways that he has changed since he was a child and what he has learned in the process of becoming an adult. He shares, “I used to be a loud-mouth. My pause button’s better. My social skills are better—well that’s actually never been a problem but, yeah. I’m not nearly as annoying and hyper.” PMC has also come to accept that he cannot get along with everyone:
I know that I can’t be friends with everybody. I know that for a truth. And that I’m not going to be accepted by everybody and I’ve accepted that…. Not everybody’s going to like me and that’s just the way it is. It’s a harsh thing to say, but yeah, reality is harsh…. I’ve just stopped caring what other people think. I’m like, “You don’t like me? Well I don’t care. This is me. I’m being myself. If you don’t like it you can go walk out the door. I don’t care.”

PMC would like people to know that he is witty, thoughtful, and determined. He describes himself as tough and brutally honest. His honesty has sometimes gotten him into trouble and is not always appreciated by his friends and family. PMC has learned to filter some of his more brutal opinions but struggles when this is information he feels they should know. He describes:

My uncle died because he was too fat. And his heart couldn’t take it. I wanted to tell him, “You’re out of shape buddy,” but I didn’t want to hurt his feelings. That’s the dilemma right there. It’s hard to be brutally honest sometimes about those things.

PMC maintains a small group of friends that he has known for many years. While he often does not get along with people his own age, he enjoys the company of older people in their late-20s and 30s. PMC states, “It’s more important to have less friends and better friends, than have a lot of friends who are crappy and not good friends for you, who take advantage of you.” When asked what advice he would give another young person in his situation, PMC responds, “I think the moral of the story is be yourself, you know? Don’t let other people tell you that you can’t do something, ‘cause you can.”

**Conclusion**

Sarah and PMC appear comfortable in rejecting social expectations and any negative judgments about being different. This may be in part due to the fact that they have a large family
and their home is a safe haven. Sarah shares that in emergencies the family comes together to protect and support one another. Both Sarah and PMC feel like they do not quite fit in, and while it seems that Sarah and PMC are accepting of the ways in which their differences make them stand out, they are also express appreciation for the critical perspective this has given them and the strengths and talents that have come with these differences. While the search for a broader community continues, for now, the family has created its own small community.
Chapter 6: Tracy

Chapter 6 examines the experiences of Tracy, an engaging and sincere African American woman in her early 40s. Tracy lives in a city in southeast Michigan in a small house with her partner, Allen, and her mother, Susan. Tracy spends her days caring for her mother and is unemployed. When Tracy was asked if there was any family member who could be interviewed with her, she said that there was no one she wanted to join the study with her. She does not like to talk to or spend time with the people who knew her from childhood, except her mother who is in poor health. Tracy was adamant that there was no one who could join the study with her, yet her story was so compelling and she expressed such an earnest desire to speak about her experiences that she was interviewed without an accompanying family member.

Tracy

When I got here, to Unity³, I felt opened. I felt that I could talk about anything and they wouldn’t judge me about it. I could speak on things, they wouldn’t judge me about it. They gave me a sense of hope.

Tracy was born in 1973 in a large city in southeast Michigan. She had two younger siblings, a sister, Annie, and a brother, Phillip. Tracy shares that she and her siblings all had separate fathers and that their mother worked hard to support them alone. Tracy was very close to her sister when they were younger, but less close to her brother because he would pick on her at times. Tracy describes her mother as her “heart.” Tracy was also very fond of an elderly cousin she referred to as her grandmother as well as her godfather and his wife. Tracy has difficulty with sequencing, numbers, and time. Tracy could tell me her age of 43, but not the age of her sister, estimating that she was 36 or 37 (Tracy was later able to recall that when she was

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³ Unity Community Resource Center is a community organization that provides residential, community-based, educational, and counseling services for children and families.
13 years old, her sister was 11). She can read and write but prefers to have the questions from the interview read aloud to her. Tracy recalls that she struggled to retain information in school and could not seem to keep up with the other children.

Tracy credits her mother for standing by her and supporting her over the years. She describes the ways in which her mother always made a special effort to make sure that she felt loved. Tracy recalls how her mother comforted her when her father would fail to visit:

I used to be kind of sad when they [her siblings’] fathers come around and spend some time with them and I feel sad because my daddy never come around. But, you know, my mom used to make it fun for me, you know, so I won’t be sad. Like she’d take me with her everywhere, like, “Baby, come on, go with me.” And I be with her and spend the time with her and stuff, and her friends.

Tracy’s mother also made sure that Tracy always had board games, puzzles, Barbie dolls, and other toys to play with. Tracy has warm memories of her mother making Tracy a special chocolate cake on her birthday and when her mother once surprised her with a boom box. Tracy shares:

My mom, she’s still amazing woman to this day. You know? After all she been through… being abused by men and all that. Being hurt, well my mom still made a house for me and my sister and my brother, so she never let that stop her…. She didn’t give up on her children.

Another important woman in Tracy’s life was an older cousin she referred to as her grandmother. Tracy grins as she shares memories of going to her grandmother’s house and sitting at the kitchen table while she cooked:
I used to sit there and watch her cook and stuff. And she used to be like, “Tracy!” You know, she’d be like, “You a pig!” And you know, just mess with me and stuff. And I used to smile all the time and she kept me smiling.

Tracy enjoyed being able to help her grandmother by picking up items from the store or pharmacy for her and helping out around her house. She shares her favorite things about her grandmother: “I like the way she smiled. My grandma, she used to smile a lot. And she used to kind of tease me.” Tracy also enjoyed spending time with her grandmother in the evenings:

Me and her watched TV and she’d be cracking up and I’d be cracking up with her. Then I look in the TV guide and I be like, “Grandma, this is coming on at eight o’clock, this is coming on at nine!” And me and her would sit there and laugh at the movie—if it was a comedy movie, we would laugh at it. I used to, you know, watch her until she fall asleep.

And then I still sit in her room for a little while before I leave.

Tracy also relied on the support of her godfather. Tracy’s godfather took her family in after her mother fled from an abusive boyfriend. Tracy’s godfather took a special interest in Tracy and her education. Tracy shares:

He was a good male role model for me. My godfather, he was a sweetheart. He used to take me school shopping. He used to buy me learning toys to help me learn and stuff. He was a very good godfather.

Tracy has fond memories of these caring and protective adults in her childhood. The love of these three supportive adults helped Tracy to survive the violence and exploitation she would experience in her youth. She shares that she was molested for the first time when she was eight years old by her step-father. She told no one about this abuse and does not say how long it went
on. Tracy does not disclose the details of the molestation, but it clearly had a traumatic impact on her.

Describing her elementary school experience, Tracy states, “Elementary school, you know, it wasn’t bad…. I was okay. You know, I was doing okay. But I wasn’t learning as fast as the other children.” Tracy shares that she struggled in many of her classes: “I was getting Es and Ds because I couldn’t keep up with the rest of the class. But I didn’t know what was going on until they tested me.” When Tracy was in fifth grade she was evaluated by the school district for special education services and was labeled with what Tracy describes as “a real bad learning disability.” After her evaluation, Tracy was placed in a self-contained special education classroom. She would remain in self-contained programs for the rest of her childhood in the education system.

Tracy shares that her favorite teacher was a kind woman in middle school. She explains, “She was a good teacher. Her name was Mrs. Dunham. I never forget her.” This teacher stands out in Tracy’s memory because she was the only teacher that Tracy feels cared about her and protected her. Tracy continues:

She was very kind to me and she never treated me different. She didn’t make fun of me. She knew I had a disability, she would work with me, she would talk to me. She was a very good teacher.

Tracy talks about the relentless bullying from the other students in the school who would mock her for being in special education, knock her down, and throw things at her, such as dirt and rocks. Tracy describes how the presence of her mother helped to buffer the effects of this abuse: “I was having people bullying me, but I didn’t pay that no attention barely, you know?... My mother worked at the school, so I was okay. You know, ‘cause I could always come to her or
whatever.” Tracy says that she never told anyone about the bullying when she was in school, afraid that the bullying would get worse if her mother intervened or that no one would believe her. During this time Tracy would play at home by herself after school. She explains:

I didn’t know what else to do so I like come home from school, do my homework, then I go in my room and close myself in. I wouldn’t even go outside. And when I did go outside, I would go in the back yard or in the front yard and sit on the porch by myself.

Tracy spent her time playing board games against herself, jumping rope on her front porch, and playing with her dolls. Tracy recalls that her mother was concerned about her lack of friends:

My mom used to wonder, like “Baby why come you alone? Why don’t you have friends?” And I used to be like, “Ma, I just don’t want any friends,” but inside I didn’t want to tell her that people’s bullying me and being mean to me. I didn’t know how to express it.

Tracy does not explain why she was bullied so relentlessly or what it was about her that was met with such hostility. It may have been the stigma of intellectual disability and being placed in special education classes. Or perhaps she simply did not respond in expected ways, and her bullies sought to put her in her place. Tracy does make reference to the hostility of girls in particular and the fact that she developed early, perhaps indicating that these girls were acting out of jealousy or to punish Tracy for receiving attention from boys.

During this period Tracy was also subjected to further sexual abuse at the age of 12 or 13 by one of her mother’s boyfriends. Tracy explains:

I told my momma about that and she got on him. Like, “Don’t you put your hands on my baby.” He was like, “She’s lying!” and I’m like, “No I’m not!”… I had a lot of people do that. ‘Cause, you know, I developed fast. I had little breasts and you know, a little behind.
I was built, you know, growing up. So men thought it was okay to put their hands on my hoo-ha and on my breasts, on my behind.

Tracy’s mother kicked the man out of her house after Tracy told her about the abuse, but the experience left Tracy even more shaken and fearful: “I really, you know, went down the well…. So, you know, that’s what made me… [I] didn’t like men.” Tracy gives no mention of ever receiving counseling as a child. While her mother left this man, Tracy does not say her mother went to the police or sought help. It appears that it was considered over, and Tracy was silenced in her capacity to speak out and express her anger and fear over these violations. This was the second time Tracy had been abused by her mother’s partner, and while Tracy is clear that she does not blame her mother for this, Tracy does not appear to have been adequately protected by her.

Tracy graduated from middle school and was enrolled in a full-service special education high school. At first Tracy felt hopeful about going to this new school. She shares:

When I wound up going to this disability school, I had friends and I had people that I can talk to a little bit. But they was just like me, so I was a little bit… safer and cooler. But it still was the same, ‘cause they was still picking at me.

Unfortunately, her transition into high school was marked by a great deal of loss. The one friend she had made in middle school found a new group of friends and began to join them in bullying Tracy. Her siblings’ fathers began to take more prominent roles in their lives, and Annie (her sister) began spending time with her father’s family and her half-sisters. Tracy recalls:

My sister, she had met her sister on her dad’s side. So she started, you know, acting funny towards me. And that hurted me too. ‘Cause I was like, “Me and you grew up
together! We were very close.” And when she started being mean to me, that hurted me too.

The bullying on the part of her classmates intensified as well, becoming more violent. Tracy’s clothes were torn and the other students would throw dirt in her hair. They would also try to get Tracy to fight:

They kept calling me, “You stupid! You in special ed! That’s why you in special ed!”

You know, making fun of me and trying to hit me because I didn’t want to fight. You know, I was never a fighter. Because I was scared to fight, you know, because I didn’t grow up being around violence. My mother wasn’t a violent woman. You know? And seeing her get hurt—you know, abused by men, so I didn’t really like all that fighting, cursing, and all that. So as I grew up, I didn’t like to fight.

Tracy had one counselor in high school who provided some refuge for her: “He was very good. His name was Mr. Smith. He used to talk to me all the time… I used to be kind of scared to come to school because kids was still bullying me.” While Tracy remembers Mr. Smith fondly, it is not clear why he and the other school personnel were indifferent to or ignored the intense bullying that Tracy experienced from the other children. Mr. Smith would allow Tracy to call home every day to check in on her mother and her grandmother to make sure they were all right, given that they both struggled with health problems. Tracy recalls one day calling her mother and receiving terrible news. Her mother told her that her grandmother was gone:

I’m like, “Where’d she go?” My mom said, “No, she’s gone. She’s dead.” I was like, man I cried on that phone. My counselor’s like, “What’s wrong?” I was like, “My grandma just died.”… When I found out she passed… I cried. Like, man, I cried like never before. Because I never thought she would leave me.
Tracy was devastated by the loss of her grandmother. She describes the difficult experience of grieving and having to say goodbye:

I was like, “How can I lose her? How? How? How?” Man, then I had to go to her funeral. I had to see her for the last time. I went to the wake. And I just laid on her chest. I just laid on her. You know, ‘cause I just couldn’t believe she was gone. And then I went to her funeral, I was crying. I couldn’t catch my breath, I was crying so bad I had, you know, lost my breath. And man, it tore me up so bad ‘cause I knew this would be the last time I see her. I’m not gonna see her no more. And they hurted me when they closed that casket and then they lowering her to the ground. I was like…I just…I just fell out, because I just couldn’t believe it, you know?... One of my cousins, her name was Ellie, she had took me outside, try to get some air because I was so upset.

Soon after, Tracy’s godfather passed away. She recalls thinking, “Ohh…everybody around me just leaving me.” Perhaps due to the compounding effects of these losses on top of the stress of being bullied and isolated at school and the trauma of being sexually abused, Tracy sank into a deep depression and attempted suicide when she was 13 years old. She relates:

I tried suicide because I didn’t want to live no more. I was tired of people hurting me, I was tired of people…you know, making fun of me. You know? I didn’t know how to deal with it at that time, I was a kid.

Tracy describes finding a bottle of pills and swallowing them all with water. She continues:

Next thing you know, I started getting dizzy. And got sick—you know, I started falling down and throwing up—my mother thought, you know, I had a virus or something. Then I told my mom… you know I just broke down… and I said, “Ma, I took some pills. I don’t know why.” And she was like, “Don’t do that anymore!” She fusses at me, but she
didn’t cuss me out or anything. She was like, “Don’t do that anymore ‘cause you coulda hurt yourself!”… I just thank God that he spared my life and my mama caught it in time and they pumped my stomach out.

Tracy recovered but began to feign illness to avoid school, missing weeks at a time. She eventually transferred to a different full-service special education high school. However, she continued to struggle with social isolation and bullying in this new school and soon dropped out of school for good. There are multiple factors that may have contributed to this decision. Tracy states that she was raped three times when she was 16, once by an ex-boyfriend. She also became pregnant and gave birth to a son, though she does not say if this child was the result of rape.

About a month after the birth of her first son, Tracy and her baby were at the house of an old family friend whom she called her uncle and his girlfriend. Tracy was alone with her uncle, and he raped her. When his girlfriend walked in on the assault, Tracy’s uncle said that Tracy had come on to him and his girlfriend attacked Tracy with a bottle. Tracy explains:

My auntie, she tried to jump on me. Like it was my fault…. she was about to hit me in the head with a glass bottle. I had to hold my hands up [holds hands defensively before face] ‘cause she wanted to hit me and she hit my arm and my arm was hurting me so bad.

So I ran home.

Tracy becomes very still as she describes this traumatic event:

I just ran—I didn’t have anything. You know, I had a shirt and shorts, but had nothing on under it. No, ‘cause I ran, I was scared. I didn’t even have on any shoes…. I ran home and locked myself in—I hid behind the furniture in my basement. I was afraid. He came to my house. I heard him everywhere he’s at. I made no noise so he couldn’t find me…. Because I was so afraid. And you know, when he came to my house, I heard the car. I
heard the car door slam. I heard him screaming, “B when I find you, I’m a kill you… You better not been told no body!” You know, and I was like, I was so afraid.

In her terror Tracy had left her month old son at her uncle’s house, and her mother was called to retrieve him. Tracy’s mother brought her son home and began searching for Tracy. Tracy recalls, “I heard her voice and she said, ‘Tracy? Tracy are you down here?’ I was like, ‘Yeah Ma…” I was crying, I cried to my mom. I was like, ‘Ma, I don’t…I don’t want to see that person again.’”

Tracy’s mother urged her to call the police, but Tracy was afraid. She explains, “If he find out, he might try to come and hurt me. And I can’t fight no man. You know, you definitely can’t fight no man.”

Tracy’s fear of men intensified to the point that she would walk in another direction if she saw a man walking down the street. She would begin to panic when around them:

I was just scared of men. I was so scared of them. I didn’t want to be around them. You know, I see a man, I go the other way. But seeing men in a crowd, I go. You know, I just couldn’t keep my head around a man. It used to make me scared. Every time I see one my heart would beat real fast and I get lost because I be so afraid.

Tracy continued to struggle with depression, anxiety, and social isolation. She struggled to understand and cope with her emotional response to her experiences. Tracy explains:

I had nobody to protect me, so I would just be afraid of men, period. I was like, “I can’t trust a man, I don’t want to see a man.” It closed me down and made me angry. It made me mad. So I was mad at the world. And the world ain’t did nothing to me, I was just mad. I used to like, have to go to anger management, because I used to like, flip over tables. Throw things.
Tracy had her second child when she was 21 years old. She does not speak about who the father was or how she became pregnant given her fear of men. Tracy was a single mother during this time and lived alone in a small apartment with a broken refrigerator. Tracy notes that she always became upset when she was away from her children. Tracy laughs as she shares that she could not stop herself from calling to check on her children whenever she left them in her sister’s care:

> I was very insecure. I used to cry when my kids left me. My sister be like, “Tracy, stop calling me!” I be like, “Girl, I just want to see how my baby doing.” She’s like, “Tracy, you just left. You outside.” “Okay, but what’s going on?” You know? I pop up and… I was just a hands-on mom. I… was very attached to my kids, you know?

After Tracy had her sons, she found a sense of hope in becoming a mother. She states, “When I had them I kind of felt some kind of justice. You know, some kind of means to—not an end, but a means to a beginning.” Tracy smiles broadly as she shares the happiness she found in becoming a mother:

> It was a joy, having my sons. Because they brung some brightness in my life, you know? ‘Cause I was real sad. You know, I was sad at what happened. I was sad at what went on. And so I didn’t think I would be capable of taking care of no children…. ‘Cause I was very sad, ‘cause of what happened. Like I was telling you about my learning disability and people making fun of me and bullying me…. But having my sons, it brung a lot of joy…. it was a link that was missing. And I guess they were my links.

Around the time that Tracy was pregnant with her third son, her mother was diagnosed with cancer, and she was no longer able to help Tracy with her children. Again, Tracy is not clear as to who the father of this child was, but she does refer to the relationship as abusive and she soon left. Nor is it clear where Tracy received an income as she did not work, though she may have
received welfare cash assistance as well as subsidies for food and housing. Tracy explains that she had to rely upon a neighbor to check on her children when she had to go out to get groceries:

I would go out in the middle of the day, and locked my kids in the house…. I didn’t have nobody to keep them ‘cause I was in there by myself. So I asked my neighbor, I said, “Can you keep an eye on my sons?” I was like, “I locked them in, but you can go in and check up on them, but they asleep. But you could check up on them for me, but I’ll be right back.” And I’d go out and get food. You know, I go get baloney, bread, and stuff like that for us to eat. And I asked the lady across the hall, “Is it okay if I keep my food in your refrigerator? Like my milk or whatever? I need it over there.” But they was very nice to me. You know, they didn’t treat me bad or whatever. ‘Cause they saw I was a single mother on my own.

While Tracy’s mother was going through chemotherapy, Tracy took care of her while also pregnant and tending to her two young sons. This was a very difficult time for Tracy, and it was frightening for her to see her mother so ill. Tracy explains the struggle to care for her mother while near the end of her pregnancy:

I didn’t have my baby yet…. He was still in my tummy…. My mom used to like, use it [lose control of bowels] on herself. So I would have to put her in the tub, bathe her. You know, I had to feed my mom—‘cause she couldn’t feed herself…. My mom told me one time—she was crying, she was like, “Baby, I’m sorry. I peed on your couch.” I said, “Mom, mistakes happen.” I washed it off and I turned the pillow over. I said, “Forget about it. You can’t help if your bowels are loose. Ain’t nothing you can do about that.” You know, so I put her in the tub—and remind you I’m eight months pregnant—I’m getting her in and out the tub. She didn’t have the strength to even get up. You know, so I
had to get her up, get her in the tub, wash her up…. ‘cause nobody was there to help me, I
was there alone. You know, and the boys was little so they couldn’t help me.

Tracy’s mother soon became so ill that Tracy urged her to return to the hospital, but her mother
refused. Tracy remembers telling her, “Mom, you need to go to the hospital… I’m about to call
my sisters and they’re gonna make you go, because if I’m sitting here and telling you, you not
gonna go.” Tracy’s sister Annie, Annie’s half-sister, and the half-sister’s boyfriend came to the
house to convince Tracy’s mother to go to the hospital. She continued to refuse even as an
ambulance waited outside the house. Tracy laughs as she explains how the boyfriend finally
made the decision to force Tracy’s mother to go: “He picked her little self up and put her over
his shoulder. And he put her in that ambulance…. I said, ‘Thank you Jesus,’ because she needed
it. She was fighting them like a B though.” While Tracy was relieved that her mother was
receiving medical care, she remained deeply worried about her:

She kept getting sicker and sicker and sicker and sicker. So it was like, it took a toll on
me. You know, and then I started getting sick, after I had my baby, that’s when I went
into depression mode thinking about her, thinking about what I went through. It was a
whole, like gang full of mess.

Soon after Tracy gave birth to her third son, she experienced a severe depressive episode and
began to once again consider suicide. Tracy’s voice lowers as she describes realizing that she
was in crisis:

I was thinking about killing my kids. Because I got so depressed, I was talking about
killing them and then killing myself. And I had called the suicide hotline. I told them, “I
need help, can somebody pick me up? Because I need to go into a mental hospital ‘cause
I don’t want to hurt myself and hurt my kids.” So they came and picked me up, took me to a mental hospital. I was in there for like two or three months.

Tracy does not say who cared for her children during this time, but as her mother was so ill, it was unlikely that she was able to care for them—especially as the youngest was only an infant. Tracy does express negative feelings about foster care in a later interview, perhaps alluding to the fact that her children had been temporarily taken into care. Tracy was relieved to know that her children were safe and hoped that she could get help, but the separation from her children was painful and deeply distressing. Tracy shares that she spent most of her time at the hospital crying: “I would cry and cry all through the day, all through the night. Like cry myself to sleep basically.” In addition to her depression, Tracy struggled with her fear and anxiety:

I would skip dinner, sometimes I would skip breakfast… because I was afraid. I just didn’t want to be around nobody. I was so depressed, so they had to talk me out of that. I mean… it was like I was in locks and chains because I wouldn’t allow myself to do nothing. They had to actually talk me out the room. They had to actually talk me out of this room because I would not leave that room for nothing in the world.

Tracy says that she was put on medication that made her feel “spaced out” and assigned a therapist. Unfortunately, Tracy shares, “Therapy wasn’t my cup of tea, so I couldn’t really express really nothing…. I wouldn’t tell her too much of nothing.” Tracy gradually recovered, but never developed enough trust to speak to her therapist about her experiences with trauma, bullying, and abuse. Reflecting on her struggles with her anger, fear, and depression, Tracy states, “I’m surprised I never went to prison. But I wind up in the crazy house, you might as well say that was prison. ‘Cause I stayed locked in. And I had 24-hour surveillance on me.”
After a period of time (recalled by Tracy as two or three months), Tracy was able to return home and was reunited with her children. Her mother’s cancer went into remission, though she remained in poor health. Tracy worked hard to keep her children from witnessing her sadness or fear. She found that the most effective way for her to manage her depression was to give herself as little time as possible to think about her past. She shares, “What I did is tried to keep my mind focused. I started going to church, reading my Bible…. I was doing stuff around the house, just to keep my mind off of what I been through.” Tracy never discusses the father or fathers of her first three children, but she does share that she experienced abusive relationships during these years and yearned for someone to protect her. When she was 25 years old, she met her current partner, Allen, who was 21 years old at that time. He is the father of Tracy’s fourth son. Reflecting on her experience of motherhood and her relationship with Allen, Tracy states:

I kind of thank God that I had all boys, because me having all my boys, it helped me feel more safer now. So I know nobody can hurt me without my sons stepping in to say, “Oh, no!” And then, you know, my honey I been with for 19 years, he also protects me so I have a lot of protection around me now…. You know, and I have that around me now, so I don’t really worry about nothing.

However, Tracy says that when her sons were growing up, it was a struggle for her to be what she considered a good mom. She shares, “I was a very closed up mother. Wouldn’t even pay attention to my kids, you know? I couldn’t even respond to them.” She also feels she was an overly permissive mother and explains that she was afraid to impose discipline on her sons:

I was soft on them because I thought that if I do be tough on them it’s going to make them regret in me, but it wouldn’t…. They told me, “Mama, if you would have been rougher on us, we would have probably be different.” You know?... But see I would
never discipline my sons... And they wanted me to discipline them, because I was they
mother, they expected me to do that.

It wasn’t until one of Tracy’s sons got in trouble with the law that this changed. Tracy explains
that she was required to attend a parenting class at Unity Community Resource Center as a
result. However, Tracy had few expectations of the class as she felt that she had never benefited
from them before: “I had really been to a lot of parenting classes, but they… never got me
nowhere. I was still standing still, you know?”

Tracy credits this parenting class with changing her life, helping her to become a better
parent and giving her a community. She reflects:

When I got in there, man, I was very amazed on how much a person can be helped
without being judged. And they helped me. I wasn’t judged by it. They made me feel
welcome. They always make me feel like whatever went on stayed there [in the sessions]
and it didn’t—it wasn’t all over the world. You know, and they made me feel good.

Tracy shares that the women leading these classes helped her to come to terms with her trauma
and to realize that she was not alone. She developed a close relationship with five women staff
members at the center in particular who helped her to overcome her fears and work to express
herself:

Mother Hanson, she was more like a mother to me than just a parenting teacher. You
know, she made me feel like, “Okay Tracy, you gotta stop feeling sorry for yourself.” I
used to sit back and say, “Yes, I have been feeling sorry for myself.” And she made me
really come out. Ms. White made me come out, Ms. Parks, Ms. Field. Ms. Hollins—they
all made me feel like, “Tracy, what you are doing, you have to learn to get out of that
shell. You have to push yourself. I know it may be hard, but you have to do it.” And so I
started feeling good. I started expressing myself more. I started using my head even more.

Tracy also met a community of women attending the class who had been through experiences and circumstances similar to her own. For the first time Tracy felt that she had found a community to which she could relate. She recalls:

I said, “Wow, I got people like me.” And it really made me open up. I was able to smile more, laugh more, have fun more, and be more open. It was like, I just felt like I was at home.

While Tracy does not maintain regular contact with the other parents she met in that class, she does see them occasionally at Unity and is always happy to talk with them. She shares: “I always give them encouragement. ‘Cause I know how they feel. And I give them big encouragement, like, ‘It took courage to do what you did.’ You know? But yeah, I would walk around the room with open arms.” Tracy finished her parenting class but maintains her relationship with the five teachers she gained as mentors from the experience. She says she has learned a great deal from them. Tracy explains how Mother Hanson helped her to recognize that she is not to blame for the trauma she has experienced. She shares:

She told me, “Tracy, this is going to stop right her and now. You’re going to stop blaming yourself for everything that goes on.” When she said that, a bell clicked in. I said, “God dog it, did she actually say this?” It came out of her mouth and through my soul, and it pierced it. And when it pierced it, I felt it. I said, “She’s perfectly correct… ‘cause I have. I have been blaming myself for what happened to me. I’ve blamed myself for closing myself in. I’ve blamed myself for isolating myself. I’ve blamed myself for everything. I need to enjoy my life more. I need to stop feeling sorry for everything—
'cause I feel sorry for everything! Everything I just feel sorry for and I just can’t feel sorry for everything. I can’t do that.”

Tracy proudly shares, “I was scared because I didn’t have the voice. You know, now I have the voice to do things, I want to do them! Because I got the voice now.” Part of reclaiming her voice was Tracy’s experience of learning to say “no.” She shares that she used to fear that she would be punished by God if she told someone “no.” Laughing, Tracy explains how her mother helped her to confront this belief:

My momma said, “One day you going to get tired of saying yes. You going to wind up saying no.”… I was like, “If I tell somebody no Mom, then God going to get me.” She said, “No He ain’t. He’s not going to get you.” She said, “You got to learn to say no to certain things you don’t approve of.” I was like, “Okay” and I started using “No, no, no!” So I made that part of my vocabulary—“No, no, no!”

Feeling more confident about expressing herself and moving forward with her life, Tracy would like to return to school and get her high school diploma. She shares that she would also like to go to beauty school and one day open a salon and clothing boutique. She smiles as she reflects:

Yeah, that’s something that will excite me, that will give me a chance to blend in with the community. It’ll give me a chance to greet different people from all over the world. It would give me a chance to, you know… be different for a change. Do something that I always fancied myself doing, seeing myself doing, but wouldn’t allow myself to do.

Community. When asked to describe a time when she felt welcome in her community, Tracy responds that it was when she first arrived at Unity:

I thought, there was people like me. I didn’t feel like that no other time. I didn’t feel welcome. I didn’t…. It made me feel like I belong. I was able to be me. I was able to
express things I was feeling. You know, but they saw it, and that’s what’s so good about it, because they had me see something I couldn’t even see. And I’m supposed to being the one who say, “I see!”

Tracy continues:

They made me see something that I wasn’t able to see. And I’m glad that they did because they help me a heck of a lot. It made me think about life more. It made me think about my journey through life…. I thank them so much for that. That’s why I love them so much. I love Ms. White, Mother Hanson, I love Ms. Parks, I love Ms. Field, I love Ms. Hollins. I love all them because they was… the strongest women I have ever seen do what they did for a person that was very weak. And that was me.

Tracy feels a deep sense of gratitude for this community and especially to the five women who helped her. She continues to rely on their support and advice as she works to move forward. She grins as she states, “I’m… growing [in]to myself now, so, I feel pretty good about it.”

Tracy has many traumatic memories of being bullied and rejected by her peers. She is suspicious of many people, often feeling unsure if they are trying to hurt her, use her, or manipulate her. Tracy is cautious of gossip, and while she tries to be polite, she maintains a careful distance from the women in her neighborhood, hinting that gossiping has hurt her in the past:

I been okay because I stay to myself—and there wasn’t no bad reason why I stay to myself, really I stay to myself because I don’t like gossip. I don’t like drama. I do not like that. If that comes around, I cannot deal. I don’t like it. I don’t like it around my sons, I don’t like it around me…. if it’s something that’s underhanded and sneaky, I cannot do it.
And that other kind of woman, I don’t even float that way. That’s not a good environment for me. That’s actually an environment I was coming from, so no, I can’t deal like that.

Fortunately, Tracy was able to find community with Unity and expresses great affection with the mentors she has met there. While she has not maintained contact with the other women she met in her parenting class at Unity, she does say that she will always greet them and offer words of support when she can.

Concluding thoughts. When asked what she would change if she was in charge of her community, Tracy responds that she would make it so people were no longer homeless. She would also like to change children being taken into the child welfare system, and she becomes emotional as she speaks about parents neglecting their duty to their children and putting their own selfish desires before those of their kids:

You don’t even know what your children are doing. You know what I mean? Your children can get hurt and you don’t even know. It could be right up under your nose, you don’t even know. Because they afraid to tell you and afraid you gonna blame them for it. And next thing you know you find runaways. And you find kids killed. And you find kids in jail. Juvenile.

Tracy would like parents to learn how to become better at parenting and protecting their children. She also wants people to stop making excuses and take responsibility for their actions.

Tracy says that she wants to be known “as a person that wasn’t afraid to tell the truth. A person who wasn’t afraid to become something and didn’t allow life to hold her back. A person who was tired of using excuses for her life.” She goes on to say:
I want people to know who I am. I want people to know that I wasn’t afraid to let life be life. And let whatever going on in they life to express it and not be afraid to express it.…

I want someone else to feel how I feel.

Tracy’s gaze is direct as she says that she wants people to know that she is real and that she was able to overcome her past, stating, “The purpose is to let a person know that this person, this real life person—‘cause I am a real life person—did this.”

When asked what advice she would give her younger self, Tracy responds:

If I can go back to my younger self, I would say, “Don’t be afraid.” I would tell myself to fight for whatever you want, be whoever you want, do whatever you want. ‘Cause you can do it. That’d be what I tell my younger self. If I could go back to my younger self, I would tell that younger self, “Don’t be afraid. Fight for what you want, be who you want to be, and leave it at that. Don’t let no one change it.”… I would tell my younger self this also: “Don’t let no one take nothing from you. Don’t. Don’t. Because it’s not a good thing.” You know? So that’s another thing I’d tell my younger self. And… I would tell my younger self, “Think before you act. Don’t let nothing push you down.”

**Conclusion**

Tracy has faced a great deal of trauma and adversity. She is now 43 years old, and the many experiences of social isolation, rejection, and abuse appear to have resulted in her avoidance of people outside of her trusted circle. There were few supportive figures in her school and none of them appeared to have protected her from the bullying she experienced, and this indifference resulted in years of mistreatment before she finally dropped out of school. Tracy feels she is to blame for this because she remained silent about being bullied, but it is shocking to think that no one in her school ever noticed or witnessed these events. Tracy continues to live
with her boyfriend and her mother. She says her sons no longer live at home. Although she struggles to conceptualize spans of time, Tracy estimates that she first attended her parenting class at Unity last year and has begun to come to terms with what she has experienced in the last few months. While Tracy has suffered a great deal in her past, she has found hope and is developing aspirations for her future. Tracy is the only participant in this study to identify a community to which she belongs. For much of her life Tracy was silenced by bullying, sexual abuse, and violence, but she credits Unity for helping her to find her voice. She has found strength, recovery, and healing in this community and shares that she wants to grow and be more open to the people and opportunities around her.
Chapter 7: Thematic Analysis

The participants in this study each shared their personal experiences with disability and the distinct ways in which it has shaped their perspectives of themselves, their social relationships, and their communities. These narratives highlight the deeply personal experience of disability and the factors that frame it on an individual and cultural level. While each of these participants has shared experiences that are uniquely his or her own, there are similarities among and differences between these narratives that speak to the broader context of disability in our culture.

**Parent Experiences**

Hanna and Sarah offered eloquent portraits of life as the mothers of children with disabilities. Their narratives revealed the ways in which their experiences with disability caused them to reframe their expectations of their own and their children’s life trajectories. They spoke to the difficulty of accessing quality supports and services, the need to maintain vigilance in the face of their fears for their children, and a commitment to forging their own path in defiance of expectations, labels, and the uncertain futures of their families. While countries such as the United Kingdom and Australia have produced a body of research examining the perspectives of families with adult children with intellectual and developmental disabilities (IDD) in recent years, the U.S. literature in this area remains sparse, especially for families whose adult children are no longer receiving educational services.

**Shifting expectations.** While the parenting of typical children and those with disabilities is in many ways similar, parents of children with disabilities face distinct challenges in raising a healthy, happy child while attending to his or her individual needs (McKenzie, Ouellette-Kuntz, Blinkhorn, & Démoré, 2016; Solomon, 2012). These parents may face the challenge of juggling
schoolwork with therapies, balancing the individual needs of the child with those of the family, and reconciling self-care with tending to the needs of one’s children (Krakovich, McGrew, Yu, & Ruble, 2016; McKenzie et al., 2016; Peer & Hillman, 2014). The needs of children with disabilities can be highly demanding and continue into adulthood. This dynamic can result in a shift in the traditional roles of parent and child, especially during the child’s transition into adulthood and the expectations of independence and self-sufficiency that accompany it. While researchers agreed that the majority of individuals with IDD reside at home with their families (Braddock et al., 2015; Hewitt, Agosta, Heller, Williams, & Reinke, 2013), there has yet to be an established consensus on the exact numbers. Braddock et al. (2015) estimated that over 75% of people with IDD reside with a family member, while the National Core Indicators’ (NCI; 2016) surveys indicated that approximately 34% of respondents reported having family members with IDD living at home.

Krakovich, McGrew, Yu, and Ruble (2016) reported that parents of young adults with IDD experience higher rates of stress and distress than their peers due to the unique challenges that they face as they strive to support the full potential and capacities of their children as well as the longer and often more complex transition from educational services to employment, community living, and/or relocation out of the home. There are also concerns about the safety and stability of housing options outside of the home. Woodman, Mailick, Anderson, and Esbensen (2014) noted that parents must contend with helping their adult children to manage the disruption of relocation—or multiple relocations—and the complex factors that go into identifying a good fit, such as staff quality, number of residence, behavioral issues, adaptive supports, and social networks.
Sarah and Hanna both expect that their sons will reside with them at home until they are prepared and desire to move out. Sarah and her husband are committed to providing their sons with a safe and secure space while they finish school, and PMC noted that Sarah was in support of the idea of him living in a small house on their property—though he later asserted that he will be living alone in an apartment. Hanna described how her son, Chinedu, was once invited to share an apartment with his friend, Ben. She recalled how this experience changed her perception of her son:

It’s hard to describe, but when Ben was showing him around that apartment, this look came over him. How can I describe it? It was like he was really checking it out! Like a young man looking at an apartment. He wasn’t looking back at me to see what I thought, he was really checking it out! And it’s just hard to describe…. It was like here’s a young man looking at an apartment!… I really did honestly think for a minute… just his countenance and his demeanor, he may want to do this. And after all that time, to be learning something new about your kid, it’s eye opening. I wasn’t sad or shocked or—it was just a new feeling.

While Chinedu has decided to continue living at home, Hanna wants to make sure that he knows this will always be an option for him. However, she is grateful he decided to stay where she can ensure that he is safe and that his needs are met. Although Hanna has struggled at times and continues to worry about the well-being of her son, she is glad he is at home with his family. She concluded:

That was not a goal for me, for him to get a job so he can get out on his own and move in with some other individuals with disabilities so I can be free on my own and live my life. That is not how I look at it. My husband and I, it’s a matter of faith that we hold very
Dear, that we’re responsible for Chinedu. And we will provide for him as long as we are able.

Hanna and Sarah recognize that the life trajectories of their children may not be able to align with those of typical adults in many ways, and they cope the best they can with this new normal.

Peer and Hillman (2014) found that problem- and emotion-focused coping styles, optimism, and social support served as resilience factors for parents of children with IDD. Both Hanna and Sarah display each of these factors to some degree. They rely on their families for both support and as collaborators in navigating care for their children. Hanna and Sarah were also able to rely on other resilience factors as well. Research has shown that factors associated with parent education, class, gender, and race can impact the experiences of parents as they navigate special education, disability supports, and social services (Blanchett et al., 2009; Erevelles & Minear, 2010; Mueller & Buckley, 2014; Solomon, 2012). Both Sarah and Hanna are well-educated, middle-class professional women. Sarah recently earned her Ph.D. in nutrition and health and Hanna holds a master’s in social work. Sarah was able to draw from her background in education to actively advocate for her sons, and Hanna was able to rely upon her experience as a social worker and her professional connections within the field to effectively navigate services and supports. While Sarah did not share any experiences of being slighted or disregarded by school staff as a result of her gender, Hanna noted that the educational staff at her son’s school seemed much more attentive and respectful to her husband than to her. Hanna stated:

The dynamics are different when you have a husband with you. A man with you. My friend and I at work were talking about this. She kind of said it almost begrudgingly because she’s very much, not a feminist, but she’s like, “What we say should matter.
Why does there have to be a man?” But you know what? Face it, when the dad is there, the dynamics change. They really do. I can remember the staff thanking him for coming. And we got home later and we talked about it, we’re like, “What are they thanking you for? That’s your son!”

Additionally, both described marginalizing experiences that left them feeling unwelcome and isolated. Sarah described her family feeling rejected by the predominantly Christian town she previously lived in and the lack of Jewish community there. Hanna described several experiences that appeared to be racialized responses—such as the cold rejection of the music therapist, the phone call from her son’s speech group telling her that there was no room for him, and interactions with unwelcoming employees at stores. However, Hanna did not directly reference race being a factor in her and her son’s treatment, and when pressed, she responds, “I don’t want to label that, I don’t know what was going on.”

Navigating supports and services. There are four primary areas of supports and services in Michigan provided by federal funding, state administered federal block grants, and state funding. These four areas are income maintenance, healthcare, long-term care, and special education (Braddock et al., 2015). Income maintenance includes federal programs like Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI), and state administered federal block grants for food and housing assistance. Healthcare encompasses federal programming like Medicaid and veterans’ medical care. Long-term care refers to community care and services (such as state IDD agency programs, vocational rehabilitation, and community mental health programs) as well as institutional services (such as nursing homes, institutional care for individuals with IDD, and mental health institutions—which are often funded through federal healthcare programs). The final area is special education, which primarily
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relies on state funding and encompasses all services and supports provided to students with disabilities.

According to the NCI (2016), 26% of Michigan families surveyed stated that they did not get the services they or their family members with IDD needed (compared to the national average of 18%). For example, 14% of Michigan families reported an unmet need for respite care. Michigan rated higher than the national average in unmet job assistance needs (31% vs. 22%), educational needs (33% vs. 17%), and housing assistance needs (19% vs. 14%). Respite care and daytime activities are rated as one of the greatest areas of need for families with adult members with IDD in addition to financial support, access to information about future planning, vocational training, therapies, and health and dental services (M. M. Burke & Heller, 2016; Lunsky, Tint, Robinson, Gordeyko, & Ouellette-Kuntz, 2014).

As people with IDD require individualized supports and services, there is no uniform conception of the factors that may act as barriers to access (M. M. Burke & Heller, 2016). However, barriers to accessing supports and services have been broadly identified as service gaps and long waitlists, lack of access to information, negative experiences that cause families to be hesitant in seeking support, a lack of flexibility in available services, a lack of qualified staff, concerns about safety and quality of care, and a lack of choice in accessing a variety of options for care (M. M. Burke & Heller, 2016; Lunsky et al., 2014; National Core Indicators, 2016).

Hanna and Sarah both articulated challenges in accessing supports and services for their sons. While Hanna has been able to rely upon her knowledge gained from her work at the organization that serves as an information hub for parents of children with disabilities, as well as her professional connections and expertise as a social worker before that, she described her struggle in accessing appropriate therapies and contending with the lack of quality she found at
Chinedu’s previous day program. While his current program could do a better job of communicating with families about the activities, planning, and choices made available to clients (see Chapter 4), Hanna was relieved that Chinedu seemed content and was no longer coming home upset:

I was just so pleased to find a program where… his person would be respected. You know, where he wouldn’t have his property violated, his money stolen, and you know, yelled at. I mean, sometimes… it wasn’t unusual for him to come home in tears or agitated.

The challenge of securing programming with qualified and caring direct support personnel (DSP) is in part due to the low wages associated with the work. According to the American Network of Community Options and Resources (2009), the national average for entry-level DSP positions is $9.37 an hour in a private setting and $12.57 an hour in state settings. In Michigan, the average rate is $8.12 an hour and as all services are provided through private or non-profit organizations, there is no applicable state minimum wage. A survey conducted for the Michigan Office of Services to the Aging and Michigan Department of Community Health by Bridges and Turnham (2013) found that of the 578 direct support professionals participating in a Medicaid waiver program approximately 80% were women and 83% identified as Caucasian. Almost 30% reported having either received a high school diploma or a GED, and 24% reported having some college. Almost 35% of respondents reported an annual household income of less than $20,000. Given the low pay many receive from this work, it is difficult to attract and retain highly qualified and well-educated staff.

Sarah faced her own challenges in accessing services for PMC. After his diagnosis and being told that there was nothing conventional medicine could do to help her son, Sarah turned to
alternative therapies—in addition to speech and occupational therapy—which she paid for out of pocket. Sarah speaks about the challenge of accessing information about potential therapies and supports. She recalls talking with other parents in waiting rooms and scouring the internet. With no quality controls or coordinated system of supervision, Sarah simply tried everything that seemed promising: “It was completely hit or miss. There is no coordinated system for alternative healthcare. But, if it was out there, I considered it. If I heard of it, I considered it.” In addition Sarah had to contend with inadequate information from her son’s schools. Sarah shared:

I remember calling the school system because I was really having a hard time teaching him to read. And the expert on the other end, this was the reading specialist for the school district said, “Teach him Braille.” I was like, “He’s not blind.” Then they tried teaching him whole language. Which means you just learn words without learning to sound them out…. Okay, that didn’t work. So finally I found a program online, Any Child Can Learn to Read, or something. And I bought it and brought it home, and guess what? My son learned to read.

Both Sarah and Hanna were able to gain access to a complex system of supports and services—as well as circumvent barriers—by relying on their educational status and qualifications, experiences in navigating bureaucratic systems, having the confidence to challenge information given by experts, and the personal wealth to secure services on their own.

**Vigilance and fear.** Parents of children with IDD face concerns about the specific vulnerabilities that can arise with this population, particularly in relation to high rates of victimization and the ways in which disability can impair understanding and communication (Office for Victims of Crime, 2016; Olsen, Kruse, Miller, & Brussoni, 2016). Harrell (2015) found that women with disabilities are nearly three times as likely to be victims of violent crime.
than women without disabilities (35 per 1,000 vs. 12 per 1,000). An individual with IDD may not be able to understand when he or she is being lied to, manipulated, or exploited. People with IDD may not be able to clearly communicate what has happened to them when they have been mistreated or assaulted, they may not understand their rights, or how to go about reporting a crime. There are also indications that individuals with IDD are disproportionately involved in crime and incarcerated. A U.S. Department of Justice special report concluded that approximately 20% of prison inmates and 30% of jail inmates reported having a cognitive disability in 2011–2012 (Bronson, Maruschak, & Berzofsky, 2015).

In a Canadian study, Olsen et al. (2016) found that parents of children with IDD’s concerns focused on three primary areas: the individual with IDD’s comprehension of danger, risks associated with physical environments, and risks associated with social environments. The researchers also reported that difficult behaviors and cognitive limitations exacerbated parents’ fears and concerns regarding the safety of their children. While all parents must be attentive to the needs of their children and take measures to keep them safe, parents of children with IDD must also contend with the fact that their sons or daughters may not be able to articulate what is wrong, how they are feeling, or who/what has harmed them. Lunksy et al. (2014) found that parents are less likely to send female adult children to day programs than males. In a qualitative study by Bianco, Garrison-Wade, Tobin, and Lehmann (2009) parents reported the need for constant vigilance to ensure the safety of their children. In addition to working on safe habits—such as locking doors and windows at night—parents also reported the need to monitor and train support staff. These concerns were echoed by mothers in a qualitative study conducted in the United Kingdom (Thackeray & Eatough, 2015). The mothers in this study reported feeling a profound need to protect their vulnerable children and a distrust of paid support staff, resulting in
the need for vigilance. One mother recalled the circumstances of a young woman in her daughter’s group home that caused her great concern:

There is nobody watching out for that young woman and she can’t talk. We have no idea whether anything has happened to her. All we know is that from time to time her behaviour deteriorates and she can’t explain why. (p. 270)

Awaiting the results of an investigation by the police, the mother was considering finding a new placement for her daughter and maintained careful watch over her. These parents communicate the anxiety and fear of being aware of the many ways in which their children could be exploited or harmed. Through constant vigilance and careful monitoring of their children, they strive to keep these threats at bay.

Sarah and Hanna have both experienced concerns for the safety and well-being of their sons. Sarah spent years trying to work with her son’s middle school to protect him from the bullying that went on there and even enrolled him in self-defense classes. While this period of PMC’s life was very difficult, he was able to articulate what was happening to him and why. Fortunately, the bullying ended when PMC left the middle school for high school where he felt safe and accepted. Hanna faced concerns about Chinedu’s difficulty with speech and describes how she learned to carefully monitor him:

I controlled his environment wherever he went because… when his language was much less developed, I had to read him. If he was ill, or what have you. A child with some language can say, “My tummy hurts” or “this pain is sharp here,” “I’m feeling hot Mommy.” No, you got a child with a language impairment, I don’t care what it is, you have to learn to read that child…. And I had to read him, I had to be in touch with him, I had to be protective of him.
It was due to Hanna’s careful monitoring that she realized Chinedu’s money was being stolen at his previous day program. Even now, she is very careful about his safety and well-being. She is watchful of Chinedu when he is in public or around children. She is well-aware that as a tall African American male, Chinedu’s actions or behaviors might be misinterpreted as hostile or dangerous. Hanna shared, “His interests are young and I can understand where parents of small children, if a big guy comes up to them wanting to talk about Micky Mouse. I can see them being concerned about that, even frightened.” Hanna believes that the desire to protect Chinedu after their negative experiences of hostile encounters in the community may have in part contributed to the family’s tendency to stay home much of the time. While Chinedu’s ability to express himself has greatly improved since he was a child, Hanna and her husband strive to respect their son as an adult while keeping him safe when they go out into the community:

When we’re with him in public we try to be respectful and talk to him as an adult and what have you. And kind of keep an eye on him to make sure that somebody isn’t going to pick up on that innocence that his intellectual and developmental disability can present, to exploit him.

Hanna and Sarah have both worked hard to advocate for and protect their children in addition to fostering self-determination and self-advocacy in their sons. Working within the bounds of their means and their circumstances, Hanna and Sarah supported Chinedu and PMC in defying expectations, celebrating successes, and striving to reach their full potential. While their paths have in many ways deviated from the norm, they continue to make their own way on a course that honors the unique needs and talents of their adult children.

*When parents fail to protect their children with IDD.* Hanna and Sarah strive to protect their children. When Hanna heard about the negative experiences her son was having with his
previous day program, she withdrew him and found Chinedu a more respectful and supportive one. When Sarah found out about PMC getting bullied in school, she actively engaged the school to help him and counseled him on managing and avoiding these encounters. But what happens when these vulnerable individuals are left unprotected? Tracy experienced sexual abuse on multiple occasions as a young girl, yet she offers no account of her mother contacting the police or securing counseling services for Tracy to work through this trauma. While her mother did kick out or leave the men who committed these acts, this left Tracy only momentarily safe as she was left to live in fear of the men who had hurt her and the men who could hurt her. Godbout, Briere, Sabourin, and Lussier (2014) found that lack of intervention on behalf of parents whose children are sexually abused can be interpreted by the children as evidence “that the abuser is dangerous or powerful because even the attachment figure is helpless in [the] face of the perpetrator” (p. 322). This may be reflected in Tracy’s assertion that women are not able to fight back against men intent on hurting them (see p. 129). Godbout et al. also reported that a lack of intervention on behalf of a parent can have a profound impact on the abused child’s sense of self and others:

Lack of intervention or deficiency of protective behaviors by nonabusive parents after learning that their children were sexually abused may contribute to the survivors’ perceptions of themselves as nonvaluable and of others as not available for help in time of need. (p. 318)

In a meta-analysis of 13 studies examining sexual abuse in children with IDD, Wissink, van Vugt, Moonen, Stams, and Hendriks (2015) reported the heightened vulnerability of children with ID due to a variety of risk factors, such as trained compliance, social isolation, and the fact that parents of children with ID are less likely to discuss personal safety issues with them. They also noted that it is not uncommon for sexual abuse against children with ID to go unreported to
the police, which is thought to be influenced by factors such as fear of retaliation, a lack of confidence in law enforcement and the justice system, and belief that children with ID will not be believed.

When Tracy disclosed the violence she experienced, it was clear that she does not blame her mother and described her mother as protecting her. Yet the abuse persisted by different men and Tracy gave no account of her mother talking to her about how to stay safe or preventing further harm by supervising Tracy when she was in the homes of family and friends. It could be that Tracy’s mother was forced to sacrifice her daughter’s safety in order to work and keep the family afloat. Or perhaps it was indifference and neglect. It could be that she feared Tracy would be taken away from her or that Tracy would be accused of coming on to these men—as her uncle maintained after he raped her. Tracy insisted on being interviewed alone, even after I offered to come to her house to speak with her mother. Perhaps she feared how her memories would reflect poorly on her mother and was trying to protect her from judgment. One cannot help but wonder how different Tracy’s life might have been if she had a mother like Sarah or Hanna to watch over, protect, and advocate for her. What might have changed if Tracy had a mother who showed her that the people who hurt her would be taken away and punished, and that she was worth protecting?

**Experiences of Individuals with Intellectual and Developmental Disabilities**

Chinedu, PMC, and Tracy have shared compelling narratives of the ways in which they perceive and experience the world. Each has unique circumstances, strengths, and relationships. Yet they have all to some degree experienced social isolation and difficult or unstable relationships with peers. They have all experienced situations in which their opportunities for meaningful choice were diminished. They have all experienced bullying to some degree. And
they have all in their own way defied expectations of what their lives should be like. There is a paucity of literature regarding the perspectives of individuals with IDD, but several studies and accounts have provided much needed insight into the capacity of people with IDD to reflect upon and express the ways in which they experience life (Biklen, 2005; Caldwell, 2010; Copeland, Luckasson, & Shauger, 2014; Kingsley & Levitz, 2007; Mooney, 2007; Pelka, 2012).

Social isolation. While the closing of state institutions for individuals with disabilities in the past few decades—in conjunction with legislation mandating access to community-based supports and services—has led to an increased number of individuals with disabilities living within communities, many people continue to face social isolation. According to the National Core Indicators Adult Consumer Survey (2016), 42% of Michigan respondents with IDD reported that they felt lonely. A further 21% reported that they were unable to see friends when they wanted to, and 22% said they were unable to see family. Twenty-four percent were unable to get transportation when they needed it, and 34% had no friends outside of family and paid staff. The lack of access to social relationships and the support and sense of belonging they provide can have a profound impact on the ways in which an individual perceive him or herself. Advocate and co-founder of People First of Ontario Patrick Worth (1989) once described this experience: “The only people I had in my life were people who were paid to be there. My life wasn’t my life; it was a service” (p. 77).

Accounts by self-advocates with IDD can offer important insights into the experience of social isolation. Actor and self-advocate Jason Kingsley co-authored a book with his friend Mitchell Levitz titled, *Count Us In: Growing Up with Down Syndrome* (2007). In his book Kingsley described feeling socially isolated and was very perceptive of differences in how he was treated from his typical peers and the opportunities he was not given. He stated, “I don’t feel
normal myself. Normal means how you look and how well you behave. I don’t feel I look normal” (p. 71). Often teased by his peers, Kingsley was sensitive to the stigma of disability that came to frame his experience as a teenager. He noted, “People who do the teasing don’t know that I have feelings. My feelings got hurt” (p. 46). Nancy Ward (2000), a prominent self-advocate and disability rights leader describes how when she began her work as a self-advocate, it took some time to become comfortable enough to speak out. Attuned to the balance of power within relationships, Ward was especially perceptive of the ways in which individuals with disabilities were used as objects of charity. Ward also struggled with the ways in which her leadership role informed her personal relationships and had a difficult time understanding whether someone liked her as a friend or just wanted access to her influence. Ward ended up devising a series of tests in order to make the determination, such as asking someone to join her in an activity outside of work. Reflecting upon her development as a self-advocate, Ward noted, “By asking when I didn’t understand, I learned many things, and that in itself made me grow. I also think it helped me to understand that my opinion was valued, and that people really cared about what I thought” (Ward & Shoultz, 2000, p. 178).

While lack of access appears to be one of the greatest barriers to social relationships, a lack of opportunity to develop and polish social skills in addition to a social context that is inflexible and unwelcoming can create further difficulty (McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006; Wilson, Jaques, Johnson, & Brotherton, 2016). There is a wide range of positive indicators associated with social networks and stable relationships, such as increased activity, better health and mental health outcomes, and an increased sense of connectedness and well-being (Wilson et al., 2016).
When asked about his friends, Chinedu listed off his classmates from his adult education program (one of whom was the young man who invited him to share an apartment). He also referred to some of the other adults attending his day program as friends, referring to them as “the gang”: “I saw the gang at the bowling!” When asked if he could describe a time when he felt left out, Chinedu responded, “I wasn’t left out.” PMC shared that he has few friends, but the friendships he does maintain are stable and valued. All of his friends are other young men. PMC stated, “I pick less friends, better quality friends than quantity.” PMC experienced a great deal of rejection from his peers in middle school, but he shared that he got along better with people in high school. He continues to struggle in getting along with his female coworkers. PMC was able to meet and make friends through his Boy Scout troop, as well as in his classes at school. Now that PMC is attending college and working part-time, he does not have as much time to socialize with them.

Tracy spends most of her time with her mother, her children, and her partner. She made few friends during her years in school, and those she did make soon deserted her. Tracy spent most of her youth playing alone in her room after her sister left. She is cautious of the other women she knows but has made connections through Unity that appear to help her feel more comfortable and safe around others. During our interviews at Unity, Tracy walked around speaking to everyone she met and was told she was welcome to make coffee in the staff room. After our interviews, a member of staff would drive her home. Tracy appears to have found a place where people care about her, her well-being, and her safety.

**Bullying.** Chinedu, PMC, and Tracy were all bullied to some extent. Chinedu experienced being bullied by a staff member at his former day program who yelled at him and stole his money. There are no accounts of him being bullied at school; however, it is not clear if
Chinedu would have recognized or been able to communicate that he was being bullied if it did occur. PMC was the victim of severe bullying in his middle school, an experience that resulted in him considering suicide. Fortunately, when he transitioned to high school the bullying stopped.

Tracy was bullied in both middle school and high school. When she transitioned to high school, the bullying worsened, perhaps in part due to the fact that she could no longer rely on her mother being present to console her. Tracy blamed the relentless bullying that she experienced for causing her to drop out of school.

In a systemic review of 11 studies examining factors related to bullying among youth with ID, Mañano, Aimé, Salvas, Morin, and Normand (2016) reported that youth with ID were more likely to be the victims of bullying than their typical peers and that parents often underestimated the number of bullying incidents their child with ID experienced. Most bullying took place in schools, and parents who had regular contact with the school were more likely to have an accurate understanding of the bullying incidents their children experienced. Mañano et al. (2016) distinguished three types of bullying: physical bullying, verbal bullying, and relational or indirect bullying. They noted that studies showed that many youth with ID struggled to understand why they were being bullied, what to do about it, or how to stop it. Christensen, Fraynt, Neece, and Baker (2012) interviewed 137 families, approximately a third of whom had children with ID. They found that lower social skills correlated with increased victimization and that being bullied contributed to feelings of depression and suicidal ideation as well as poorer school performance. The authors noted that bullying of students with ID tends to decrease after middle school and posited that the increase in victimization experienced by students with ID could be due to less developed social skills and the stigma of disability. Hong and Espelage (2012) emphasized the role of the bystander (both antagonistic and protective) in inciting
bullying behavior and highlighted students with ID as particularly vulnerable to victimization. They posited that this may be due to the fact that individuals with ID are perceived as more passive, less likely to seek help, and more likely to be blamed by school officials if the bullying leads to a physical confrontation. Further, the authors stated that students with ID may be more likely to respond to bullying in a way that results in further abuse (for example, reacting with distress rather than ignoring). Hong and Espelage also highlighted the role of social skills and communication, particularly the ways in which struggles in these areas may inhibit effective negotiation of peer interactions. Lastly, Hong and Espelage noted that students with ID were less likely to receive training in bullying awareness and anti-bullying strategies.

**Opportunity for meaningful choice.** Novak-Amado, Stancliffe, McCarron, and McCallio (2013) highlight choice as a vital aspect of self-determination and an important factor in measuring community participation. The opportunity to make choices about how one will live and what one will do is an integral component of personhood. Many individuals with IDD lack opportunities for meaningful choice and expressing preferences about the way they live (Wehmeyer & Abery, 2013). This is especially true for individuals who lose guardianship over themselves and no longer have the right to make decisions about their finances, living arrangements, or support staff (Power et al., 2013; Uekert & Van Duizend, 2011).

A legal case involving a young woman with Down syndrome named Jenny Hatch—*Ross v. Hatch* (2013)—resulted in a shift in the legal conception of an individual’s rights in relation to guardianship and supported decision making. Following a bicycle accident, Hatch had moved in with her employers and friends while she recovered. The parents of Hatch were granted temporary guardianship, which included the power to decide where she would live. After Hatch was placed in a group home against her wishes, she proceeded to repeatedly run away over the
course of the following year. In 2013 the judge agreed to allow Hatch to move back in with her employers in accordance with her wishes. This decision reflects a dramatic shift in guardianship law and the recognition of the rights to supported decision-making for individuals with IDD. While recent years have seen a push in supported decision-making and forms of partial guardianship to allow individuals to retain self-guardianship while getting necessary supports in planning, studies have found that full guardianship is still awarded in the majority of cases (Jameson et al., 2015; Millar & Renzaglia, 2002). While many parents or family members may be concerned that their children with IDD will make choices about their lives that are harmful or reckless, research has shown that with appropriate supports—such as development of self-advocacy skills, goal setting, planning, and problem-solving skills—individuals with IDD are capable of this fundamental right of personhood (Palmer, Wehmeyer, Shogren, Williams-Diehm, & Soukup, 2012; Shogren, Palmer, Wehmeyer, Williams-Diehm, & Little, 2012; Wehmeyer & Abery, 2013). Meaningful choices go beyond what one is having for dinner or what shirt to wear for the day. They entail being able to make decisions about fundamental aspects of one’s life and to pursue the aspirations and experiences that one finds fulfilling.

Chinedu has had opportunity for meaningful choice regarding where he would like to live and which of his passions he would like to pursue. His parents are committed to making sure he is aware of his choices and has the opportunity to follow his aspirations. Chinedu can decide how he spends his time at home, he follows the alarms on his phone when it is time for him to take his medication for his seizure disorder, and has chores that he completes at home. When asked if there was anything he would like to do but has not gotten the opportunity to do yet, Chinedu responded, “I won’t think of it here [I can’t think of anything].” Chinedu’s choices outside of the home are not as clear as he does not articulate the options available to him through his day.
program and his mother has not received information about it beyond that the clients in the program vote on what they want to do. PMC is also able to choose where he lives. He has the opportunity to choose to go to school and work. He has the support of his parents to follow his passion for music and running. He aspires to be a famous musician and plans to finish school in 2018. When asked his future aspirations, PMC spoke of his desire to play more music at public venues and that he would like to be in a romantic relationship someday.

Tracy’s opportunities for meaningful choice have been truncated in many ways. She has suffered a great deal of trauma and appears to have many symptoms of post-traumatic stress disorder (PTSD). She described having anxiety attacks when she saw men in public. Tracy dropped out of school and has not been able to hold down a job. Her circumstances growing up greatly diminished her confidence in making choices, and most of the choices she did make were focused on self-preservation. Tracy is now developing confidence and is able to pursue her aspirations with the support of her community at Unity. She shared that she would like to complete her education and find fulfilling work: “I didn’t get to finish school. So that’s my goal right there. To finish school, get my diploma, and go to hair school. Either hair school or do something that can help some people.”

Defiance of expectations. The voices of experts carry a great deal of weight for families of individuals with IDD, and the decisions of these authorities can have a profound influence over the opportunities individuals with IDD may have. Low expectations inform decisions and can be internalized by individuals with IDD to become a self-fulfilling prophecy (Campanella, 2015). Disability rights leader Nancy Ward did not realize that she had a disability until she was sent to a segregated middle school for students with disabilities (Ward & Shoultz, 2000). It was there that Ward first heard herself referred to as “retarded.” Finishing high school with a special
education certificate, Ward spent 12 years working in food services and retirement homes. She eventually returned to school to earn a GED. In 1980, she began working in a sheltered workshop at Goodwill. Despite being good at her job and filling in for the position of an absent manager, Goodwill refused to allow her to apply for a management position, and when they demanded that she train the replacement manager, she quit (Pelka, 2012). Ward helped to found one of the first self-advocacy groups in the United States called Advocacy First of Lincoln, Nebraska, in 1978. Reflecting on the power of labels, Ward stated, “I feel that either we shouldn’t be labeled at all, or if we have to be labeled we should be helped to understand and deal with it” (Pelka, 2012, p. 175).

At times unable to defy the policies that regulate opportunities and limit their ability to exercise self-determination, individuals with IDD also described periods within which they attempted to regain control over their lives. Ward was able to establish herself as a valued member of her community and found stability and support in these relationships. Kingsley (2007)—the co-author of Count Us In—struggled to “overcome” (p. 14) his disability and was discouraged by his inability to conform to seemingly unattainable life of independence, success, and respect. There is both resistance and resilience manifested when one defies expectations and refuses to accept that one is incapable or helpless.

Chinedu’s parents have been supportive and respectful of his abilities and passions. He went to inclusive schools and participated in inclusive programs, such as the glee club. While there were indications of lowered expectations at school—such as when he came home with coloring pages from high school—Chinedu appears to be content with the choices available to him now and is capable of voicing his dissent when he disagrees. It is not clear how Chinedu experiences or interprets the expectations of others, though his defensive behavior regarding the
Baby Huey (see p. 77) speaks to an awareness of the stigma of disability and his resistance to it. However, it is clear that the expectations of medical professionals greatly influenced the ways in which Hanna perceived her son and his capabilities. She cried when she disclosed how she was told that he would never speak or read, that he could not learn, but was “trainable.” It was not until she realized that he was teaching himself to read that Hanna perceived how this label had informed her view of Chinedu and recognized the need to know him on his own terms.

PMC has spent a great deal of his life being told that he was incapable of things. His mother recalled being told that he would never read, drive, or hold down a job. PMC now does all of those things. PMC is an active self-advocate and does not hesitate to criticize a lack of support from those who are supposed to help him. As an adolescent and now as a young man in community college, he rejected accusations from teachers that he was not working hard enough to keep up with his classmates and advocated for his learning needs. Sarah has been PMC’s role model for challenging the assumptions of those in authority and circumventing barriers that impede his goals.

Tracy did not directly speak to the ways in which negative expectations have framed her experiences, though she shared that she is working on not blaming herself for everything that has happened to her. Tracy also appears to have internalized the positive expectations of her mentors at Unity, which has given her hope and motivated her to pursue her goals. Tracy endured many experiences of violence and brutality as well as profound loss and anguish. Yet she has somehow persevered and is intent on moving forward, determined to make a different life and continue growing into the person she wants to be.
Conclusion

Disability is not the only signifier or ascribed identity that impacts our perceived value in society. Intersections exist with factors such as race and ethnicity, class, gender, and physical appearance, which act to compound and inform context-dependent marginalization and exploitation or, conversely, privilege and power. Vast inequities exist throughout our society and it is within this web of injustice, violence, and control that disability spans and potentially links all human statuses and identities. Confronting various degrees of marginalization and oppression, this diverse community of *Others* faces the difficult balance of fighting for inclusion in a violent culture today while striving to make it a culture worth living in in the future. Given the hierarchized manner in which we frame, interpret, and assign value to meaning and difference, it is not greater access to an unwelcoming and oppressive culture that is needed; rather, it is a transformation of the value systems informing this culture. This begs the question: Inclusion to what?
Chapter 8: Inclusion to What?

This dissertation has examined the question of how adults with intellectual and developmental disabilities (IDD) and their family members perceive and make meaning of their experiences with community, exclusion, and social relationships. Participants have shared their stories of the ways in which interpretations of disability have framed their lives and their endeavors to find a place to belong. This chapter presents an analysis of what makes a community inclusive and the challenges to be confronted in pursuit of that goal, and it concludes with recommendations, limitations, future areas of research, and final reflections.

Disability Revisited

Disability can have a profound impact on how an individual perceives and interacts with the world (Shakespeare, 2014; World Health Organization, 2011). It can also frame the ways in which people will respond to and understand that individual, shaping social experiences and contributing to his or her understanding of self (Ingstad & Reynolds-Whyte, 1995, 2007). Interpretations of disability are constructed through the myriad of lifeworld encounters and experiences that connect meanings—and often stigma—to the condition of difference interpreted as disability.

Disability through the CDT lens. CDT offers an analytical tool to examine the ways in which broader cultural expectations, priorities, and values framed the experiences of the participants of this study. The following section examines the narratives of participants with IDD in relation to personhood and dignity, voice and resistance, and access and inclusion. Personhood and the rights of membership ascribed to it are grounded in a recognition of the inherent dignity of all. Voice and its recognition are integral components of personhood and resisting or confronting the denial of personhood. Opportunities for access allow for community connection
and engagement but rely upon the people within the community to be welcoming and inclusive. In what ways have Chinedu, PMC, and Tracy experienced recognition of these fundamental rights and the opportunities they are intended to provide?

Chinedu’s opportunities to voice his choices and claim authority over his own person are afforded to him primarily because they are defended by his family. His parents protect his opportunities to work and engage while navigating the complex bureaucratic network of services on his behalf. Chinedu is known and appears to be accepted within his small community, yet the extent to which his personhood and dignity are respected outside of his family is unclear. He was mocked and treated with hostility in the past. If a negative encounter occurs while he is out on his own, Chinedu may not know how to respond or what motivated an individual to react that way. Chinedu’s day program did not respond to requests to observe him out in the community during the day; however, there was a small note taped to the wall by Chinedu’s computer. It read: “Safety Rules ACS [Adult Community Services]. 1) I will not yell at staff, 2) No name calling, 3) Do not stand up like that, just sit down and eat lunch, 4) Always stay in the seatbelt until the van stops.” While these rules refer to being civil and behaving in expected ways, only one appears to specifically refer to safety. The remaining appear to indicate that Chinedu must still contend with spending his days under the authority of those who will tolerate a certain spectrum of behavior before setting limits with which he must comply. Chinedu must rely upon his family to stand up for his rights and to lend their voices to his. If something were to happen to his family, it is hard to imagine that these same courtesies would be provided by the staff who would step in to supervise his care.

PMC is a firm self-advocate who is well aware of his rights and how to take advantage of the services that are available to him. PMC is comfortable asserting his voice and resisting
attempts to discourage or deny his personhood. He became angry and frustrated when his needs were not taken into consideration in school, but he can rely on the support of his family, their collective experiences, and their resources to bypass many barriers in the educational system. He has a piano tutor and an academic tutor who has worked with him since he was a small child. PMC asserts his personhood and is more than willing to confront those who would deny it. However, he continues to live in relative isolation and feels he is treated with little respect at work. PMC craves recognition of his talents and achievements, but he has yet to find a community that accepts and welcomes him as he is.

Tracy is gradually reclaiming her power over her life and where it will lead. She is working through the trauma she has experienced and developing aspirations that speak to the ways in which she wants to grow as a person. Tracy expressed eagerness to reclaim her voice and referred to her participation in this study as finally having the opportunity to tell her story. She often appeared self-conscious when she spoke, but she also seemed to challenge herself to assert her needs and gain recognition for her experiences and survival. Tracy’s personhood and dignity were denied by many people throughout her life who appear to have left her unprotected and/or hurt her. Unity Community Resource Center provided her with a space where she feels respected and valued, yet she continues to regard the outside community with anxiety and suspicion.

**Disability and the human rights framework.** The United States has ratified and committed to the implementation of two human rights conventions, the International Covenant on Civil and Political Rights and International Convention on the Elimination of All Forms of Racial Discrimination. These international treaties draw from the UN Declaration of Human Rights to outline provisions such as the recognition of equal dignity, self-determination, and
universal rights as well as the assertion that all people have the right to life, liberty, and security. They are entitled to equal recognition as persons before the law and have an equal right to education. Further, all people have the right to freely participate in the cultural life of their community. In examining the narratives of Chinedu, PMC, and Tracy one cannot help but wonder, are they treated with respect by those outside of their families? Do the social institutions that they interact with prioritize respecting their personhood and preserving their human dignity? Have they been able to freely participate in the cultural lives of their communities?

**Critical disability theory and the human rights framework.** CDT and the human rights framework serve to highlight and confront inequity, its historical roots, the ways in which it functions in our society, and how this contrasts with our established ideals. As a nation, we have committed to a standard of human rights for all. But are they for all in this nation? Human rights require a commitment to the universal application of this standard, yet it appears that our commitment has faltered in relation to many groups who have suffered historical forms of discrimination, based on race, ethnicity, religion, gender, social class and disability. CDT helps illustrate the ways in which language, privilege, and interpretations of difference serve to erode personhood and promote the fallacy that human rights should only be bestowed upon those who are deemed “normal” enough to deserve them. However, these rights are inherently universal, inalienable, and equal. We must be willing to ask questions: Who benefits from the exclusion of individuals like Chinedu, PMC, and Tracy? Why is difference met with derision or disgust? If Chinedu were to stand on the sidewalk in his community, flapping his hands and reciting scripts from a favorite Disney cartoon, how would he be perceived? As a danger in need of supervision? An object of derision? Or as a young man enjoying time outside? What goes into informing these perceptions? There is a great deal of work to be done to confront and work to change the
attitudes and assumptions that reinforce and reproduce the stigma of disability. However, the human rights framework allows for a standard of treatment to which all individuals are entitled. It does not matter how one is perceived, one is the recipient of inalienable and equal rights. This is our standard. We have committed to this ideal as a nation and we must honor it.

**Inclusive Community**

There is no universal conception of inclusive community as the dynamics, circumstances, and contextual factors of every community differ. A community is made up of the unique individuals residing within it. However, there are some common characteristics that can help make a community accessible to all, such as a place that ensures the safety of all members, strives to be welcoming and respectful, and recognizes value in the diverse experiences and perceptions of all members. Sarah noted that it also helps to have accessible furniture, minimized clutter, and plenty of food available. Hanna focused on the welcoming and accepting attitudes that make a community feel inclusive. Chinedu did not articulate what makes a place inclusive, but he smiled warmly when describing the opportunity to make friends. PMC emphasized the importance of feeling respected and valued, while Tracy focused on a sense of trust and security.

**Recommendations**

The narratives shared by the participants of this study help to increase our understanding of the ways in which individuals with IDD and their families experience disability, community, and exclusion. Moving forward, there is a great need for transformative actions and practices that foster inclusive community and create opportunities for challenging the stigma and ignorance around disability while promoting affirmation of the qualities and skills that individuals with disabilities display. These efforts are primarily addressed through the areas of policy and rights, and social and educational recommendations.
Policy and rights. The primary recommendation that emerges from this research study is the United States ratification of the CRPD (2006). This international treaty and the rights enshrined within it echo earlier human rights conventions with a greater emphasis on the unique circumstances of individuals with disabilities and the challenges they face. For example, Article 8 directs nations to develop coordinated educational campaigns to combat the stigma and stereotypes of disability with a focus on promoting inclusion of individuals with disabilities and the talents they can share. Article 16 confirms the right to freedom of exploitation and abuse both inside and outside of the home and directs nations to provide services to individuals with disabilities, their families, and caretakers to help them avoid, recognize, and report abuse. Article 19 defends individuals with disabilities’ right to community inclusion. Article 24 of the CRPD safeguards access to education and further establishes the purpose of education as striving toward:

a) The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;
b) The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;
c) Enabling persons with disabilities to participate effectively in a free society. (art. 24, para. 1-3)

The CRPD outlines the human rights required to enact real and lasting change in the ways in which our society interprets and responds to disability. These ideals provide a robust standard of treatment and opportunity to promote equity and inclusion for all. The rights enshrined within the CRPD overlap with and/or complement the following recommendations:
• Implement a coordinated system of adult supports that are accessible and understandable to individuals with IDD and their families
• Implement information campaigns that educate people about different kinds of disabilities and acceptable ways to respond to them
• Increase oversight of group homes and increase opportunity for client self-determination, choice, social relationships, and support for independent living skills
• Implement funding to allow for greater pay of direct support workers to improve retention of quality staff
• Provide supported employment for individuals with IDD that offers a living wage in meaningful work
• Improve support for parents through information hubs and outreach workers
• Offer help for parents in terms of financial support, respite care providers, and affordable, quality therapies
• Improved access to and coordination among disability rights and advocacy organizations (such as the National Council of Self Advocates, the Autistic Self Advocacy Network, and Americans Disabled Attendant Programs Today) to create a united and cross-disability movement for positive change

**Social and educational recommendations.** Inclusion needs to be a practice that is considered and discussed within the context in which it takes place. Accordingly, our schools and community centers need to work with all students and community members to understand why inclusion is important and how it reflects the values we would like to see in our communities. Schools need to express respect for different kinds of minds and reflect this respect in the presentation of academic content so as not to privilege some modalities of learning over
others. Students with disabilities need a stronger education regarding their rights and improved opportunities for choice-making in addition to social skills workshops and self-advocacy activities. These students should have the opportunity to perceive themselves as rights holders, recognizing when their rights are violated and developing strategies that assist them in defending against and reporting violations of their rights. They need to know how to practice weighing the consequences of a decision. Students need the opportunity to develop the confidence to make choices for themselves rather than always deferring to parents, educators, and staff. They need the chance to learn to recover from poor choices and how to use these consequences to inform future decisions. There is also a need for more inclusive activities outside of the school, such as greater support for social engagement, either through coordinated clubs or online groups for those who are unable to leave their homes.

The issue of bullying must be confronted and attention given to the specific vulnerability of students with disabilities. The U.S. Education Department’s Office for Civil Rights has clarified that unaddressed bullying on the basis of disability in schools can constitute a violation of Section 504 of the Rehabilitation Act (1973) and Title II of the Americans with Disabilities Act (1990), in addition to IDEA’s (2004) provision for FAPE (Lhamon, 2014). Implementation of bullying interventions must be comprehensive and targeted to all levels of the school community. School administrators need to employ anti-bullying programming that includes a focus on disability, provide anti-bullying training for staff to improve coordinated adult supervision, and build clear policies and practices around tracking, reporting, and monitoring bullying of students with disabilities. Recognizing the powerful influence of their own behavior on the classroom community, educators must carefully monitor the ways in which they respond to students with disabilities. Educators need to model welcoming behaviors that foster inclusive
community by actively recognizing and valuing difference while also identifying and confronting bullying when it occurs. They also need to help their students to recognize when bullying occurs and how to respond to it. Students with disabilities need guidance on understanding bullying behavior (for example, identifying when an act is an accident versus being deliberately hurtful) and who they should go to for help when being bullied. Students with disabilities need to be provided with support when bullying does occur, and they need to know that they deserve to be protected. Resources such as the Federal Stop Bullying program (U.S. Department of Health & Human Services, n.d.) and PACER’s National Bullying Prevention Center (n.d.) offer guides, activities, advice on self-advocacy and intervention for administrators, educators, parents, and students.

Educators are uniquely positioned to have a profound impact on the ways in which students experience school, especially for students with IDD. While it can be initially daunting to find that a student with a disability will be included in one’s classroom, it is important for educators to remain focused on the fact that this individual is a child, not a burden. Like their typical peers, students with disabilities have unique strengths and weaknesses that will inform their learning, and it is important to play to their strengths. While it is valuable for a teacher to educate him or herself about the type of disability with which the student has been labeled, it is equally important to recognize the diversity within that broad category and the unique ways in which this disability informs the experience of an individual student. Additionally, educators need to work with the parents of their students with disabilities and take advantage of the insights they provide as experts on their children. Perhaps most vital, educators need to strive to perceive the world from the student’s point of view in order to ensure that they do not take the behaviors of their students with disabilities personally nor impose meanings on these behaviors that the
student does not intend to convey. Educators need to observe how their students with disabilities perceive and interact with the world in order to develop an understanding of the students’ internal worlds and the ways in which these students communicate.

Many of these educator recommendations can also apply to faculty in higher education; however, recommendations specifically focused on the higher education context include the need for familiarity with the disability policies of one’s institution and the disability resources it offers—such as the process of implementing a letter of accommodation (LOA). Faculty members need to be welcoming and accessible to students with disabilities. Within this context, students with disabilities must advocate for themselves, and faculty can support these students by inquiring about what types of accommodations work best and identifying areas of strengths and weakness. Further, if a student chooses to disclose his or her disability to a faculty member, the faculty member must recognize the confidential nature of this disclosure and work with the student to apply the accommodations within the LOA to course requirements.

**What the Study Is Not and Limitations**

This research was a small-scale qualitative research study and while the experiences of the participants can lend insight into their personal contexts and speak to the broader issues they face, the findings of the research are local and specific. However, as Geertz (1973) points out, “small facts speak to large issues,” and the life stories presented here are exemplaric narratives that speak to many other individuals with IDD. As is common in phenomenological research, the intent is to speak to rather than generalize about. Hence, as this study employed convenience and snowball sampling, it does not claim to be representative of the broader population of individuals with IDD and their families, but the lives illuminated by an in-depth exploration of their lifeworlds speak to other lives in similar contexts.
It is noteworthy that the participants who did join the study had the means and time to do so, meaning that those who do not may have offered very different experiences. They also all wanted to tell their stories as a way of giving back and in the hopes of helping other families, which may offer insights specific to these factors. All of the participants with IDD lived with their families, so there are no perspectives of individuals living in group homes. All participants with IDD could also communicate verbally, consequently there was no representation of the nonverbal experience or those who use AAC devices to communicate. All of the participants had to retain self-guardianship to participate in the study, so individuals who have lost guardianship were not included. No fathers or siblings were interviewed; hence, these perspectives are missing and may provide very different insights.

**Areas of Future Research**

Areas of future research should include the perspectives and experiences of fathers and siblings of individuals with IDD. Additionally, there is a need to investigate the perspectives and experiences of those from rural regions, those living in group homes or out-of-home placements, and younger participants who are still in school. It would also be informative to conduct a comparative study of the United States and another country that has a more robust support system for self-advocates and has ratified the CRPD, such as Australia, Denmark, Sweden, and the United Kingdom. A great deal of the current research addressing the experiences and perspectives of individuals with IDD is being authored by researchers in these countries, and their emphasis on and commitment to upholding the ideals of the CRPD while addressing challenges that arise through its implementation can offer guidance and insight toward pushing through ratification of the CRPD in the United States. Further, greater insight would be gained from a longitudinal study that explored the ways in which these families changed over time. It
would also be beneficial to examine the perspectives of those who feel they are successfully included in their communities and the factors that have gone into supporting them. There is a need for a greater understanding of the diverse ways in which disability is experienced at the intersection of race, ethnicity, gender, and class. These voices are largely missing in the literature, as are those of immigrants and refugees with disabilities. There have been few efforts to capture the perspectives of individuals with severe impairments, those who rely on AAC devices, and those who cannot communicate in traditional ways.

**Conclusion and Final Reflections**

When I started this research process, my only hope was that it could make a difference in some way. I felt driven by the needs of former students, many of whom are no longer the small children I knew and now sit on the cusp of adulthood. I wonder if these students will find a place where they can belong and find fulfillment. I worry about what will happen to them when the coordinated educational services fall away and they and their families face the patchwork of nonprofit organizations, private companies, and state services that step into their place.

After meeting the families who participated in this study, my focus shifted in some ways. While I am still concerned about the state of adult services, my understanding of them and the ways in which they can frame the experiences of individuals with IDD and their families has been deepened and transformed by the opportunity to have a window into the lives of these individuals. At times I felt overwhelmed by the gratitude I felt at being trusted with their stories. I still feel the immense responsibility to do justice to them and honor the voices of these families. I worried that my efforts would not be equal to what these families had offered. They surprised me by how gracious they were in welcoming me into their lives. They allowed me to share their
sadness, fears, and disappointments as well as their joys and successes, large and small. I approached these interviews as a student of their lives, and they taught me a great deal.

From Hanna I learned about fragmented dreams reassembled and the strength and patience needed to see them through. Chinedu taught me about the lyrical nature of early animation and the seamless weaving of music and animated clips. I was able to witness how Sarah’s confidence and drive helped her to be a fierce advocate for her four sons and their dreams. PMC shared his intense focus and discipline as well as a deeply reflective sense of self. He was brutally honest and could be unflinchingly critical of others as well as himself. Tracy taught me about the strength of hope and the potential of finding community. Her resilience and capacity for joy amazed me.

At the end of this dissertation, I find myself reflecting on the journey to this point and the ways it has changed me—and not simply as a qualitative researcher becoming more proficient in my technique. I come away from this process humbled by the trust that was given to me. I am more appreciative of the small ways an individual can create positive change, and I am feeling more connected with the people around me in recognition of our shared experiences. I wanted to make a positive difference, and I hope this work can do that. I hope this research will allow the reader to see beyond the label of disability to the shared experiences of living beings. I hope the reader can recognize aspects of him or herself in the lives of the participants. I also hope that this recognition of shared humanity will provide the reader with an appreciation for the gifts of different kinds of minds and how they can contribute to a broader understanding of personhood and community. I want this research to contribute to efforts to make communities more welcoming to those exhibiting differences and the creation of spaces that are inclusive to all. Lastly, my hope is that this research will highlight the need to bring forward marginalized and
often silenced voices to tell their own stories. Everyone has a story to tell, but sometimes we
must learn to communicate with people on their own terms before we are able to understand it.

Language that dehumanizes and excludes has the power to shape how people are
interpreted and perceived. Voices that are silenced result in the public erasure of personhood, and
the fundamental rights this status confers. In order to protect the rights of vulnerable individuals
in our diverse society, such as those with IDD, it is important to defend their humanity and rights
to access community, including education and employment. We suffer a loss when our culture
silences the voices of individuals labeled as different. The destructive and exploitive discourses
operating within our culture not only normalize the privilege of those able and willing to
conform to dominant notions of personhood under the illusion of a meritocracy, but also conceal
the exploitation and oppression of those who can or will not conform. We face the ethical
obligation to bring forth silenced voices to contribute to efforts directed towards challenging
oppressive policies and practices, and urge all members of a community to reimagine voice in
ways that allows for the inclusion of all. Efforts toward a just and equitable society cannot
succeed without the active inclusion and protection of all voices present within it. Our voices
arise in response to the culmination of all of the voices that exist around us and all of the voices
that have come before. The autonomous individual is an illusion maintained through the
oppression and exploitation of the invisible, voiceless majority. We cannot stand in defense of
our voice unless we stand in defense of all voices.
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Publishers.


Roeher Institute.


APPENDICES
Appendix A: Interview Guides

Adults with IDD:

**Interview 1: Guiding Questions**

1. Can you share a memory from when you were in school?
2. Will you tell me about your friends when you were a child?
3. Can you tell me about one of your favorite memories from when you were growing up?
4. What kinds of things did you do for fun as a child?

**Interview 2 (May also include follow-up questions from Interview 1)**

1. Can you tell me about where you live now?
2. If someone asked you about your community what would you tell them?
3. Can you tell me about a time you felt welcome in your community?
4. Can you remember a time you felt left out of your community?
5. If you were in charge of your community, what would you change?
6. Where do you go to have fun in your community?

**Interview 3 (May also include follow-up questions from Interview 2)**

1. What has changed about you since you were a child?
2. What are your favorite things to do?
3. What is something that you want to do, but haven’t been able to do yet?
4. What would you like your life to be like in 10 years?
5. If you could offer advice to your younger self, what would it be?
6. When I introduce you in my book, how should I describe you?
Family Members:

**Interview 1**

1. Can you share a favorite memory of your child?
2. Will you tell me about your experience with disability when you were growing up?
3. Can you tell me about what it has been like to have a family member with a disability?
4. Tell me about the community you grew up in, what was it like?

**Interview 2 (May also include follow-up questions from Interview 1)**

1. How would you describe the community you live in now?
2. Tell me about a time when you went into the community with your child
3. Can you tell me about a time you felt that you and your child were included in your community?
4. Can you remember a time you felt that you and your child were left out of your community?
5. What are the most inclusive/welcoming places in your community?

**Interview 3 (May also include follow-up questions from Interview 2)**

1. What makes a space feel inclusive and/or accessible to an individual with intellectual and developmental disabilities?
2. If you had the power, what would you like to change about how adults with intellectual and developmental disabilities are supported in their communities?
3. What could people in your community do to be more welcoming to people with disabilities?
4. What do you wish that people in your community knew about intellectual and developmental disabilities?

5. What would you like people to know about your child?
## Appendix B: Visual Supports

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<th>Description</th>
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<td><img src="pause.png" alt="Pause Button" /></td>
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<td><img src="x.png" alt="X Mark" /></td>
<td>I am ready to end the interview</td>
</tr>
<tr>
<td><img src="question.png" alt="Question Mark" /></td>
<td>I don’t want to answer that question</td>
</tr>
<tr>
<td><img src="confused.png" alt="Confused Bear" /></td>
<td>That question is not clear</td>
</tr>
<tr>
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<td>I have a question</td>
</tr>
<tr>
<td><img src="pause.png" alt="Pause Button" /></td>
<td>I want to talk about something else</td>
</tr>
<tr>
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<td>Yes</td>
</tr>
<tr>
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Appendix C: Recruitment Flyer

Research Study Investigating the Perspectives of Adults with Intellectual and Developmental Disabilities, Their Family Members, and Their Support Staff

Consider participating in an important dissertation research study:

- Are you an adult (between the ages of 18 and 64) with an intellectual and/or developmental disability?
- Are you an adult family member of an adult with an intellectual and/or developmental disability?
- Do you work as support staff for an adult client with an intellectual and/or developmental disability?

If you answered YES to any of these questions please consider participating in a research study investigating the perspectives of adults with intellectual and developmental disabilities, their family members, and/or support staff.

The purpose of this research study is to investigate experiences of social participation and opportunities for community inclusion for individuals with intellectual and developmental disabilities. Participants will enter the study as a group of two or three (made up of an adult with an intellectual or developmental disability, a member of his or her family, and/or a member of his or her support staff). Participants will be interviewed about their experiences and beliefs around disability, inclusion, and community. All responses will be confidential and the identities of participants will be protected through the use of pseudonyms. Participants will receive a $25 gift card to Target or Amazon to help compensate them for their time.

Please contact Chloe Wilson at cwilso35@emich.edu for more information.

Approved by the Eastern Michigan University Human Subjects Review Committee
UHSSC Protocol Number: 860351-1
Study Approval Dates: 03/16/16 - 03/16/17
Appendix D: Consent Forms

Adults with IDD:

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Informed Consent Form

Purpose of the study
I am a doctoral candidate in the Educational Studies Doctoral Program at Eastern Michigan University. I am interested in understanding what you think about the ways that people talk to you when you visit places in your community. I also want to know about your friendships, the things you do for fun, and how you feel about spending time in your community.

Here are some important things to know about the study:
- Participation in this research study is your choice and you may leave the study at any time with no negative consequences
- Participation involves doing three interviews that will take about an hour each and be recorded with a digital audio recorder
- In these interviews I will ask you questions about your life, your community, and the people you spend time with
- Participation may include observations at recreational activities, like bowling or community concerts
- You will be able to decide what time and what location works best for you to have the interviews
- You will be given a gift card for $25.00 to Amazon or Target for participating in this research study after the final interview

Are there any risks for participation?
There are no expected risks to you for participating in the study. If any of these question make you feel uncomfortable, you do not have to answer them.

Are there any benefits to participating?
This study will help people to better understand the thoughts and feelings of people who have intellectual and developmental disabilities and could help you to think about things that matter to you and what should be changed.

How will my information be kept safe and private?
I will keep your information safe and private by using fake names instead of real names. You can choose a fake name and when what you say is written about, the fake name will be used in the place of your real name. The names of your family, workplace, school, and community will be given fake names as well.

Study contact information
If you have any questions about the research, you can contact Chloe Wilson at cwilso35@emich.edu or by phone at (734)368-1107. You can also contact Chloe Wilson’s adviser, Dr. Valerie Polakow, at vpolakow@emich.edu.

Approved by the Eastern Michigan University Human Subjects Review Committee
UHRC Protocol Number: 860331-1
Study Approval Dates: 03/17/16 – 03/16/17
For questions about your rights as a research participant, contact the Eastern Michigan University Human Participants Review Committee at human.participants@emich.edu or by phone at (734) 487-3090.

**Statement of Consent**

I have read this form. I have had time to ask questions and I understand and am happy with the answers I received. I give my consent to participate and to be audio recorded in this research study.

**Signatures**

__________________________
Name of Participant

__________________________
Signature of Participant  Date

I agree to be audio recorded for this study.

__________________________
Signature of Participant  Date

I have explained the research to the participant and answered all his/her questions. I will give a copy of the signed consent form to the participant.

__________________________
Name of Person Obtaining Consent

__________________________
Signature of Person Obtaining Consent  Date

Approved by the Eastern Michigan University Human Subjects Review Committee
UHSRC Protocol Number: 86031-1
Study Approval Dates: 02/17/16 – 03/16/17
Family Members:

RESEARCH @ EMU

Informed Consent Form: Family Members
The person in charge of this study is Chloe Wilson, a doctoral candidate at Eastern Michigan University. Her faculty adviser is Dr. Valerie Polakow.

Purpose of the study
The purpose of this research study is to better understand the views and experiences of individuals with disabilities, their family members, and their support staff in regards to social relationships, community, and inclusion.

What will happen if I participate in this study?
Participation in this study involves:

- Three interviews that will be approximately an hour long and take place in a setting within which the participant is comfortable and familiar. Interviews will be recorded with a digital recorder and additional data will be collected in the form of observational notes taken during the interviews.
  - The first interview will focus on life history and perspectives on the experiences of the family member with an intellectual and/or developmental disability.
  - The second interview will focus on the personal experience of the participant and his or her perspectives on the experiences of the family member with an intellectual and/or developmental disability.
  - The third interview will focus on reflecting upon the experiences and ideas discussed in the previous two interviews.

- Participation may include observations at recreational activities in public settings.
- Participation in the study will last the duration of the interviews and observations. There may be a gap of a few days to two weeks between an individual’s interviews—depending on the availability of the participant. Participation will end following the final interview.

I would like to audio record interviews with you in this study. While security precautions will be taken to keep this data private and secure, it will be possible to identify you through your voice. If you agree to be audio recorded, sign the appropriate line at the bottom of this form.

What are the anticipated risks for participation?
There are no anticipated physical or psychological risks to participation. Some of the interview questions may be personal in nature and may make you feel uncomfortable. You do not have to answer any questions that make you uncomfortable or that you do not want to answer.

Are there any benefits to participating?
The benefits to you as a participant may be an opportunity to reflect on your own perspectives on and experiences of social relationships, inclusion, and community for your family member who has an intellectual and/or developmental disability as you describe them in the interview process.

What are the alternatives to participation?
The alternative is not to participate.

Approved by the Eastern Michigan University Human Subjects Review Committee
UHSRC Protocol Number: 860351.1
Study Approval Dates: 02/17/16 – 06/16/17
How will my information be kept confidential?
I will keep your information confidential by using a code to label data. The key to the code linked to identifiable information will be stored separately from data. All real names of people, organizations, and locations will be assigned pseudonyms. Your information will be stored in a password-protected computer and all transcripts of interviews will be stored in a locked filing cabinet in a secure location. I will make every effort to keep your information confidential, however, we cannot guarantee confidentiality. There may be instances where federal or state law requires disclosure of your records.

Other groups may have access to your research information for quality control or safety purposes. These groups include the University Human Participants Review Committee, the Office of Research Development, or federal and state agencies that oversee the review of research. The University Human Participants Review Committee reviews research for the safety and protection of people who participate in research studies.

I may share your information with other researchers outside of Eastern Michigan University. If we share your information, I will remove any and all identifiable information so that you cannot reasonably be identified.

The results of this research may be published or used for teaching. Identifiable information will not be used for these purposes.

Storing study information for future use
I would like to store your information from this study for future use related to disability, inclusion, and community. Your information will be labeled with a code and not your name. Your information will be stored in a password-protected or locked file. Your de-identified information may also be shared with researchers outside of Eastern Michigan University. Please initial below whether or not you allow us to store your information:

__________ Yes __________ No

Are there any costs to participation?
Participation will not cost you anything.

Will I be paid for participation?
You will be given a gift card for $25.00 to Amazon or Target for participating in this research study after the final interview.

Study contact information
If you have any questions about the research, you can contact the Principal Investigator, Chloe Wilson, at cwilso35@emich.edu or by phone at (734)368-1107. You can also contact Chloe Wilson’s adviser, Valerie Polakow, at vpolakow@emich.edu.

Approved by the Eastern Michigan University Human Subjects Review Committee
UHSRC Protocol Number: 200351-1
Study Approval Dates: 05/18/16 – 03/16/17
For questions about your rights as a research participant, contact the Eastern Michigan University Human Participants Review Committee at human.participants@emich.edu or by phone at (734)487-3090.

Voluntary participation
Participation in this research study is your choice. You may refuse to participate at any time, even after signing this form, with no penalty or loss of benefits to which you are otherwise entitled. You may choose to leave the study at any time with no loss of benefits to which you are otherwise entitled. If you leave the study, the information you provided will be kept confidential. You may request, in writing, that your identifiable information be destroyed. However, we cannot destroy any information that has already been published.

Statement of Consent
I have read this form. I have had an opportunity to ask questions and am satisfied with the answers I received. I give my consent to participate in this research study.

Signatures

Name of Participant

Signature of Participant ____________________________ Date

I agree to be audio recorded for this study.

Signature of Participant ____________________________ Date

I have explained the research to the participant and answered all his/her questions. I will give a copy of the signed consent form to the participant.

Name of Person Obtaining Consent

Signature of Person Obtaining Consent ____________________________ Date
Appendix E: IRB Approval

RESEARCH @ EMU

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<tr>
<th>UHSRC Determination:</th>
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<td><strong>DATE:</strong> March 17, 2016</td>
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| **TO:** Chloe Wilson  
Eastern Michigan University |
| **Re:** UHSRC: # 860351.1  
Category: Expedited category 7  
Approval Date: March 17, 2016  
Expiration Date: March 16, 2017 |
| **Title:** Claiming Community: Perspectives of Individuals with Intellectual and Developmental Disabilities, Their Families, and Their Support Staff |

Your research project, entitled Claiming Community: Perspectives of Individuals with Intellectual and Developmental Disabilities, Their Families, and Their Support Staff, has been approved in accordance with all applicable federal regulations.

This approval included the following:

1. Enrollment of 20 subjects to participate in the approved protocol.
2. Use of the following study measures: Interview Questions for Adults with Intellectual and Developmental Disabilities; Interview Questions for Family Members; Interview Questions for Support Staff
3. Use of the following stamped recruitment materials: Recruitment Flyer
4. Use of the stamped: Informed consent forms (Adults with Intellectual and Developmental Disabilities; Family Members; Support Staff)

**Renewals:** This approval is valid for one year and expires on If you plan to continue your study beyond , you must submit a Continuing Review Form by to ensure the approval does not lapse.

**Modifications:** All changes must be approved prior to implementation. If you plan to make any minor changes, you must submit a Minor Modification Form. For any changes that alter study design or any study instruments, you must submit a Human Subjects Approval Request Form. These forms are available through IRBNet on the UHSRC website.

**Problems:** All major deviations from the reviewed protocol, unanticipated problems, adverse events, subject complaints, or other problems that may increase the risk to human subjects or change the category of review must be reported to the UHSRC via an Event Report form, available through IRBNet on the UHSRC website.

**Follow-up:** If your Expedited research project is not completed and closed after three years, the UHSRC office requires a new Human Subjects Approval Request Form prior to approving a continuation beyond three years.

Please use the UHSRC number listed above on any forms submitted that relate to this project, or on any correspondence with the UHSRC office.

Good luck in your research. If we can be of further assistance, please contact us at 734-487-3090 or via e-mail at human.subjects@emich.edu. Thank you for your cooperation.
Sincerely,

Joan Cowdery, PhD
Vice Chair
University Human Subjects Review Committee
Appendix F: Accessible Chapter Summaries

Chapter 1: Introduction

- This research explored the lives of people with intellectual and developmental disabilities and their families.
- There are many people with disabilities living in the United States, yet many communities and neighborhoods are not welcoming to people with disabilities.
- People with disabilities should be valued as members of their communities and it is important that they speak out about the things they have experienced.
- Everyone has talents they can share and everyone should have the chance to develop and use these talents.
- People with disabilities should be respected and included in their communities.
Chapter 2: Literature Review

- We often call differences in the ways people see, hear, move, feel, or think disabilities when they are not seen as typical or normal.
- Some people believe that disabilities are a sort of punishment or that they should be cured.
- Other people believe that a disability is simply a difference that some people experience and that people with disabilities should have a right to supports that would allow them to work and live in their communities.
- People with disabilities used to be sent away from their families to live in institutions, but parents of children with disabilities, self-advocates with disabilities, and their allies worked hard to change this.
- Now people with disabilities have a right to an education and to live in their communities thanks to laws such as the Americans with Disabilities Act of 1990.
- There is still much work to be done to fight for the rights of people with disabilities.
- We must be committed to treating people with disabilities with respect, listening to what they have to say, and protecting their right to make choices for themselves.
Chapter 3: Methodology

- In this research study, people with intellectual and developmental disabilities and their family members were interviewed in order to better understand their lives.

- During these interviews, it was important for me to carefully listen to what people said and try to understand how they saw the world.

- I also had to make sure that the people who joined the study had the supports they needed to prepare for the interviews and share their experiences (such as a list of interview questions before each interview).

- Five people were interviewed for the study, three people with intellectual and developmental disabilities and two family members.

- Everyone who participated in the study chose a fake name so that no one would know their real names and their identities would be protected.
Chapter 4: Hanna and Chinedu

- Chinedu lives at home with his mother Hanna and his father Udo.
- Hanna is an African American woman in her 50s who works for an organization that helps families with children with disabilities to find resources and information.
- Chinedu is an African American man in his 30s who has autism and a seizure disorder.
- Chinedu spends his mornings and early afternoons at a day program for adults with developmental disabilities and he works on making music videos when he comes home.
- When Hanna first found out that Chinedu had autism, she was scared because she did not know how it would affect his life.
- Now Hanna is proud of her son and happy that he can spend time doing things he enjoys and is good at.
- Chinedu taught himself how to use an editing program to make his own music videos of his favorite songs and cartoons (he calls these music videos his inventions).
- Chinedu enjoys showing people his inventions, listening to music, collecting YouTube clips to add to his library, and spending time with his pals.
- Hanna and Chinedu do not go out into their community very often because in the past people have been rude and unwelcoming to them.
- Hanna hopes that communities will become more welcoming to people with disabilities and that Chinedu will be able to continue doing things he enjoys and making choices for himself.
Chapter 5: Sarah and PMC

- PMC lives at home with his mother, Sarah; his father, Ben; and his three brothers.
- Sarah is a Caucasian woman in her 50s who work in finance and also teaches online courses at a university.
- PMC is a Caucasian man in his 20s who has a traumatic brain injury and a visual impairment.
- PMC spends his days working at a restaurant, taking classes at a community college, exercising, and playing music.
- When PMC was young, Sarah was told by teachers that he would not be able to read, work, or drive a car. She did not believe them and worked with PMC to be able to do all of those things.
- In middle school PMC was bullied, and this made him feel very sad. He had a much better time in high school and was able to make friends. He also enjoyed being in Boy Scouts and became an Eagle Scout.
- PMC loves playing music and writing songs. One day he wants to be a famous musician.
- Sarah hopes that when people meet PMC they will be welcoming and willing to get to know him.
Chapter 6: Tracy

- Tracy was interviewed alone for this research.
- Tracy is an African American woman in her 40s who lives with her boyfriend and her mother. She has an intellectual disability and is the mother of four sons.
- Tracy was bullied in school when she was young and had no friends. She would often play by herself with Barbie dolls and board games. The bullying was so bad that Tracy dropped out of high school and did not get to finish her degree.
- Tracy was abused by several men when she was younger, and it made her afraid to be around men.
- When she grew up, Tracy did not spend time with people outside of her family until she went to a parenting class at a community organization called Unity. There she met some kind and welcoming people who supported and helped her.
- Tracy wants to share her experiences so that people in similar situations can have hope that things get better. She is learning to speak out when something bothers her and to not blame herself when something goes wrong.
- Tracy has overcome many difficult experiences and hopes to one day return to school to finish her degree. She would also like to open a clothing store and a salon.
Chapter 7: Thematic Analysis

- The experiences shared by the people interviewed for this study can help us to understand how disability has affected their lives.

- The parents in this study (Hanna and Sarah) were both very supportive of their sons and worked hard to help them learn and grow at their own pace.

- Hanna and Sarah talked about how it was often hard to find good therapies or supports for their sons.

- These mothers also talked about how they worried about the safety and happiness of their sons and how they tried to protect them from people who were rude or mean.

- The people with intellectual and developmental disabilities (Chinedu, PMC, and Tracy) faced challenges such as having few or no friends and being bullied.

- Chinedu and PMC were able to make choice about the ways they wanted to live their lives and how they spent their time.

- Tracy did not have many choices, and this was sometimes upsetting and scary for her.

- All of the people in this study should have a community that welcomes and values them, yet many do not.
Chapter 8: Inclusion to What?

- Our communities are often not welcoming or easy to get around in for people with disabilities. We need to work to make them more welcoming and accepting.

- This chapter offers ideas for how to help communities become more welcoming.

- People with disabilities should have their rights respected. An international agreement called the Convention on the Rights of Persons with Disabilities would help to protect the rights of people with disabilities to work and live in our communities. The United States should adopt this agreement.

- People with disabilities should be able to get the supports and services they need.

- The people who support individuals with disabilities should be well-trained and well paid.

- Communities should help everyone to understand disabilities better and how to be welcoming to people with disabilities.

- People with disabilities need to learn about their rights and have the chance to make choices for themselves about how they want to live.

- Schools and teachers need to do a better job of protecting students with disabilities from bullying and help students who are bullied to understand how to deal with it and who to go to for help.

- Teachers need to work to get to know their students with disabilities and help them to learn in ways that work best for them.