

MEANING MAKING AND IDENTITY FORMATION  
AMONG ADULTS WITH INTELLECTUAL  
DISABILITY: A RELATIONSHIP-BASED APPROACH

By

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Abstract: Research using a storytelling approach to examine meaning making and identity formation processes among adults with intellectual disability have shown to be a source of individual empowerment (Grove, 2012). The current study aimed to amplify the voices of adults with intellectual disabilities by seeking to understand their personal and social identities and meaning making processes of lived experiences. Furthermore, the current study employed and examined the use of a relationship-based storytelling methodology taking an intimate inquiry approach through a storytelling lens as a relevant method for examining identity and meaning making among adults with intellectual disabilities. The current study examined the relevance of using an intimate inquiry approach through the theoretical lenses of storytelling and a strengths-based socio-ecological model to understanding identity among young adults with an intellectual disability. Results of the storytelling analysis revealed three overarching themes related to current identity: pathways to independence, relationships, and spirituality. Furthermore, results demonstrate intimate inquiry through a storytelling lens as an appropriate methodology for examining identity formation and meaning making processes among adults with intellectual disability.

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## CHAPTER I

### INTRODUCTION

The concept of identity is essential for understanding and interpreting human behavior and phenomena (Groves, Rayner, & Muncer, 2018). “Identity is composed by individuals as they articulate and share their life stories” (Henderson & Bigby, 2019, p. 429) deriving meaning from lived experiences. However, in the field of intellectual disability, understanding of meaning making and identity formation largely relies on reports from caregivers and professionals. Furthermore, when employing self-report from adults with intellectual disability, researchers often assume that disability is central to identity (Beart et al., 2005), drawing harsh conclusions about adults when they do not disclose disability as part of their chosen identity (Povee, 2014). As such, the voices of adults with intellectual disability have further been marginalized in the field. The current study seeks to amplify the voices of adults with intellectual disability to understand their meaning making and identity formation processes utilizing relationship-based qualitative methodologies. Meaning making and identity formation processes maintain their interrelatedness as both are derived from societal understandings’ interrelations with personal lived experiences (Henderson & Bigby, 2019). Unfortunately, for much of

history, societal understandings have been the foundation for stigma, discrimination, and oppression of adults with intellectual disability (Wehmeyer, 2013). Despite experiencing such stigma and oppression in their lives, many adults with intellectual disability maintain a positive sense of self (Strnadová, Johnson, & Walmsley, 2018), demonstrating resilience through their lived experiences.

While much is to be explored with regard to meaning making and identity formation processes among adults with intellectual disability, studies have demonstrated that mental models of reporters and researchers need to be understood to interpret the results. When scholars assume that disability is central to the adult's identity, scholars tend to make harsh conclusions regarding the cognitive capacities of the adults or lack of acceptance when the adults fail to emphasize disability as central to their identity (Beart et al., 2005). However, when disability is not assumed to be central to adults' identity, scholars have found meaning making and identity formation processes to mirror processes undertaken by adults without disability (Povee, 2014).

### **Key Constructs**

Several terms referred to within the current literature review can often be misconceptualized due to lack of consensus among scholars in their definition. For this reason, the terms *intellectual disability*, *meaning making*, *ascribed identity*, and *chosen identity* are defined here.

## ***Intellectual Disability***

Intellectual disability has been widely misused and tends to be largely misconceptualized as an individual deficit (Wehmeyer, 2013). For this reason, meanings associated with intellectual disability as noted by Brown and colleagues (2017) are presented. Brown et al. highlight four meanings associated with developmental disabilities: *personal*, *public*, *critical*, and *definitional*. Personal meaning is the meaning of developmental disabilities held true for the individual with developmental disabilities in which disability does not exist. The best understanding of personal meaning comes from the stories and interactions one shares with individuals with developmental disabilities. Public meaning regards society's general perception and depiction developmental disabilities and is a result of both literal (semantics) and sociocultural meanings associated with the term. Emphasizing the need for equality and self-advocacy, critical meaning relates to oppression of individuals with developmental disabilities by individuals without disability in positions of authority and power. Definitional meaning is associated with diagnostic criteria such as those set forth by the American Association on Intellectual and Developmental Disabilities (AAIDD) defining intellectual disability as “a disability characterized by significant limitations in both intellectual functioning and adaptive behavior” (pg. 13) and originating prior to the age of 22. Intellectual functioning captures problem-solving, learning, and reasoning (Shalock, Luckasson & Tassè, 2021). Adaptive behavior is defined as the assembly of skills which are practical, conceptual, and social in nature and how they are demonstrated in one’s everyday life (Tassè et al., 2012). The review of literature emphasizes the personal meaning associated with intellectual disability.

### ***Meaning Making***

Meaning making is a process of deriving meaning or personal truths from one's lived experiences (Henderson & Bigby, 2019). Critical for identity formation, meaning is often derived from personal stories about lived experiences. Having safe spaces and capacity to share personal stories are critical for the meaning making process (Phillips & Bunda, 2018).

### ***Ascribed Identity***

Ascribed identity is the culmination of definitions that other's use to dictate one's identity (Sutherland, 2005). While some aspects of ascribed identities are held true by oneself, ascribed identities assume others have the power to define a person (Gillman, Heyman, & Swain, 2000).

### ***Chosen Identity***

Chosen identity is the collective of definitions one holds true for themselves. Chosen identity is influenced by cultural and lived experiences and can only be dictated by the person holding the identity (Castells, 1997).

The subsequent chapter, Chapter 2, discusses current literature on meaning making and identity formation among adults with intellectual disability. Chapter 3 presents the current methodology for the current study. Chapter 4 presents the results of the current study. Finally, Chapter 5 discusses the implications of the current study as well as directions for future research.

## CHAPTER II

### REVIEW OF LITERATURE

Fundamental in understanding and interpreting human behavior and phenomena is the concept of identity (Groves, Rayner, & Muncer, 2018). Identity is important as it provides individuals with a continued sense of self across social roles and experiences and informs research, yet continues to be largely unexplored. The majority of what little we know about identity in the field of intellectual disability is rarely informed by individuals with intellectual disability (Beart, Hardy, & Buchan, 2005). Arguably, this has less to do with communicative and participative abilities of the adults themselves and more to do with the lack of accessibility of research within the field. Furthermore, when adults with intellectual disability are involved in the research, many researchers enter the field with mental models of disability as central to identity (Povee, 2014). This presents further challenges to our understanding of identity. As a result, the voices of adults with intellectual disability have widely been excluded from research in the field of meaning making and identity formation. Identity is best understood through an examination of its personal meaning (Stryker, 1968). Research using a storying approach to examine meaning making and identity formation processes among adults with intellectual

disability have shown to be a source of individual empowerment (Grove, 2012). The current study aims to amplify the voices of adults with intellectual disability by seeking to understand their chosen and ascribed identities and meaning making processes of lived experiences. Furthermore, the current study examines the use of relationship-based, intimate inquiry as a relevant method for examining identity and meaning making among adults with intellectual disability.

### **Meaning Making and Identity Formation**

Meaning making and identity formation have long been studied and understood as a complex phenomenon impacted by environments (Beart et al., 2005). As literature on meaning making and identity formation among adults with intellectual disability is scant, the current literature draws from identity theory's assumptions of identity construction to understand identity formation generally and among adults with intellectual disability.

#### **Meaning Making**

Meaning making is the process by which meaning is derived from an experience or situation. As it relates identity formation, meaning making is the process by which meaning is derived from lived experiences (Henderson & Bigby, 2019). The retelling of lived experiences through stories provides a channel for deriving meaning from lived experiences. Personal stories are born from one's repertoire of narratives and experiences, such as culture and family history, situating oneself meaningfully in their world through unification of one's past, present, and future (Phillips & Bunda, 2018; Singer, 2004). Deriving meaning from one's life experiences provides a personal sense of purpose and is critical for understanding identity formation (Singer, 2004).

## **Identity Formation**

“Identity is a life story” (McAdams, 1987, p. 187). Identity is viewed as a collaboration among social and personal constructs which capture one’s biography (Shakespeare, 1996). Social identities, often ascribed and sometimes chosen, are derived from one’s social position which defines their affiliation within a larger group through shared meanings (Burke & Stets, 2009). Chosen identities are the identities held true, or chosen, by the person, demonstrating one’s own uniqueness. The focus of identity theories is on social structures and their relationships with identity, emphasizing the impact of such social structures on identity association to families, employment, and culture (Stryker, Serpe, & Hunt, 2005) as shared meaning links identity to role performance or behavior. Identities are viewed as salient in a socially structured hierarchy. In this way, identities are tied to role performance; therefore, identities, both ascribed and chosen, often change in different social structures (Burke & Reitzes, 1981).

## **Meaning Making Among Adults with Intellectual Disability**

Societal understandings of intellectual disability are critical for understanding meaning making and identity formation among adults developmental disabilities (Wehmeyer, 2013) as language and communication play key roles (Gallus & Jones, 2017). Language used by others in the presence of adults with developmental disabilities appears to infiltrate into their identity (Grove et al., 2018). Unfortunately, “for much of history, what [adults with intellectual disability] have learned about themselves is that they are the problem” (Wehmeyer, 2013, p. 125). Until recently, deficit-based mental models have commonly been used to understand disability. These deficit-based mental

models are drawn from historical perceptions of intellectual disability as a “disease” that required segregation and isolation until “fixed” (Wehmeyer et al., 2017). Through growing, yet still limited, understandings of disability as a natural part of human diversity, research has begun to move towards strengths-based mental models which regard disability as the result of environmental demands mismatched with individual functioning, instead of the other way around (Shogren et al., 2017). Through increased employment of strengths-based models, adults maintain a positive sense of self and meaning despite negative societal perceptions (Strnadová, Johnson, & Walmsley, 2018), reflecting resilient identities.

Personal lived experiences for adults with intellectual disability are more likely to be impacted by societal understandings of intellectual disability (Wehmeyer, 2013) and are fundamental to meaning making. Lived experiences are best shared through stories (Singer, 2004). Stories, once told, can be used to make meaning of life experiences by drawing inferences to provide additional insight into the self and the world around oneself (Phillips & Bunda, 2018). Stories are built upon one another, each offering new opportunities for meaning making and situating oneself on pathways towards their personal life goals. With greater self-knowledge comes greater continuity to one’s sense of identity (Singer, 2004).

### **Identity Formation Among Adults with Intellectual Disability**

Identity can be understood as “an explicit theory of oneself” (Moshman, 1999, p. 78). Identity is plural and fluid. Identities are both sources of meaning and lived experiences, differing at the personal and social levels. Some identities are ascribed



(Kittelsaa, 2014), however, only the identities that have personal meaning and have been internalized become chosen identities (Castells, 1997).

### **Ascribed Identity**

Ascribed identity is the collective of definitions dictating one's identity (Sutherland, 2005). Ascribed identities are more common among marginalized populations, such as adults with intellectual disability, as societal perceptions create negative stigma towards categories of people. Disability is often viewed as a "master status," obscuring all other identities (Becker, 1973); yet, for adults with intellectual disability, intellectual disability is typically an ascribed identity as the adults are rarely the persons to seek out the initial diagnosis (Kittelsaa, 2014).

Adults with intellectual disability were often introduced to the language of intellectual disability through their parents, who are introduced to the language of intellectual disability through a diagnosis by the diagnosing professional (Gallus & Jones, 2017). While diagnoses are beneficial for the provision of services and supports for individuals with support needs, intellectual disability diagnoses are often misused as a stereotyping label; a label that is associated with negative societal perceptions (Wehmeyer, 2013). For these reasons, acceptance of intellectual disability label can create personal conflict as the benefits of acceptance tend to come with a price. While some adults have noted that intellectual disability provide opportunities for systems of supports, many adults highlight that they coexist with stigma, discrimination, and oppression (Logeswaran et al., 2019).

## *Stigma and Oppression*

Stigma is “the process by which the reaction of others spoils normal identity” (Goffman, 1963, p. 5). In other words, stigma occurs when others react negatively to one’s normality. As it relates to intellectual disability, stigma is especially prevalent and associated with negative stereotypes that are widely accepted, such as being child-like and invariably impaired (Gilmore et al., 2003; McCaughey & Strohmer, 2005). Of great importance are the conditions in which stigma occurs: through power imbalances. Stigma is thought to meet human needs for those stigmatizing others as a function of survival - allowing one to discount the unknown to maintain or increase one's self-esteem. Adults with intellectual disability are often disempowered by those with greater power within a social institution because of the unknown (Scior, 2016). Despite indisputable improvements in attitudes and accepted beliefs about intellectual disability over time (Wehmeyer, 2013), adults with intellectual disability are consistently viewed towards the bottom of social hierarchies. Unfortunately, "as long as intellectual disability is viewed as impeding someone’s contribution to society, it will continue to be stigmatized" (Scior, 2016, p. 7). Oppression of adults with intellectual disability is often the consequence of stigma and discrimination (Groves et al., 2018).

The conceptualization of intellectual disability has evolved over the years from a deficit-based mental model to strengths-based mental models defining disability as a mismatch between a person’s functioning and environmental demands (Schalock, 2013). While many strides have been made towards this shift in thinking, much of what we know about identity formation among adults with intellectual disability continues to assume intellectual disability as central to one’s identity as researchers have the tendency

to assume that intellectual disability plays a primary role in the personal identities of adults with intellectual disability (Povee, 2014). When this is the case, assumptions are made regarding the cognitive abilities of adults if they do not highlight intellectual disability as central to their identity. These adults are often believed to be in denial of their intellectual disability, lacking cognitive capacity to understand their intellectual disability, or protected from their intellectual disability (Beart et al., 2005). However, when the researcher's mental models shift from this biased thinking and allow the young adults to speak for themselves, the literature supports high levels of awareness and varying levels of acceptance of intellectual disability but maintains intellectual disability should not define the adults (Kittelsaa, 2014).

Diagnoses and labels become stigmatizing when the person's strengths and uniqueness are ignored while the label becomes the emphasis (Shakespeare, 2006). Assuming that a person would associate with the identities and labels that are ascribed to them by others in society assumes that others have the right to define a person's identity (Gillman, Heyman, & Swain, 2000).

### **Chosen Identity**

Intellectual disability is rarely emphasized by adults with intellectual disability as critical to their chosen identity (Logeswaran et al., 2019). Chosen identity, also known in literature as personal identity, is the makeup of the definitions one holds true for themselves (Castells, 1997). Instead of being defined by their intellectual disability, most adults highlight their ordinariness and normalcy of everyday living noting their personal characteristics, capabilities, talents, skills, hobbies, interests, roles, and relationships as

central to their identity (e.g. I am kind, a hard worker, a good cook, artistic, and helpful; Kittelsaa, 2014; Robinson et al., 2020). Each of these chosen identities mold and are molded by belonging (Strnadová, Johnson, & Walmsley, 2018).

### ***Belonging***

Belonging is at the core of identity (Shakespeare, 1996). Carter (2021) describes belonging as “the intimacy, affiliation, membership, reciprocity, and relationships that people often yearn for within a community” (p. 2). To belong, Carter argues, is to be *present, invited, welcomed, known, accepted, supported, cared for, befriended, needed, and loved* within a community or group. Belonging is about focusing on each individual while inclusion tends to lose sight of individual agency. Belonging extends beyond inclusion to include the depth of connection and reciprocity that young adults with intellectual disability desire. As one adult noted regarding the difference between inclusion and belonging, “they include me. That is different to when I belong” (Strnadová et al., 2018, p. 1094).

“Belonging is rooted in relationships. Having people in our lives who know us, like us, accept us, need us, miss us, and love us is at the heart of our wellbeing” (Carter, 2021, p. 1). Robinson and colleagues (2020) identified feeling safe, welcomed, recognized, known, and valued as core components of belonging. In their study with young adults with intellectual disability, Robinson et al. conducted semi-structured interviews to examine belonging finding family relationships, friendships, group memberships, and positive relationships with support workers to be of most importance. The young adults in the study felt they most belonged when they were surrounded by familiar faces and felt

connected to others. These experiences of belonging are also common among young adults without disability (Warr, 2015), highlighting the ordinariness of belonging.

“Belonging is not a special need, it is a universal need” (Carter, 2021, p. 6).

Chosen identities among adults with intellectual disability reflect many of the same characteristics of chosen identities for adults without disability (Povee, 2014). Despite these congruencies, there are some striking contrasts. Unlike adults without disability, adults with intellectual disability are often presented to adult life in a structured sense, offering limited roles in adulthood (Schalock, 2004). Parents and professionals are primary influences on the pathway to adulthood for adults with intellectual disability. As such, they contribute to the processes of enablement and disablement through their work as well as their mental models. In this way, the identities of adults with intellectual disability are often constructed by parents and professionals, dictating who the young adults are and their possibilities of being in the future (Morris, 2004). However, meaning making and identity formation are very personal processes and should be understood on a personal level.

Adults with intellectual disability must have opportunities to share their lived experiences and what constitutes their personal identity – without assuming disability as central to their lives (Beart et al., 2005). Understanding the chosen identities of adults with intellectual disability is critical for creation of communities that foster belonging and implementation of individualized systems of supports designed to foster achievement of personal goals and aspirations. To understand these complex phenomena, engagement in purposeful dialogue with adults with intellectual disability is necessary (Gallus & Jones, 2017).

## **Theoretical Frameworks**

To understand identity formation and meaning making among adults with intellectual disability, the current study is modeled from two theoretical frameworks: the socio-ecological model of disability and storytelling. The socio-ecological model of disability is the theoretical lens in which the current study conceptualizes intellectual disability. Storytelling is the theoretical lens in which the meaning making and identity formation processes will be understood and examined. The collaboration of the two theories fit well together in that they both emphasize individual voice, choice, empowerment, and accessibility.

### **Socio-ecological Model of Disability**

Consistent with current literature examining identity and meaning making among adults with intellectual disability (see Gallus & Jones, 2017), the current study employs the socio-ecological model of disability as the primary theoretical framework for conceptualizing intellectual disability. The socio-ecological model of disability holds roots in the social model of disability, which is commonly used to understand disability more broadly. The social model of disability was derived from the Fundamental Principles of Disability (UPIAS, 1976), arguing disability is a result of societal barriers instead of individual impairment (Oliver, 2013). The socio-ecological model of disability is a broad framework that acknowledges and emphasizes the unique strengths and limitations that make up one's profile. In this view disability resides at the intersection between an individual's profile and the demands of the environment. Disability is fluid,

not static as historically perceived. The socio-ecological model of disability regards intellectual disability as a natural part of human diversity (Shogren et al., 2017).

The AAIDD's multidimensional model of human functioning is an example of a socio-ecological model approach to intellectual disability as it acknowledges multiple domains of human functioning and the interplay between those domains. This socio-ecological model of disability provides a clearer understanding of human functioning and lays the foundation for provision of personalized supports (Schalock et al., 2010). Strengths-based approaches have the potential to positively impact the field of intellectual disability. Furthermore, as strengths are emphasized alongside individualization of opportunities for adults with an intellectual disability, overall wellbeing of these adults may be improved (Wehmeyer et al., 2017). The socio-ecological model of disability provides a strengths-based framework for understanding meaning making and identity formation in the field of intellectual disability (Schalock et al., 2013).

## **Storying**

Telling stories about lived experiences and having those stories heard is critical for understanding identity among adults with intellectual disability as identity is about storying which encompasses safe spaces to share stories with attentive audiences (Shakespeare, 1996). Defined by Phillips and Bunda (2018) as “the act of making and remaking meaning through stories,” (pg. 7) storying is multifold in research as theory, design, and data analysis. Grounded in accessibility and amplifying marginalized voices, storying as theory makes five assumptions: 1) the mind, body, and soul is nourished

through the act of storytelling and listening; 2) historically marginalized voices are claimed through storying; 3) shared meaning making is manifest through storying; 4) storying is an intersectionality of the past and present; and 5) collective ownership and composition is achieved through storying.

Drawing from Pinnegar and Daynes (2007), research employing storying esteems the various ways of knowing and being with the utmost respect and regard for the experiences of others. Storying must be flexible in its approach to adapt to the needs of the storier as a co-collaborator in the development of knowledge (Phillips & Bunda, 2018). The act of storying goes beyond memory retrieval and into a meaning making process. Many scholars argue for a non-Westernized approaches to storying that model practices of indigenous peoples in which the focus is on both the story itself and how the story was conceptualized (see Callaway-Cole, 2019; Grove, 2012; Grove et al., 2010; Phillips & Bunda, 2018). Storying has been employed within several population-focused studies to include Australian Aboriginals (Phillips & Bunda, 2018), Mexican-American families (Callway-Cole, 2019), and adults with intellectual disability (see Grove, 2012; Henderson & Bigby, 2019).

Grove (2012) argues for a broadening of our ways of knowing to amplify the offerings of individuals with intellectual disability through collaborative storying. Collaborative storying entails close attention to the structure and content of a story as well as vocal pitch, tone, volume, and pauses to capture meaning and invite co-tellers to flow with “the cadences of the narrative” (Grove et al., 2010). Focusing on best practice in communication, such as active listening, attentiveness, and reverence for others, with individuals with intellectual disability demonstrates concern for being (Kennedy, 1995).



Hymes (1981) suggests employing an ethnopoetic score in storying research which registers such cadences through careful notetaking. An ethnopoetic score allows for an examination of narrative cadences alongside the story's content to capture the deeper meanings of the story being told. This is especially important in storying research among individuals with intellectual disability who have complex communication needs (Grove, 2012).

### **Current Study**

The current study employs a relational approach to understanding identity among adults with intellectual disability by way of storying with emphasis on intimate inquiry. As noted above, adults with intellectual disability have historically had others' voices used in place of their own. Therefore, the proposed study is tri-fold. First, the current study examines identity and meaning making among adults with intellectual disability using a qualitative approach. Second, the current study seeks to amplify the personal voices of adults with intellectual disability. Finally, the current study examines the relevance of using an intimate inquiry approach through the theoretical lenses of storying and a strengths-based socio-ecological model to understanding identity among adults with an intellectual disability. Specifically, the current study seeks to answer the following research questions:

- 1) What shapes the identity of adults with intellectual disability?
- 2) Is intimate inquiry through a storying lens an appropriate method for understanding the meaning making processes and experiences that shape the identities of adults with intellectual disability?

## **Study Rationale and Potential Implications**

Identity begins with a voice (Shakespeare, 1996). To amplify one's voice, their voice must first be listened to and heard. An intimate inquiry lens may give the opportunity for adults with intellectual disability to tell their stories and share their lived experiences (Laura, 2013; Phillips & Bunda, 2018). As storying is a process of meaning making, employing storying in data analysis has the potential to derive a deeper understanding of the experiences of adults with intellectual disability which have shaped their identities by emphasizing closeness to quandary (Laura, 2013). Despite evidence for storytelling as a source of empowerment for individuals with intellectual disability, the employment of storying is less prominent among individuals with intellectual disability that have more complex communication needs, but not due to their inability to communicate (Grove, 2012). The current study has the potential to open new avenues for understanding identity formation and meaning making processes among this population.

## CHAPTER III

### METHODOLOGY

#### **Research Design**

Drawing from the work of Callaway-Cole (2019), the current study employs a relationship-based, qualitative approach to examine and understand meaning making and identity formation processes among young adults with intellectual disability and examine whether such approach is a relevant method for examining meaning making and identity formation processes among adults with an intellectual disability. The research design for the current study emphasizes the socio-ecological model of disability, recognizing importance of individualization, by leaning on study participants as the experts in their own lived experiences, asking them to guide their own stories and storytelling processes while supporting them where support is requested.

#### **Storying**

According to Phillips and Bunda (2018), storying is defined as “the act of making and remaking meaning through stories” (pg. 7) and, in research, is multifold: as theory, data, and process. Storying is positioned in the ethical foundations of accessibility, which aligns with the complex support needs of young adults with intellectual disability and

centered on positioning those who have historically been marginalized to the forefront of emphasis, such as adults with intellectual disability. Furthermore, telling and understanding stories is critical for understanding one's identity (Bruner, 2003). Similar to identity theory's emphasis on malleable identities (Stets & Burke, 2000), stories are fluid in that they are constantly changing alongside the humans living them (Phillips & Bunda, 2018), which is of importance as young adulthood is commonly marked by new experiences. Gallus and Jones (2017) emphasize encouraging individuals with intellectual disability and their families to share their own lived experiences through narrative as means for navigating their own identities with help from professionals. In research, storytelling values the many ways of knowing and existence with respect and regard to the lived experiences of others (Pinnegar & Daynes, 2007).

### **Intimate inquiry**

Laura's (2013) intimate inquiry is a process of data collection grounded in the understanding of "truth" being the reality that one constructs and underscores the importance of getting close to the source of the quandary to best interpret the meanings of such truths and what they tell us. Similar to narrative inquiry, intimate inquiry spends time gathering the narrative from research participants; however, intimate inquiry depends on the quality of relationship between the researcher and the participant.

Intimate in this sense refers to the internal emotional and personal aspects of life and is inspired by the work of Nel Noddings (1992) who reminds us that "to care and be cared for are fundamental human needs" (p. xi). To care is to be concerned with what happens in the lives of the people in our lives. We can attend to our people by asking the basic questions of who, what, where, when, and why with purposes of bringing about a new

level of mindfulness to the ways we receive, recognize, and respond to others as well as ourselves. Drawn from the work of hooks (2000), research in intimate inquiry is not performed on subjects, but with *my people* and are to be treated with the same reverence and regard as intimate inquirers would extend to their own family. In intimate inquiry the inquirer is positioned to give freely of themselves in the research process to share intimate aspects of their own life with *their people*. Intimate inquirers operate under the assumption that both the process and the product of their scholarship has actual and substantial consequences for the lives of *their people*. Structured around witnessing, engaging, and laboring with and for our people whose lives we aim to shape, intimate inquiry is inevitably subjective taking an individualized, person-centered, and perspective-based approach to scholarship, which is consistent with the theoretical framework guiding the research design, the socio-ecological model of disability (Shogren et al., 2017).

### **Using Storying and Intimate Inquiry**

Storying and intimate inquiry as data collection methods are very similar in that they follow a narrative inquiry approach, analyzing the data presented through participants' voices. Storying is often used interchangeably with narrative inquiry, but the language of storying is preferred to narrative inquiry as the term storying is culturally sensitive and extends beyond narration to allow for various forms of storytelling (Phillips & Bunda, 2018). Intimate inquiry takes a similar approach to storying as a methodology but depends solely on the relationship between the inquirer (researcher) and the narrator (participant). Intimate inquiry cannot be employed without the critical closeness between the inquirer and narrator (Laura, 2013). In other words, intimate inquiry cannot be

performed in research without an existing or developed relationship with the narrator in that the inquirer is let in to the personal and emotional aspects of the narrator's life.

Intimate inquiry through a storying lens recognizes the importance of closeness and relationship between the inquirer and the narrator to allow space for fluidity of identity, stories, and meaning making processes. Storying presents the voices of the storytellers, using their unique languages to uphold integrity of storytellers' personal identities. Use of intimate inquiry through a storying lens in the current study included the development of trust and trustworthiness between the researcher and the participants, despite the existing relationship the lead researcher had with her participants.

### **Inclusion Criteria**

Due to the emphasis of storying and intimate inquiry on relationship between the researcher and participant, eligibility for the current study was decided with careful intention to the relationships I had begun to develop in my time as a co-facilitator for a self-determination program offered by a center within a local university. Adults selected for the study were between the ages of 31 and 36. Due to the intimate nature of the study, adults in the study needed to have a trusted adult they could talk to about their role in the study and make an informed decision to provide consent/assent without feeling a sense of obligation to the researcher. Finally, adults could not be currently enrolled in the self-determination program to avoid confusion between the current research study and the self-determination program and avoid the adults in the study feeling obligated to complete the study in order to participate in the self-determination program.

A records review through the University's center that provided self-determination training services to adults with developmental disabilities was conducted to determine eligibility of the current study based on the inclusion criteria above. While inclusion criteria was used to determine that the participants in the study were adults with intellectual disability, the nature of the study does not make assumptions whether disability is central to identity. Therefore, inclusion criteria was used purely for the purposes of examining identity formation and meaning making processes among adults with intellectual disability.

### **Recruitment**

Using purposeful and relational sampling, participant recruitment was drawn from former self-determination training groups that I had the opportunity to develop relationships with group members throughout my time as a co-facilitator over two semesters, Spring and Summer of 2022. Upon meeting inclusion criteria for the study, four potential participants were identified based on my perception of the strength and overall quality of relationship as well as the adult's willingness and availability to meet during the data collection period. Quality of relationship was determined by the amount of time I had spent with the adult in professional settings and my perception of the adult's openness and willingness to share about their experiences. The potential participants were contacted using their preferred contact person via email to inform them of the study and set up a time to discuss their interest in co-collaborating for the proposed study. This meeting was held via Zoom Communications. During this initial meeting I discussed the study, the role of the adults in the study, my role in the study, perceived risks/benefits, and the adult's voluntary participation as well as their ability to withdraw

from the study at any time without penalty (to include without penalty to their participation in future self-determination training programs offered by the state university. The adults in the study were asked if they had questions about the study and if they wanted to talk to anyone about their participation in the study prior to participating. One of the four potential participants became unreachable and thus was not included in the study. The final three adults in the study each reached out to a trusted person to discuss their participation in the study before providing written consent through an online survey. One adult in the study had a legal guardian and obtained written consent by their legal guardian prior to providing written assent, both via online survey. Each adult was asked if they wanted me to read the consent/assent form to them and took me up on my offer.

### **Study Participants**

Three adults between the ages of 31 and 36 were recruited for the current study, all from the Central United States. Each of the adults in the study were asked to select a pseudonym to maintain confidentiality. However, the pseudonyms the adults selected were determined by my dissertation committee to be too identifying, given the entangled nature of the disability services community. Therefore, I was asked to further de-identify their identities so I contacted the adults and asked them to provide a different pseudonym that could not be linked to them by local members and professionals within the disability services community. The first adult to engage in intimate inquiries within the study was Ella. Ella, a white female, 31 years of age at the time of data collection and living in a group home with two housemates and 24-hour staff supervision. The second adult to consent was Fabulous, a white female at the age of 36 during the data collection period.



Fabulous lived alone in her own home and had just celebrated her one-year anniversary in that home after transitioning from a group home under 24-hour supervision since she was 19 years of age. The third adult to consent to the study was Isaac, a black male living alone in his own home at the age of 31 years. Isaac had just moved into his own home a few months prior to the data collection period. Prior to moving into his own home, Isaac lived alone in an apartment. Isaac had a legal guardian at the time of data collection, therefore, guardian consent was obtained prior to obtaining Isaac's assent.

### **Data Collection**

Data was collected through video conference, in-person meetings, and my observations during the inquiries as well as the adults in the study's responses to the environment in which the inquiries were being held. Zoom video conferences were audio and video recorded and in-person inquiries were audio recorded. Adults in the study were informed they were able to invite important persons to the inquiries if they desired. Adults in the study were also informed that inviting important persons to inquiries was not necessary as these inquiries were about the adults themselves. All important persons invited to inquiries provided informed consent prior to the beginning of the inquiry and were not compensated for their time. After each inquiry, I took careful notes (written and/or orally) on my observations. Each adults in the study was paid a total of \$60, \$20 for each of the first three inquiries. All inquiries after the third were unpaid. For the first participant, Ella, two inquiries via Zoom were held for 1 hour and 23 minutes, and 1 hour and 36 minutes, respectively. The third and final inquiry with Ella was held in-person at a restaurant local to her community. For the second participant, Fabulous, four inquiries were held via Zoom at intervals of: 1 hour and 22 minutes; 1 hour and 27 minutes; 1 hour

and 33 minutes; and 57 minutes, respectively. The fifth and final inquiry with Fabulous was held in-person within Fabulous' community as she and the lead researcher spent four hours exploring her community and places Fabulous likes to frequent. For the third participant, Isaac, seven Zoom meetings were held; of which, four meetings included an important person in Isaac's life. One inquiry was held in-person with an important person in Isaac's life. The average length of the eight total meetings with Isaac (with and without important persons) totaled 1 hour and 49 minutes. See Table 1 for further details of data collection inquiries.

### ***Data Security***

All electronic data files (to include audio and video recordings, transcripts of recordings, consent/assent forms, etc.) were stored in a password-protected cloud-based web service that only I have access to. All printed and handwritten notes were kept in a locked file box that only I have the key to access. All data will be protected indefinitely. Any uses of this data subsequently will contain only de-identified information.

### ***Storying and Inquiry***

A storying and intimate inquiry protocol was developed to be semi-structured and intended to allow time for the conversation to be guided by and at the pace of the adults in the study. The protocol contained prompts for the adults to share stories about childhood experiences, experiences in school, friends, family, belonging, who they identified as currently, what shaped their current identity, and when they felt like their best self. The protocol was developed to provide a guide for me through the intimate inquiries should the adult need prompting. However, I did not need to prompt the adults

with probing questions because they tended to discuss the topics I had laid out naturally and without prompting through the stories they shared about their lives.

A minimum of three inquiries were audio and/or video recorded and held via Zoom or at a location of the adult's choosing. Each of the adults in the study consented to being recorded. The adults in the study guided the number of intimate inquiries we engaged in throughout the month of February as data collection was scheduled to end before March 1<sup>st</sup>. The inquiries were scheduled at the rate of each adult in the study during the month of data collection as well. Saturation was met among all adults, some well before the inquiries ended. These additional inquiries provided me with rich detail that helped support my meaning making process and further exemplified relevant findings. Therefore, the number of intimate inquiries varied among each adult in the study. Adults in the study were also given the choice whether they would like for important persons in their lives to participate in the inquiries and those important persons were asked to sign a consent form prior to participating in the study.

I was flexible to allow space for the adults in the study to share stories at their own discretion, on their own time, and through guiding the inquiries while also taking an approach modeled after Fierros and Delgado Bernal (2016) which included sharing my own stories with the adults in the study and only asking of the adults what I was willing to share of myself. This not only promoted transparency, but also promoted strengthening of relationships with adults throughout this process and, hopefully, beyond the study. In several instances, this transparency and openness of myself led the adults in the study to relate through sharing of their own stories that may not have otherwise been told. For example, one of the adults in the study asked me about my childhood experiences. When

Table 1. *Data Collection*

	<b>Ella</b>	<b>Fabulous</b>	<b>Isaac</b>	<b>Total</b>
Total Number of Inquiries	3	5	8	15
Length of Inquiries				
Inquiry #1	1 hr. 23 min. (Zoom)	1 hr. 22 min. (Zoom)	1 hr. 44 min. (Zoom)	
Inquiry #2	1 hr. 36 min. (Zoom)	1 hr. 27 min. (Zoom)	1 hr. 46 min. (Zoom)	
Inquiry #3	1 hr. 30 min. (In-Person)	1 hr. 33 min. (Zoom)	2 hr. 22 min. (Zoom)	
Inquiry #4	N/A	0 hr. 57 min. (Zoom)	1 hr. 22 min. (Zoom) <sup>±</sup>	
Inquiry #5	N/A	4 hr. 0 min. (In-Person)	0 hr. 24 min. (Zoom) <sup>±</sup>	
Inquiry #6	N/A	N/A	2 hr. 9 min. (Zoom) <sup>±</sup>	
Inquiry #7	N/A	N/A	3 hr. 20 min. (Zoom) <sup>±</sup>	
Inquiry #8	N/A	N/A	1 hr. 30 min. (In-Person) <sup>±*</sup>	
Total Length of Inquiries	4 hr. 30 min.	9 hr. 19 min.	14 hr. 37 min.	28 hr. 26 min.
Average Length of Inquiries	1 hr. 30 min.	1 hr. 52 min.	1 hr. 49 min.	1 hr. 43 min.

*Note:* Participants were paid for three meetings (a total of \$60). All meetings after the 3<sup>rd</sup> were unpaid and at the participants' request to continue.

<sup>±</sup> denotes inquiry in which participant invited an important person in their life to join. These persons provided informed consent prior to the inquiries. Invited persons were not compensated.

\*denotes non-recorded inquiry.

I shared some difficult experiences I had endured at a young age, she was prompted to share a similar story, relating our lived experiences. Each of the adults in the study expressed the importance of trust and trustworthiness throughout the inquiries, sharing stories with me that they expressed they had only shared with a select few people prior to the inquiries. Furthermore, one adult in the study trusted me with more of their stories than they wanted published. Of course, these stories were removed from data analysis and are not included in the results of the current study.

Intimate inquiries were largely guided by the adults in the study. During the first inquiries with each adult, I asked them to tell me about who they are and what makes them who they are. From there, the adults shared various stories about their lived experiences. Occasionally, the adults would prompt me to ask questions for them to answer about their lived experiences, seeking to find out what I wanted to know about them and their lives, at which point I would usually follow up on stories they have shared or ask about childhood experiences, belonging, and future aspirations. Each intimate inquiry opened up with general conversations, catching up on life since our prior inquiries. From there, the adults generally led our inquiries into their story by sharing a story they wanted told, which was evident by their statements similar to “Another part of my story is...” On a few occasions I would prompt the adults to share stories by asking, “What do you want to talk about today?”

I listened and watched mindfully for acquiescence in each intimate inquiry as scholars have demonstrated concern with acquiescence in their research with individuals with intellectual disability (Sigelman et al., 1981). Acquiescence was not suspected in any inquiry. Emphasizing the socio-ecological model of disability and storying’s

foregrounding of accessibility, the loosely structured nature of the inquiries provided ample flexibility for individualization to meet the needs of the adults in the study while providing a guide for facilitating the discussion to be led by the adult.

### ***Participant Observations***

As storying is more than words, I was prepared to take thorough notes related to body language to provide additional context to the stories shared by the adults in the study. However, after noticing the first two adults in the study change their demeanor and presentation of the story by stopping to allow me to take notes before beginning again, and sometimes losing track of where they were in the story, I relied on writing and/or recording notes following each inquiry. During the data cleaning process in which videos were watched on several occasions to ensure accuracy of transcription and begin initial coding, I took additional notes regarding my impressions, analytic ideas, and things previously forgotten, drawing from Geertz (1973)'s thick description approach to participant observations and Lofland's recommendation for capturing field notes (as cited in Bailey, 2007). This helped to provide clearer understanding of the story being told by the adults in the study and seemed to uphold the integrity of their stories by contextualizing their story, place, and space. Field notes also provided insight into personal biases held either before, during, or after data collection and allowed me to challenge such biases before, during, and after member checks as well as prior to disseminating the stories and results of the study.

## **Data Analysis**

### **Data Transcription and Cleaning**

All audio and video files to include Zoom recorded inquiries, audio recordings of inquiries and voice memos of field notes were sent to *TranscribeMe!* transcription service to be transcribed. *TranscribeMe!* follows confidentiality policies set forth by my university's Institutional Review Board. A total of 383 pages in transcripts were received from TranscribeMe! Of those, 71 pages are from intimate inquiries with Ella, 96 pages are from inquiries with Fabulous, and 216 pages are from inquiries with Isaac. Upon receipt of transcript data, I checked for accuracy by rewatching/relistening to the recorded file and comparing the recorded file to the associated transcript. I also removed filler words such as "um," "uh," and "like." Finally, I removed general conversation from the beginning and end of the intimate inquiries in which the adults and I would discuss our day, plans for the upcoming week/weekend, or planning for future intimate inquiries. Maintaining commitment to amplify the voices of the adults in the study, I included all stories shared during the intimate inquiries for member checking and removed any stories or content that the adults asked to have removed. During this data cleaning process, initial codes were developed, as coding is a cyclical process linking data pieces to their emerging themes (Saldaña, 2013).

### **Data Coding and Analysis**

Once the data were cleaned, the stories were coded by theme, carefully collapsing and acknowledging the work done in the initial coding stage. Each story shared by the adults in the study was coded into themes that emerged naturally in the shared stories

such as childhood, adolescence, transition to adulthood, independent living, familial relationships, friendships, romantic relationships, spirituality/faith, and future aspirations. From there I combined the stories by theme, regardless of participant. For example, all childhood stories shared by the adults in the study were grouped together. Grouping the stories together by theme removed the meaning making processes from the stories, so I grouped the stories thematically by adult. This draft of results still seemed to be missing the meaning making processes, as each adult in the study shared stories in their own unique way. For example, Ella started with her birth and shared stories chronologically to present identity. Fabulous started with her present identity and shared stories as I probed about different experiences. Isaac started with his birth and began to share stories chronologically, but spent time describing the wisdom he had gained from his experiences throughout and tended to bounce back and forth from childhood through adulthood experiences.

Because each adult in the study was asked to share their current identity as well as the stories that make up this current identity, I decided to separate their current identity from their lived experiences that shaped this identity. This approach also coincided with the research questions as the first research question seeks to answer what shapes current identity and the second question seeks to answer whether the methodology is relevant for examining identity formation and meaning making processes. Therefore, the findings are presented to share the stories told by the adults in the study, but not in a traditional thematic nature per se. Instead, the findings are divided thematically by “current identity” and “identity formation and meaning making processes.” Data analysis focused on the stories themselves and how they were conceptualized.



Data analysis proved to be a much more difficult task for me than expected as I found that dissecting the stories into codes led to a loss of the identity formation and meaning making processes the adults demonstrated during data collection. Compounding this loss, the dissection of themes to be presented according to traditional qualitative methods led to increased likelihood for taking stories and statements out of context. This was evident through stories shared by all adults in the study. However, it was through the dissecting of stories that allowed me to see the entanglement of the overarching themes, yet the need to share the stories by adult instead of by theme. Stories are shared in a multitude of ways and these ways of sharing differed among the participants. Therefore, data analysis not only focused on finding common threading themes of identity and the lived experiences shaping identity formation and meaning making processes, but also on recognizing the unique storytelling processes of each adult in the study, which are all presented in the results of the current study.

Throughout the process of coding and data analysis, I followed the strategies for trustworthiness as developed by Saldaña (2013) such as: ensuring accuracy of interpretations by checking them with the participants who told the stories themselves; completing initial coding during the data cleaning process; and maintaining analytic and journal notes throughout the research project. I was the sole data coder and analyst; therefore, I met frequently with my academic advisor, who happens to be the scholar from which the current study drew its methodology, Dr. Callaway-Cole (2019).

## **Member Checks**

Storying (Phillips & Bunda, 2018) was employed to derive meaning from the story data and member checks were employed to ensure participants' voices and stories were accurately captured and portrayed. During this process, each adult in the study took their own approach. Two adults requested to keep the story as it was presented. The other adult in the study decided what they wanted captured in their story from the various stories they told and removed the remaining stories. Member checks provided the opportunity to demonstrate trustworthiness, understand unclear concepts within stories, provide clarity of interpretations, and for the adults in the study to further voice their desires as it relates to presentation of the stories they shared which have shaped their identity formation and meaning making processes throughout their lived experiences. During the member check process, the adults in the study expressed how important trust was in being able to open up and tell their stories as well as having them retold in the light they were intended to be heard.

## **Rationale**

The current study takes a novel approach to understanding identity among adults with intellectual disability by amplifying their historically marginalized voices. Taking the approach of intimate inquiry to capture the stories told by the adults in the study made space for developing and strengthening my relationships with the adults in the study. This is especially important to understand their stories which have shaped their identity and worldview as well as the meanings they have applied to their lived experiences. Employing storying and intimate inquiry to capture the stories told by individuals with

intellectual disability, of whom I have had the opportunity to develop relationships with over the past two years, amplifies their historically silenced voices and lived experiences while providing new insights to themselves, myself, and peer-reviewed literature.

### **Researcher Identity**

Wrapped up in a hospital blanket after an intense several hours of labor, the doctors brought me to my mother explaining that I had rare physical arm and leg deformities that were undetected in ultrasounds and asked if my mother wanted to keep me. Horrified by the audacity the doctors had to ask such a question, my mother demanded the doctors hand me over to her and leave the room, not coming back until they had something positive to say about her beautiful newborn baby girl. My mother tells the story of that night saying “I promised you I would take you around the world to make sure that you had all of the care you needed. I prayed that God would give me the means to make it happen.” While it wasn’t until my early 20s that I stepped off American soil for the first time, the world was brought to me long before then. After being studied by doctors from around the world for the first seven years of my life, I was finally given a diagnosis; one that was unique only to me, and I was written up as a case study in the American Journal of Human Genetics.

Despite having been born with physical disability and undergoing 21 surgeries before I turned 18, I lived a fairly “normalized” life. My family emphasized the importance of focusing on what I can do and the belief that “this is not an impossible situation.” My mother handled my IEP meetings and fought hard behind-the-scenes to make sure I was treated as an equal at the school while also receiving the

accommodations that I needed. Honestly, I was oblivious to my physical disability until I was 12 years old and even then my disability was never perceived as a limitation in my life as I knew I was going to be a doctor one day.

Now a PhD student studying Human Development and Family Science at Oklahoma State University after receiving both a B.S. and M.S. from the same department, I was introduced to the field of intellectual disability through my assistantship at OSU's Center for Family Resilience where the 2020 annual Chautauqua: Conference on Family Resilience highlighted the importance of belonging for individuals with intellectual disability. Through this conference my eyes were opened to the harsh realities of exclusion and discrimination faced by individuals with disability and the need for communities to reach beyond creating inclusivity to foster belonging for individuals regardless of their support needs. While I had a mother who fought every system that I was engaged with to ensure I had an equal chance, many families don't have the resources and knowledge they need to advocate for themselves in the same way. I had no idea this reality even existed, let alone for so many individuals.

In the months to follow the 2020 Chautauqua, I found myself frequently in thought about the impact that conference had on me personally and knew that I needed to get more involved in the research. I was offered a teaching assistant position for a Developmental Disabilities course as well as an opportunity to co-facilitate book clubs and self-determination trainings for adults with intellectual disability through OSU's Institute for Developmental Disabilities. Through my co-facilitation experiences, my internal dialogue and perception towards individuals with intellectual disability was completely turned upside down. See, like many individuals, I was blind to the realities

faced by individuals with intellectual disability and my perception of individuals with intellectual disability was severely muddled by the stereotypes that society have been placed on them. I ignorantly believed separation, as opposed to integration and inclusion, was best for individuals with intellectual disability to reach their own version of success. I ignorantly believed that most individuals with intellectual disability were unable to cultivate the skills associated with self-determination. I ignorantly believed what society wanted me to believe about individuals with disability by listening to the stories of society instead of the stories told by individuals with intellectual disability. I wasn't even halfway into my first book club meeting with community members with intellectual disability that every ignorant belief I had about the capabilities of individuals with intellectual disability was challenged and I was forced to begin understanding their truth and the vast differences between their truths and the truths told by the rest of society.

In Spring of 2022, I taught the undergraduate Developmental Disabilities course at OSU, which emphasized the socio-ecological model of disability and disability as a natural form of human diversity. I used films, in-class lectures, peer-reviewed articles, and personal testimonies from individuals with developmental disabilities to teach students about the importance of individualization as opposed to standardization and challenging public mental models of intellectual disability.

My research has always focused on marginalized populations; however, I have always employed quantitative methods for understanding phenomenon experienced by marginalized populations. As my eyes have been opened to the beauty of storying, my research will focus on amplifying historically marginalized voices because I truly believe lived experiences and lived truths are as important as factual truths, if not more so. I had

to confront several personal biases that I had throughout the storying processes such as perceiving Ella's childhood before the age of 7 as traumatic while she explained to me that she had a great life until then; and perceiving several of the friends that I met of Fabulous' and Isaac's to be disingenuous despite both Fabulous and Isaac describing the relationships as authentic and caring.

I feel a sense of responsibility to use my platform and opportunities that I have been afforded to amplify marginalized voices. Very few people are doing storying work and, to my knowledge, nobody had used storying with individuals with intellectual disability. But to amplify a voice, their voice needs to be heard. I have absolutely had my work cut out for me as I found myself challenging biases every step of the way, but I also know that this work has the potential to positively impact the field of research on intellectual disability, paving the way for a person-centered approach to research in the same way research has paved the way for person-centered planning in service delivery.

## CHAPTER IV

### FINDINGS

Thematic analysis revealed three common overarching themes among all adults in the study related to their current identity as well as their identity formation and meaning making processes: (1) *pathways to independence* (childhood, the transition to independence, and future aspirations); (2) *relationships* (family, friends, peers); and (3) *spirituality* (faith and belief in God). While these overarching themes and subthemes connect the stories of each adult in the study, these themes are entangled in the lived experiences of each adult and the stories they shared. By disentangling the meaning making processes of the stories that shaped identity among the adults in the study, the processes would be lost. This was evident in the initial coding and analysis when I tried to fit the shared stories into categories. Therefore, results are presented uniquely by each adult in the study instead of by themes derived from the result. This decision was made to honor the unique voices and stories that each adult in the study has vulnerably shared as their voices have historically been marginalized in the field as a whole (Povee, 2014) and storying is grounded in claiming historically marginalized voices through storytelling and having those stories retold how they were intended to be heard (Phillips & Bunda, 2018). Member checks were performed with each adult in the study to discuss their individual results and gain an understanding of how each adult wanted their stories to be told. Each

adult in the study provided feedback on their results. One adult bravely asked that certain pieces of their identity not be shared in publication. Each of the adults in the study's requests have been honored. In addition to member checks of results, adults in the study were asked to select a pseudonym and were not given any guidelines or stipulations on the name they chose. Each adult in the study carefully selected their pseudonym to be used throughout their results. Adults in the study told their stories in their own unique way and each asked for their stories to be retold uniquely as well which is why results are presented differently for each adult.

Taking an accessible approach to presenting the stories draws from the socio-ecological model of disability (Schalock et al., 2013), making space for demonstrating each adult in the study's unique meaning making processes, which is critical for examining identity at the personal level (Stryker, 1968). Furthermore, to take the traditional path to presentation of results deemphasizes the critical process of situating oneself in their pathways of unifying one's past, present, and future through the retelling of stories (Phillips & Bunda, 2018). As stories are built upon one another, each offers opportunities for meaning making (Singer, 2004); thus to disentangle the stories to represent the overarching themes resulting from thematic analysis would be doing a disservice to the adults in the study, the stories they courageously share, and the field as a whole.

In each adult's stories, take note of the entanglement of the three overarching themes that resulted from this work: pathways to independence, relationships, and spirituality. As this entanglement is observed, notice how disentangling these stories to present their themes would lose the voices of the adults in the study and the identity



formation and meaning making processes emphasized by the entanglement of each adult's lived experiences. These processes will be revisited in the next chapter, Chapter V. Discussion.

There are a few terms and acronyms that the adults in the study used that I will provide context for. These are HTS, program coordinators (PC), group home, and staff. HTS stands for Habilitation Training Specialist. The role of an HTS is to provide care for individuals with intellectual disability to include personal assistance, emotional support, and personal care (Oklahoma Office of Disability Concerns, n.d.). The role of the PC is to monitor service recipient needs and individualized plan. A group home is a supported living facility that houses 3-6 individuals with intellectual disability. Group homes support activities of daily living and are supervised with direct support staff 24 hours a day. Group homes are managed by a house manager (Oklahoma Department of Human Services, 2017). Staff is the term the adults in the study often used to refer to any direct support professional in the disability field. Staff includes, but is not limited to job coaches, HTSs, patient coordinators, and group home house managers.

We will first begin with Ella's story. Then we will experience Fabulous' story. Finally, we will turn to Isaac's story. We will learn about each participant's current identity before going on a journey of the lived experiences that shaped their unique identities as well as the meaning making processes they engaged in throughout. The subsection, Current Identity, within each adult's story is guided by the stories shared after being asked, "Who are you today?" The subsection, Identity Formation and Meaning Making Processes, contains the remaining stories shared by the adults in the study.

## Ella's Story

### Current Identity

Ella is a female, 31 years of age, residing in a group home in a rural area. Ella and I meet early in February of 2022 via Zoom, in the midst of the COVID-19 pandemic. Ella is using the desktop computer in the staff office area of the group home she lives in which directly opens to the group home's living room. One of Ella's housemates are present in the living room during this meeting. After consenting to the study, I asked Ella to tell her story. Ella begins by recounting her birth in another state and her journey of how she came to be the person she is today. Ella described her current identity,

*I am a survivor. If it wasn't for [the pediatric psychiatric hospital I aged out of], the [group home I live in now], my aunt, my sister, my husband, my counselor, and my [housemates], I wouldn't be who I am today. Right now, I'm a loving person. I'm a wife. I'm a survivor. I'm God's gift. That's what I am. I am a leader. I am a wonderful person. I am a roommate. I'm just a wonderful person. That's who I am. I'm very thoughtful. I have a big heart. [But] if you're going to be disrespectful to me, I'm going to be really coldhearted to you. That's just the way I am. I was taught by my foster mom and by [my trusted staff member that] respect has to be earned. [I'm my best self] when I'm happy and when I'm around my husband, roommates, when I'm around people.*

Ella enjoyed going to the casino with her husband and having overnights with him too.

*[My husband] has been my rock, and he's been there for me. [My husband has] been there for me so many times. When I had my wreck, when I had deaths in my family, [my husband has] been there for me more than I can count.*

When asked about the important things in life, Ella explained:

*Things that are important things in life, friends, family. Relationships can be important, companions, food, and water. I think mostly companionship, love, as long as you have those. Respect. As long as you have those, you're good.*

## Identity Formation and Meaning Making Processes

When I prompted Ella to describe “Who are you? What makes you you? Tell me about you.” she replied,

*You are going to be shocked because I wasn't as nice.. when I was little.*

Ella moved on to tell the story of being born on the west coast of the United States and moved to the central part of the United States at the age of 4. Noting that her “*parents were not really there*” for her, Ella described her parents as “*drug addicts*” and her dad as “*very abusive,*” explaining that

*[My dad] molested all of us kids.*

Born a twin, Ella is one of seven children, some of which are full siblings and some are half siblings from both mom and dad. At the age of 4, prior to moving to Oklahoma with the woman she describes as her grandma who was not related to her, but was her landlady, Ella lit her dad's bed on fire after he had locked her in a pen with their pet German Shepard. She utters,

*[The dog] wasn't really into little kids. It almost killed me. I got scars from it.*

After moving to Oklahoma with her grandma, Ella described that her mom and dad:

*Just skipped town, got caught in California, and went to prison.*

Her dad is still in prison today. She believes he is never getting released. Shortly after her move to the central part of the U.S. with her grandma and four siblings, the father of her sibling sisters took her sisters back to the west coast. Ella recalled,

*That really hit me hard because I was close to [my sisters].*

Ella continued to recount her childhood.

*I had a great life until I hit 7 years old. Then that's when the bad stuff started happening. My grandmother would prostitute me out [from the age of 7 through 14]. When I was 14, I ran away. I was on the streets for a couple of days. I ran away to my foster mom's house where I knew it was safe.*

After arriving to her foster mom's house, Ella's foster mom called the Department of Human Services. Ella said,

*I didn't say anything [to DHS] 'cause I was scared. I didn't know what was gonna happen. I was on drugs and alcohol when I was 14 and I was really angry. My foster mom and dad couldn't control me and I kept running away.*

Ella found herself admitted to a pediatric psychiatric hospital where she says,

*I tried to see God, but it didn't work and [I] got into a lot of fights. [The pediatric psychiatric hospital] got me clean.*

At the age of 8, Ella's baby cousin was born. Ella described babysitting her baby cousin frequently. On Easter, when Ella was 10, she and her baby cousin were riding on a combine shredder that her grandpa had put them on:

*I was babysitting [my baby cousin] and I was sitting in the back of her and she was in front of me. We hit a bump and she fell in. Killed her instantly. It tore me up. I blamed myself [for 6 years] until I met my counselor [at age 16].*

At age 16 Ella found herself in an alternative group home (AGH). When asked how she came to live in the group home, Ella replied,

*I don't know. I was aging out at, at [the pediatric psychiatric hospital]. And, next thing I know my brother was adopted by some family. And his aunt had came to see me and said 'Well, I would like to adopt you.' I go to her house a*

*couple of times. She took me out to the zoo and stuff like that. I got attached to her. The day I was supposed to leave [the pediatric psychiatric hospital], my therapist calls me and say, 'they don't want you.' It tore me up. I was 15 years old. I didn't know the reason. So it made me act up even more. So from there, when I hit 16, I had aged out. The head [patient coordinator at the AGH] came to see me and gave me an IQ test. [The head patient coordinator at the AGH] said, 'We can fit you in.'*

Shortly after moving into an AGH, Ella met her now husband. She laughs as she recounted the day they met:

*We was at a carwash. I just had gotten in the [AGH] and that's when I spotted him. Me and him gotten into [arguments] for a couple of weeks. After a couple of weeks he started looking me up and down, just being friendly. Then, [one day] I was at the common [AGH] house smoking and one of my best friends came to me and said 'Ella, [my now husband] wants to go out with you.' And I'm like, 'What?' So I have this big old smile on my face, and I'm like, 'What do you mean he wants to go out with me?' And he's like, '[He] wants to go out with you.' And I'm like, 'I need to think about this for a minute.' And I'm like, 'Well, okay. We'll try it.' [My husband and I have] been together ever since. We're like two peas in a pod [now].*

Ella lived in the first AGH for about two years.

*I loved it [at the AGH] until two weeks after. Then [the AGH] wasn't working for me. [AGH staff and housemates] started bullying me, trying to beat me up. My house manager bolt locked me in my room. My [AGH] staff would beat me. I kept on running away. I kept on running away and trying to beat up the other [housemates] because they were beating me up. There was one time [AGH] staff and one of my housemates held me down while another [AGH] staff would beat me up. None of that stuff got reported 'cause I never reported it. I always went to school with fat lips and black eyes. There was one teacher that was really suspicious, but she didn't say anything. [The teacher] sat down with me and talked to me about it, and I told her nothing was going on, that me and my roommates have just been getting into it. I had a case manager [who] knew everything that was going on. [The case manager] would ask me about it. [The case manager] would ask me how [the AGH staff] were treating me. One year on my birthday, I had turned 19 and [the AGH staff] didn't throw me a party. [AGH staff] didn't take me out shopping, they didn't do anything for me. My case manager was pissed because [AGH staff] didn't do anything for me, but [AGH staff] did stuff for the other [housemates]. There was one time [a housemate] had a birthday. My [AGH] house manager had bought [the housemate] a Gucci purse and gave [the housemate] \$300 in a Walmart card.*

*It made me feel like I was left out, like I was being mistreated, like I was with my grandma again. [The AGH staff] wouldn't let me talk to my family 'cause they knew I would snitch.*

Ella moved into another AGH for three years.

*Then when I was 20, 21, I got into a wreck. A bad wreck. I was scalped. I broke my back, my ribs were broken, [and] my right shin was completely shattered. I had a punctured lung [and] my liver was split. I actually died three times.*

Ella shared that while she was being revived by medical professionals,

*I actually had an out-of-body experience. It was actually nice. It was peaceful. I got to see my [baby] cousin. I remember Jesus standing there. I didn't get to see [Jesus'] face, but I did get to see my [baby] cousin.*

After moving out of the second AGH she lived in, Ella moved into a group home.

*We had a house manager that abused us [in the first group home]. [The house manager] actually treated me like a redheaded stepchild. [My housemates and I] had to put up with [the house manager] for five years. It was just like being with my grandma again.*

When asked how the situation was handled, Ella said she could not talk about it due to

HIPAA violations:

*But, I can tell you that I did get so frustrated with the house manager that I gathered all my stuff up and waited till the night shift fell asleep, grabbed my money out of the desk, and took off. I hitchhiked [over 250 miles]. They didn't find me after a week later. I stayed for two weeks. I had to do something. I couldn't have my house manager treating me the way she was. If no one was gonna do something, I had to do something myself.*

Fortunately, Ella had a staff member who she trusted and remained a staff member that cared for her as she moved from one group home to the next and continues to provide staff support to her today. Ella told me,

*Even though if you don't have family, people that's not even blood can be your family. [My trusted staff member] is the one that taught me that. [My trusted staff member] is my rock, my mom. She been there for me since when I had that incident with my old house manager.*

When asked if she ever felt like there was a certain place she belonged as a child, Ella described feeling as though:

*I belonged nowhere 'cause of the way I was treated. I was bullied in school. I was bullied at home. I was bullied everywhere I went. I didn't think I belonged nowhere. I tried to kill myself several times when I was a kid. I tried hanging myself. I tried shooting myself. I tried doing everything. But when I got older and I met [my counselor], [my counselor] brought God into my life and that's who I live for [now]. God is my number one person.*

Today, Ella feels she most belongs with her husband, roommates, and staff. When asked why she felt belonging with them, Ella replied,

*'Cause I know they care about me and I know they won't hurt me. My roommates look up to me so much and it's a good feeling. [I] never had that when I was a kid. When I was younger, I was a bitch. I was mean as hell. I was angry. I was angry at everybody, even to the people that tried to love me.*

When asked what created the shift from feeling angry with everyone to where she is now, Ella replied,

*I grew up. I'm more mature now. I'm more respectful.*

Thinking about her future, Ella shared with me about her desire to live with her husband.

*[My husband has] talked about moving down with his mom. [My husband is] not his own guardian, so he has to talk to his team about that. So, as soon as [my husband talks with his team] and he [moves in] with his mom, I'm signing myself out, and I'm going to go with him. I've already talked to my counselor about it. She says I can sign out anytime. But, if he's still in the [group homes] and I sign out, I can never see him again. That's what my team said. That's why I'm trying to stay in here as much as I can, because we're married. I don't want to separate from my husband. I asked [my*

*husband] if he was scared to talk to his team. And he's like, 'Yeah, I am scared.' And I was like, 'Well, you got to get over that fear. If you want to go live with me and get married and have kids, you've got to get over that fear.'*

Ella also described aspirations of sharing her story with young girls and women in hopes they can learn from her past experiences. Ella told me:

*The thing is, I've always wanted to share my story with people. Me and my counselor have always wanted to publish my story, write a book about this. Me and my counselor was actually talking about me going to church and talking about my story and going to schools and talking about how my story is, you know, talking to girls and groups about how I survived. I want molestation, prostitution, [and] sex trafficking to never happen to any girls. Like it never happens to anybody. It never happens to little girls that live with their grandparents. [For me personally], I think it would help a lot by getting a lot of things off my chest for one. And for others, if somebody has been touched, they could feel safe to tell someone. That's what I'm gonna tell them. 'Don't ever be scared to tell someone because that's gonna hurt you in the long run.' 'Cause I didn't tell anyone 'till I was 16 'cause I was scared. It hurt me in the long run. I just don't want it to happen to anybody else. Like I've always wanted to [share my story]. I'm really glad you came to me.*

### **Fabulous' Story**

Fabulous is a female, age 36 years, residing in her own home in a rural area.

Fabulous and I met four times via Zoom in which Fabulous is home alone for each meeting. For each Zoom meeting, Fabulous joined on her cell phone. The fifth and final meeting was in-person. I drove Fabulous around her town as Fabulous pointed to the local places she frequented. Fabulous took me to the local Walmart to show me what she buys regularly. Fabulous describes these in-person experiences as important to see deeper into the lives of others. All meetings took place in February of 2022.

### **Current Identity**

Fabulous described herself.



*I'm young, beautiful and courageous through my own very eyes of my heart and soul. I will never forget the great Fabulous I am right now. The greatest Fabulous I've ever been through my whole wide world. It's not because of my family. God comes first in my life. God knows. I'm there for each other, and I'm here for my friends. I'm here for my family. God goes first, and then family, and then friends, then comes my peers, then goes my coworkers. For me, I have to say, I'm more excited, have my own ways in going through things I can focus on now. Even today, I'm so glad God is telling me, "I'm proud of you, buddy, doing a good job. Keep the hard work up and doing what you need to do. Keep focus on everything you wanted to be in your life. And now, um, you got a wonderful house, got a wonderful family. You got wonderful camp friends, camp family I love, wonderful coworkers, wonderful boss at the school."*

*I'm so wonderful, having a great time by myself without my HTS. I love those moments. I don't want some HTS up here all the time because I can do things on my own without a HTS here. I can relax more. I can play more. I can clean more. I can do whatever I want to do in my life like go to [the local nutrition shop]. I just kick back, relax, and have fun by myself and do things I wanna get done, I can do my dishes anytime I want without nobody here. I'm here to realize-- this is my priority number one, to make sure my household is clean before I leave out the door. I make sure my friends and family and everybody coming here says, "I'm so proud of you. You're really doing a good job and keeping things up, and doing things you've never done before, and we're so proud of you. You keep that hard work up." And that's the best thing in my life, not just to have family around.*

*I'm living the greatest life out in this world than living in a group home. I broke my wall down. I decided I'm not that shield anymore. I need to work on with playing cornhole or watching TV or go see my family. Or do what I want to do. Have a life, a relationship. Have a house to care of and hang out with friends. And it brights my heart to see those moments of my life. I made this change to this life. When I first moved in, [I felt], "I can do this. I can be strong, take care of myself."*

*It's like now I am focusing on my life instead of living with my parents. And same way with my sister. I know it's great to have new friendships and relationship with my sister now because now I'm living on my own and now I can do things much better. I am more comfortable with what God is trying to do for my life. I know I love God. I know I love Jesus. And then someday if I see something down the road, I want to face that. That's how much I really love to be who I am. I'm glad God gave me this way.*

*Like with me, the real Fabulous tonight.. It's Friday night, and I'm glad for tomorrow for camp. I can go out and do more things and play games or do some activities or watching TV or call my friends, see how they doing. And each time I come out [to my living room], I see a picture of my grandmothers. I tell them how much I love them and miss them, and write down my feelings book or call [my counselor]. Or call whosoever. I can take your pictures and play my guitar, or I can relax on my chair. I will vacuum. Sweeping, mopping and finish my laundry and do my dishes. That's the kind of stuff I do a lot. Or clean the bathroom or clean my bedroom, not have a pigsty anywhere.*

I asked Fabulous is there was a place or people that she felt she most belonged. Fabulous replied,

*I know I belong with somebody. I'm trying to find somebody. Somebody I can really trust, not steal nothing, or love me who I really am because I am ready for that relationship. I am ready to have a boyfriend by now. I am almost in my 40s. I can't stay that long being [maiden name] that much more longer. I want to get married. I want to live in the country. I want a big house with my boyfriend, with my stud muffin. I want to go in the countryside and have an ocean right there the back of my porch, and have that wonderful waves and sunlight.*

Fabulous mentioned she had not dated lately. Fabulous described her mother's wishes for her to focus on living alone for a while before starting to date again. When asked how she felt about her mom's wishes to enjoy life before she dates, Fabulous said,

*I just think be better off, like, to find somebody I can love because I'm into those things. And I can't help it because the reason why I am ready for a long-term relationship is because I'm almost in my 40s. And I want to get married before my mom dies. Who's going to be in my wedding? Who's going to be my maid of honor? Who's going to be my bridesmaid? Who's gonna walk me down to the aisle for a dream of my life. If it's a guy or a girl no matter what, you know, I want somebody to love me and honor me and, and in holy matrimony with me one day.*

Fabulous was asked what she wanted out of a partner:

*With a partner I want someone that can help my desires with everything, not just with finances or helping me to cook and assist me with the oven. I want somebody in, I'll say, Army. I want somebody strong and has muscles.*

Fabulous continued to express the value she places on relationships,

*It's that I want everybody to know I care about each one of them. If someone doesn't know me, They have to get a chance to get to know me. They need a chance to love me for who I am. I have Down syndrome with alopecia. My hair will never grow. With those people that doesn't know me, I love to be around people and I love to see each one of them get to know me a little bit more. I love going to a lot of different places, and I love people does not know me to get a chance to get to know me, who I am. I appreciate everything they do, everything they do for me. I'm lucky to have all these friends and all of these people. And the people who does not know me, hey, once in a while we can do things or once in a while, you can pick up the pieces and show me who you are and what you do for a living. I'm totally awesome and everything I do in my heart, and powerful in my life. I want people to have the experience of their lives, to understand about me. I'm Down syndrome and I'm proud of it, baby! I don't care I've got alopecia. I don't care I've got everything what's wrong with me or my speech therapy and everything. I wear hearing aids because I'm proud to hear, better.*

### **Identity Formation and Meaning Making Processes**

Fabulous recalled her childhood,

*Before my mom and dad got divorced, I [was] always [a] spoiled brat. Because my oldest sister got new shoes and I took my shoes off and threw them out the window, 'I want new shoes too. That's not fair.' [My] dad said, 'You're going to pick them up, take them with us,' and I got grounded for that. Mom said, 'Really? I didn't know you would do that.'*

When asked what it was like growing up, Fabulous said,

*I'm always staying with some friends of my mom's or Grandma or my cousins. I got a lot of people who took care of me and my sisters, and that's a better gift.*

Fabulous recalled some childhood memories:

*One of [my childhood memories] was a Christmas book. I cannot find it, maybe the tornado took it. It was my favorite book. It has all my family in it. My stepdad's name was in it. My dad's name was in it. I felt very special back*

*then for that Christmas book I got for Christmas. I have to say, maybe I was two or three years old, I think.*

*And then in my childhood, I remember this house over, on, the corner, it's on the left side. I used to live in that house before with my mom and my dad, that was the second house we moved in. I was just a baby. We used to live closer to my dad's work for a while. We lived all over. Each time, I didn't want to move. I like to stay in one house.*

Fabulous [grabs Reba McEntire book]

*I read this most of the time because this is my Reba. I have a picture hanging somewhere in here. My uncle gave me [the Reba McEntire book] for my graduation in 2005. I did not know he was doing that. I was so shocked. And I was so, so happy and blessed he did that for me because he loves me, he cares about me, he knows how much I love Reba.*

*When my uncle came up and found [Reba McEntire], he told her, "I have a niece who really loves you dearly and she wants your picture and autograph." I got to meet her! I got to meet her at the [local arena]. She was roping cows, bull-racing. My uncle used to rope for her. I was so glad she did that for me. I got to sit by her and that's the greatest thing in the universe. I'll never forget, never forgot. I was so young back then. Maybe I was, maybe, 7 or 8 at the time, I think.*

Fabulous recounted being in junior high.

*I was in junior high, and this one guy, he was so nice to me telling me, he wanted to have a dance with me. And he did. I didn't feel good. And-- he let me dance with him. It was so nice. I was bullied a lot from every school.*

When asked why Fabulous thought she was bullied, Fabulous responded,

*Nobody doesn't love me who I am. Nobody doesn't care about me. Like, I'm a Down syndrome.*

Fabulous continued,

*When I was in high school, I tried to break up that bully from my friend. I try to stand up against her, and she never stopped. I tried to help her. And I had*

*some witness help me with that, and she started bullying me, too, along with her.*

*In my last year in high school I was 18 going on 19. And then after I graduated high school in 2005, I moved in a group home. I was 19 when I first moved in there. I've been [in a group home from age] 19 through 34. When I moved in [to my own home], I was 35. Now I'm 36.*

When asked what her experience was like living in a group home, Fabulous said,

*It was a good idea for me in a group home, but I like to have my independence and be in my own apartment to myself. I was young back then when I moved in. I was 18 at the time. Let's just say it was fun at first to live on my own and do things differently. Then I always had problems a lot back then. I'm the most independent of any girls in that group home. And in 2020, my mom finally decided to let me live on my own. I finally got my wish. It was Christmastime. My mom said, "Do you want to move out?" I said, "Yes!" I told her about this place, about this house. And I told them I was in love with it. I was so excited. Then a couple months later I tell [group home staff] "I'm moving out, and I will always love you. I want to make sure I do everything right." [The group home staff] was so proud of me. I'm glad my mama took me out. I'm glad I've been in my house a year already. Now, to live my life differently.*

Fabulous was asked what it was like to transition from the group home into her own home. Fabulous replied,

*I have to say this is very great for me to live on my own and do things that I really care about doing that I've never done before when I used to be in the group home. I just had a bed, stay in my bedroom every time, not do things with the girls, only [the things] they trust me with. I stay by myself. Now I got a lot more things to do, and I'm doing things what I want to do. Now I can do things much better. I can clean anytime I want. I can mess up anywhere I want, and still clean it and move it back. It's like now I can play the Wii or stay up all night long if I want to. That's how great I am.*

Fabulous's family is very important to her. Fabulous described her mother as a gift:

*And it's no better gift that I have not just with my mom. My mom is my soulmate mother, never forget or never forgot.*

Fabulous is the youngest in the family. She lives near her mom and stepdad and one sister. One sister lives in Alaska. Fabulous has several nieces and nephews.

*I'm not a farmer like my parents are. My mom is being a farmer lady with my papa. And my step-dad's always been on the farm when he was in Ames, Iowa.*

*I never get to know my step-dad very well. I didn't like him back then. Now, I love him. Trying to experience my life with him. Trying to get to know him more. Now through the years, I'm so glad he's my step-dad, and I'm very lucky to have him.*

Fabulous continued,

*My sister takes care of our dad because he's not doing so well, because of his diabetes. His mom passed away. I'm the one who took care of her. She died when I was with her at the time, in 2010. And that made me so upset, not seeing her, not seeing [my newborn nephew]. When I heard [my baby nephew] told me, "I see a ghost. It's grandma watching over me." That touched my heart when he said that. I was so glad Grandma finally got to see him. They always loved my hugs and kisses back then. Now, they're young and they're going to different places. I'm so proud of them. I want to be fun and hippy cool aunt to them boys because they are my priority. I want to watch some sports. Now, I'm happy because I can do those things here. My mom's not in town. I have my sister. She's always been a mother to me, ever since I was a baby, all the way up. She's always been there for me. She's always fond of me, cherished me. And my mom is an incredible hairdresser and she's amazing leader to my heart, with four wonderful girls. I'm glad to have each one of them in my life. No matter what they've given me, no matter what they gave me peace and love. Sometimes we fought, sometimes we fight. It's the way we love. It's the way we fight. towards we love each other.*

*I've been through a lot when I was sick back then, when I was a baby. And doctors asked my mom, "Do you want to take care of a Down syndrome baby?" And she said, "Yes. It doesn't matter who she is, Yes. I will still take care of her, no matter what." She's very lucky and I love her. My mom is powerful, too, like I am. Because she is amazing and beautiful and she does a lot of stuff for me, a lot of stuff for all the girls. And it's a great opportunity to be who she wants me to be. If I've made mistakes. I made mistakes. She still loves me, no matter what.*

*Like, it doesn't matter for I believe in myself, I believe in Jesus. The greatest book I can turn to is not just this; also, I turn to my mom because I trust my mom. She's the greatest mom in the universe because she is lovable and she is caring, a wonderful person. And no better gift she gets for everybody. She loves her nieces. She loves her nephews. She loves her grandkids. She loves her great, great grandkids. She's in the world for everything. I'm just glad she made me my day, and I appreciate her because she's a great mother toward me when I was Down syndrome. Doesn't matter. I do things with her. Doesn't matter. She's a part of my life. I'm just glad. This family is a great family. They raised me and they love me for who I am. And I'm just grateful my family is here for me. I'm grateful for my friends.*

In conversations with Fabulous , it was evident that, alongside her family, friends, coworkers, and her local community played a critical role in shaping her identity by bringing out Fabulous 's best self and creating spaces in which Fabulous felt she most belonged. Fabulous described feeling her best when going out with friends:

*[I feel like my best self] when I am with my friends and they take me out for ice cream. We might go joyriding in the car and listen to music and talk about feelings or romance or any kind of stuff we want to talk about. Sometimes we go out for dinners and sometimes to the movies. I go to book club and do field trips [with book club friends]. [My friends] do a lot for Special Olympics. [My friends] take me to church, listen to me when I need help, and listen to the greatest times from the Bible at church. That makes my heart and soul happy.*

Fabulous continued,

*[I have a friend] who is valuable to because she has been my rock, and she's always been a wonderful person in making sure I'm doing the right things. We also go a lot of different places. And we learned to teach each other different things. We're all valuable with people who care for me and love me. It doesn't matter I'm Down Syndrome or not. They could still love me no matter what. We talk to who we love. We have to be there for each other. Be there for each other. And it's a great way to recognize achievements that come their way. And I think is the greatest gift. It's what God thinks what's best for us and what's best for the rest of our lives.*

Fabulous described her coworkers as friends who have supported her at work and as people she looks up to:

*They've always been not just my friends, they also have been my co-workers, helping me with what I'm supposed to be doing and what I need to do. I've got things I want to do, like they want to do. They've been there a lot more years than I have ever been there.*

Fabulous described the community she has in her hometown, citing her favorite places to frequent and naming people by name. Fabulous expressed,

*Love is always spread around. With friends or with family or coworkers. I am blessed to have this community and this village to take care of me no matter what. I know I belong in [my hometown]. I love my community.*

When asked what her life would look like in 10 years in her perfect world, Fabulous replied,

*I might be going to college and do magazine editor work, have my own business on my own, and do what I'm supposed to be doing, what I feel like to be doing more of than working at the school. I love working at the school now. And between five or ten years, or maybe if I can retire, I might go to Bahamas and live by myself with nobody, except for a couple people, they would be my HTS or my nurse or my friends or the people from the school. My people is not coming up except for business.*

When asked if she had ever been to the Bahamas, Fabulous replied,

*I have not and that's my dream because my, my allergies are not very good [where I live] and I'm allergic to everything, though except for food. I think it'd be better if I just go live in Bahamas because that will help and I can go places. Ooh. I can go build me a house and have an extra house just in case. I can pay that off. I'm not taking a lot of people with me. I'm only taking maybe [a few friends] and my family would be staying here, but they can come and visit me. I want my own life. They can have their own life because my life is up there. I'm working on the way I want to be doing. From the goodness of my heart, I know I got people who can come up and help me and make sure I'm doing okay. We can go swimming every day, go mess around, go high jumping, floating down the river coast, and have a good time. And*



*have an ocean breeze, have a big pool, hot tub, and, have a sauna. I want a gym. I want a basement. I want a game room. I want an office. I want maybe 9 or 10 bedrooms. And each part of my family and my friends will come and we'll have parties, and they can stay overnight, and then they go back. I want to make sure each one of them have a office, back massager, a home from home. And then you, [talking to the PI], will be coming to live with me too. You are family. I want to have, like, a four or five story house. I want a field with cornhole games, track and field, and I want a bocce ball game set. I want hockey. I want baseball, basketball, and all different kind of sports from Special Olympics so I can practice from there. Then I can go to Clearwater, Florida and have my own team, be a coach one day, and then take photographs with all different people I never met and do magazine editor photography.*

Fabulous continued to describe her perfect world:

*My whole world, and our world, is just something I can really, really trust myself in faith to get married someday. If I get married, I would do a cut-out person between each of my family, if they are dead by that time. Same way with Betty White and some other superstars. And then, if I do get married one day, it will be tons of tons of people. It will be a big party, a big wedding and lots of expensive stuff. Maybe God is telling me [to marry a friend from camp]. It just doesn't matter who I want to be with the rest of my life. I'm ready for that step to get married one day, and I can't wait that long because I'm almost in my 40s. I don't know if I'll have [a baby] or not. If I decide to adopt a baby, I have to take care of them and love them, feed them. And I know it costs a lot of money though, but I know I can do it with family and friends around me. I love my family. I know I want to cherish myself and I want my family to know, I want to take care of myself and I want to do this all by my own. I love my family dearly. It's just, it's my turn to take care of myself. And it's my turn to experience this opportunity to have a wonderful family.*

Before closing out the conversation about her future, Fabulous shared,

*I want to go to a TV show. I want to be famous. I want to be just like Reba. The reason why I want to be famous, I want to tell my story to the whole world. I want people to hear my account, get my book, and see what I've been through.*

## Isaac's Story

Isaac is a Black male, aged 31. Isaac lives in his own 3-bedroom home and has lived there for a year. Isaac and I meet on seven different occasions, all on Zoom. For each inquiry, Isaac is at his home. The first three inquiries were just between Isaac and myself. For the last four inquiries, Isaac invited important people in his life to give their testimony of Isaac's lived experiences from their unique perspective.

### Current Identity

Isaac described his daily routine:

*So basically, my routine in the mornings are, getting up-- if I have time, I will shower. If there's time to where I am running behind and I don't have time to shower, I will just get my armpits and my important parts, and just get dressed. Sometimes I've got to do that really fast. Being in a wheelchair is a little bit more difficult because sometimes your body is tighter. Sometimes when the weather acts up my body is tighter than other days, especially when it's wintertime, and I have to have somebody coming to my house to stretch me or to help me get up because my body is so tight because of the cold. I have it now where it can take me 30 minutes to get ready for the day and it just depends how my body's going to react, and I'm not sure. Sometimes I have accidents, and most people will be like, "Well, you're independent and you've got to do this." It happens sometimes, and you don't have staff to be there. You have to be the one to clean it up after it's happened. You don't have anybody around to do it for you. It's you, and that's what you have to do. So I've learned how to clean my own mess up. Sometimes I've wet the bed, where I've had to literally wash my sheets and re-put my whole thing back together. Sometimes it's hard because sometimes I can't get up in time to do those type of things. I realize that it's okay and it's just a part of life, and you have to learn how to adapt. When you're independent and you have to learn how to do all of that. So sometimes you've got to do things that you don't think that you can do, and the way that you're going to learn is if you don't let people do things for you. Then you can be like, "Well, I've got this," because then when other people see that you're responsible, you can be able to reach other people as well in that process.*

I asked Isaac about his job:

*I am a safety mentor/manager, but they consider me more of a mentor than a manager's position. What they kind of consists of is just making sure that everyone is following safety, that everybody's being safe when they're processing things. They have to wear gloves and if they're doing boxes, they have to kind of weigh them themselves. If they do furniture, doing a team lift together instead of trying to do it by yourself. When you lift things, you go by the knees not with your back. So just those kind of things that we try to emphasize on quite a bit. In my position, I go through a safety checklist and we all follow ADA accessibility as a requirement. There are 36" for me to fit in each section. Then making sure the washrooms are ADA accessible. I go through a checklist of the bathroom to make sure they have safety gloves and all of those kind of situations.*

I recalled Isaac being excited at the time of Self-Determination Learning Model of Instruction (SDLMI) training when he got a job at a local retail store:

*We get paid every week, I mean, I was like, "Oh my gosh. I'm getting five or six hours more than I was originally getting from my original job." It shows a big difference. The pay difference is nice because now, I can pay more things faster and doing that kind of stuff to be more independent. I'm working two jobs. It helps when you have more stability to be able to do more things, and when you have two jobs, when you have a little bit more of a support system where you can be able to pay things quicker, the better your job is.*

Isaac told me his hours had been cut from 20-22 to 12 hours per week, said it was due to end of quarter and this would change. Isaac described having not been prepared for this cut in hours:

*I've been very independent. I had made a mistake recently where I had to, to pay some credit card bills and I got kind of in a scam. It's just different things, then I have to just face them and keep going. One of the things that I'm learning is that you have to pay the bills first before you can help other people. I'm very kindhearted, and I think sometimes it's really hard for me to say no. It's hard because you see somebody that's struggling, and this is why I don't have the rent. I'm one of those people-- I'm willing to give you everything on my back. I'm giving everything I have as long as I'm helping people. I'm learning that sometimes I have to tell people "no" because people will take advantage of that, and a lot of people don't realize when you're going through things that are really hard and you can see somebody else is struggling worse than you are, the first thing you want to do is you just want to jump and you want to just*

*be like, "I want to help this person." But in reality, you have goals that you have to take care of first, and that's a part of it I want people to know.*

Isaac was asked where he is in the dating world. Isaac replied,

*Well, I mean, okay. I'm going to be honest. So I'm dealing with two different people because for one, the one that I'm sleeping with, he lives all the way in California. I don't see him very much. Not at all and he just feels so, so connected. He feels so connected, but I just don't because he's not so close. And so I just say that I'm single, and then I try to-- like, with another guy person, eventually, and it just doesn't work. So recently I met a guy, and thing is that I knew for a while, I had asked him, literally-- like, yesterday I said, "Uh, would you be willing?" He's like, "Yeah. Sure." To date him. I told him-- I was being very upfront about I just want to cuddle. I don't want to do anything, you know, personal. I just want somebody to be close that I could be opened up to, and to be personal with because sometimes you need that, one-on-one where it's not girlfriends or something like that. If you can find someone that values you that you can feel like you can be close to, or you want to cuddle with that person, I think that that's okay, but just make sure that they respect your heart. And yes, I get tested all the time, just because I want to make sure that whoever I'm with that I don't give them anything. Communication is key --with anything.*

I asked Isaac what his favorite thing to do is. Isaac responded,

*Just enjoy life with friends, and as long as I get to be around friends that are positive, as long as I'm making a difference in them, that's what counts. It doesn't matter how the situation is.*

Isaac was asked where he felt like he most belonged and who was around:

*I think it's with my church family. Me and my mom don't get along, but I have friends that I can go to that I can say that value me.*

Isaac was asked when he felt like his best self:

*Like, when I feel great, I feel like I can take on the world, I guess you can say that. I think it's having really good friends; really good relationships with friends. I can say with friends I hang out with, to have the intentionality of, like hanging out and wanting to get to know me and wanting to go to the movies, and doing things, to being a part. That's when I'm feeling my best.*

*When friends wanna hang out with me and it's just feeling like a whole reunion and that I know that I'm not alone. I could call that friend when I'm feeling the worst, and they can make it 10x better. But in reality, you're only gonna have two or three best friends in your entire life. Most people hate when you say that, but it is the truth in itself. The reality is, everyone is not gonna be your friend and you have to understand that. I'm one of those people where I want everyone to be my friend and see the positivity that I have, or the impact that I have on something. But I think the reality moment is, you can't please everyone and I'm learning that too.*

Isaac continued,

*I think it's also to value time with one another so that you can grow. It could be just like an hour and just getting to know someone, or somebody that's going through a hard time and listening to them, which is really huge. I may deal with personal things, but that's okay. We're all dealing with something. I think that is something that we have to all know and that we can work on together. That is something that I'm learning how to value better now. I'm learning how to value [my friends] as a person, and that we can go through those things together, and we're not by ourselves. I think that's just what we have to realize, you never get to know someone until you kind of get into their life and knowing their story. And it's really cool.*

## **Identity Formation and Meaning Making Processes**

Isaac described his childhood:

*I was born in 1990. I have what is called cerebral palsy. [Cerebral palsy] is basically where my muscles are tighter than normal and I have to work harder to kind of tell my brain to do certain things or certain functions. I've went through therapy and I've also went through Shriner's Hospital. I basically didn't have bone structure that was in the right form, and so, Shriner's Hospital was kind of the big thing of starting my life and surgery. I ended up having a lot of surgeries over course of time. I've had 13 [surgeries] in my entire life just because of not forming, so being in cast for six weeks, still going to school that kind of thing. Then, having to do therapies six weeks after the casting through the whole process of still going to school, being strong. There were times when I had problems seeing. I was just id and out of going back and forth from school to going to the hospital and doing different surgeries. [I was] doing the school at Shriner's Hospital which, I did that quite a bit as I was going through my 13 surgeries.*

*I don't remember exactly [when I learned that I have cerebral palsy], but I think it was when I was, two or three. Some of the doctors said, "He's not gonna be able to be play football," and things like that. I remember going through 12 different surgeries that I had to have as far as treatment in my legs, being in fiberglass cast a lot of the time with rods to keep my legs straight and being in braces a lot of the time to be able to walk and do things like that. I had to be in casts for six weeks and then intensive therapy six to eight weeks. To get back in the routine wasn't easy, because there was a lot of pain. They had to do a lot of stretching to loosen those [muscles] that had been in cast for very long. It was real hard. Sometimes when you're in cast, you're basically in diapers at my age and having to have someone change you, it wasn't easy. The hardest part was being very itchy and buying a vibrator to kind of help the itchiness and just dealing with a lot of dry skin and things like that. It just wasn't easy. I mean, 'cause you only get to rest one day in your bed and [hospital staff will] bring you your favorite video game you want to play. But after that first day, you have to be up and around, moving. They give you medicine, it's a big deal. So, it wasn't fun or easy. I went through a lot, but one of the things I liked is when they had mealtimes, they would bring you food. I think my favorite part was when we had to go out on Wednesdays and we got to get out of the hospital for an hour. One time I was there for Christmas and I had to walk in those fiber casts to see Christmas lights. I loved people that I met through Shriners [Hospital] and, those are memories that I'll always remember. We used to go to different things and to different movies and used to go to other Shriners' houses to kind of just be a part of their family a little bit and it was really nice.*

Isaac continued,

*Usually after surgery [the hospital] will only let you stay for 6 weeks and then you're home the rest of the time. I think you're in casts for 12 weeks. I was with just my aunt. She was basically there for the entire time. My dad really wasn't that supportive when we had those 'cause he would be working on the house. My mom felt like he didn't do such as a great job because my dad was more of the spoil type and my mom was the big, tough mom. She wouldn't make anything easy for me, so I mean-- literally, she was a toughie. My mom was one of those, when I was in pain, she would be like "You gotta keep going, and keep fighting."*

Isaac described his mom:

*I had a parent that was very headstrong, wanted me to know that she was gonna treat me normal no matter what the issue may be. She wanted to give me as normal [life] as possible, and that was one of the things that's made me strong today is because, like, my mom says, "Well, you'll do everything like a*

*normal kid does. And we're not gonna be limited because you're in a chair. You're gonna do everything else—like everyone else does."*

Isaac clarified who he is referring to when he discusses his mom and dad:

*My [biological] mom, is in Michigan. The story that I was told with that situation was basically that my aunt [who I now call my mom], which is my [biological] mom's sister, couldn't have children so my [biological] mom wanted to bless her to be able to raise me. I don't know my real dad because he was dealing with some kind of drugs or things that my mom didn't want me to get involved with that kind of situation. It was one of the things where my [biological] dad, I would call uncle. I would love that my dad [which was my biological uncle] used to go with me on zoo trips and spoil me and swing me hard like a normal kid would. When I would be gone on my surgeries, my dad would redo the house because at the time my house wasn't handicap accessible, so my dad would do these different things of building a ramp and redoing the wall and things like that. Sometimes my dad would be doing different construction work while I would be gone for those six weeks to kind of help, but as he was getting older, it was getting harder and eventually my mom and dad kind of split up, but I still got to see him. My dad worked a lot with a lot of contracts and doing a lot of different constructions and homes. I also worked a little bit. I worked beside him answering phones and things like that. That was during the summer when I was older and started to work.*

Isaac recalled his dad giving him his first cell phone:

*My dad would give me my first cell phone and [my mom] worried I got that. We had, back in the day, pay phones and you had to put minutes on it. [I remember] thinking that was the coolest thing ever. I would text my friends and not think about 'you need to get off the phone and take your chores that needed to be done.' My mom would always, say "Well, you have these chores to do." I would have to do dishes or something like that, would have to cook something. If I didn't, I would get grounded from my phone for like three to six months. There was one time I was grounded from my phone for a year because I would sneak and get it. My mom would find out that I've climbed out of my chair and she would try to put it somewhere high and I would figure it out. She would get so mad, she would say, "How did you get to this point?"*

Isaac described his childhood home:

*I lived in a small house. It was a one-bedroom, one living room, one kitchen, and one bathroom. It was one of the toughest moments, but, there I was and*

*learning how to transfer to getting into a tub, bathing myself. My mom was always trying to make me independent. Even when I was living with mom, we had this rug that was really getting deep, and I had to learn how to roll it up by myself and how to pop a wheelie and to push myself in the house. Even when we didn't have a hot water tank, I had to learn how to boil water, sit it on my lap, and then pour it in the tub. Sometimes it would be scary, where I've actually scalded myself a few times. It takes a lot of practice and a lot of will to get things which you need to have done.*

Isaac continued to describe his childhood,

*I got grounded a lot when I was living with my mom because we didn't get along. We would get into fights sometimes. I didn't like being at home a lot and that would be like one of our major issues. My grandma would tell me, "Well, you gotta be able to listen to her," and it just never worked. Me and [my mom] would be doing yelling matches across the room. A lot of the time I didn't talk about the difficulties that we have with my mom. A lot of times we would have altercations just because I didn't understand, and of course, you know, I'm thinking I basically understood. So me and [my mom] would be kind of in physical arguments that would cause disagreements and sometimes fights. If I wanted to get away from my mom, I walked to my grandma's house with my walker and she would spoil me with hot dogs and a can of pop. You know, it's one of those things that I miss, 'cause she's gone now. I mean, I know that she's in a better place and I got to see her before she passed. It's having those special moments.*

Isaac was asked what he and his mom (aunt) had conflict about:

*I mean, it was over really stupid stuff. I would think that my mom wouldn't take care of me when I was with family. Or when trying to tell her something that she should listen to, she'll be like, "Well, I already know what you're gonna be thinking before you would have to say anything." It used to bother me very, very much. I mean, it still does, but it's not as bad. I used to get so mad and so upset where we would be in physical fights, and she had to literally put her heels against my shoulders, because it was so bad. I would get so angry, and sometimes scar my face in the carpet, and things like that. It was really hard, but when I was really young, we didn't have as much as issues until I got older.*

Isaac described an example of an issue he had with his staff as an adult due to conflicts with his mom:



*I had one time when I had a HTS that told me that because me and my mom didn't get along, that I was gonna go to hell. It was really intense. It was very hard. [My mom] wanted me to make sure that I used my walker everywhere, even when I didn't want to. Then there was things that we tried to settle, and it just never worked. We still have fights now. I think since I'm older, like, she doesn't want to hear it, and she'll hang up the phone or she'll say, "I don't wanna fight," and, "I'm too old for that." It just wasn't really easy. Sometimes I'm trying to tell her something, she thinks she knows what I'm gonna say, and she wouldn't let me say it. It would make me so angry.*

Isaac confirmed most arguments resulted in not feeling heard by mom. Isaac was asked if he felt heard now to which he replied,

*Sometimes. It just depends on the topic.*

Isaac returned to his childhood:

*I grew up in a church. It's where I grew up with my mom. I was doing the Easter programs and doing different things in Sunday School programs. When I was a kid, my mom wanted me to be into some things that was kind of like a brotherhood, which is like the miniature Masons. It kinda teaches you unity and how to respect one another and to be there for one another. They would do three different events that kinda give you the respect of how to be a man. I wanted to lead and to do different things. I got to go to different dances and how to plan and to kind of guide that way of life as I'm growing up. I learned a lot about how to memorize things and how to do that well. [The fellow masons are] all being respectful at this time. They learn how to deal with me. It was really cool because there was times where we would go to different things and sometimes, the functions were really nice. We would get five-star dinner and we're learning this as boys. We're dressed in suits from head to toe.*

Isaac continued to reflect on his childhood, describing his experiences in school.

*I've always been kind of in the human services area which is basically where you would have an IEP with the school district, and then you would meet with someone that was through DHS once a month to kinda know how things were going. I basically tried to enjoy life as much as possible. One of the things that I had issues with was hygiene, which was kind of a big thing. It's better now since I'm older, but, it was a really big thing. One of the issues that I have struggled with, still to this day is like tying shoes and buttoning and things like that. I'm still kinda going through that process there. Getting up to*

*going to school, I would sometimes run late and sometimes the bus would be like to have to wait on me and sometimes my mom would have to take me to school because I didn't like getting up early. I loved riding the bus. We had the buses where, back in the olden days, they would bop up and down. Things have definitely upgraded since I've been in school.*

Isaac explained how he felt about going to school:

*I liked not being home. I always loved school. That was one of my favorite things. It's so fortunate to go to school. Even if I was sick, I didn't want to leave. I went through elementary school growing up and having some best friends, going to gym and doing those kind of things and doing reading buddies. I think one of my favorite moments when I was in elementary school was doing conflict management at class. [Conflict management is] basically where if there was a problem, we would be one of those students to come out and fix it. So, if we saw somebody having a snowball fight or having a disagreement, then how would you want to kind of compromise that conversation and to fix that issue? We would come in with yellow shirts and help with different issues. That was kind of a cool thing in my school. I had some really smart teachers. [One teacher] was one of my greatest teachers that I grew up with. I had almost the perfect penmanship back in the day and she wanted me to know that I could write in cursive. We did different projects, and I would always ace things and did math and things like that.*

Isaac continued to describe his experiences in school.

*Later on in life when I got to middle school, things started going a little bit faster and it started to be a little more difficult because I needed more assistance. I lost some of that writing skills that I had and reading skills because I had surgeries and some memory loss because of a seizure. So, I kind of just learned to sit and learned how to deal with posture because I did a lot of sitting back in the day. It was one of those things where it wasn't easy. When I got into middle school I was pushing myself around and a lot of times it was causing me to be behind, so, I had a lot of accidents going into school. What that kind of looked like was sometimes when I had to be in class and I had to go to the restroom, sometimes I didn't make it at those times. Some teachers would get frustrated, and they would say like, "Why didn't you tell us?" But I was more wanting to get to class on time. So, that was kind of one of the difficult things that I had to go through in my life.*

Isaac continued to describe the difficulty of faster pace in middle school:

*It's kind of harder when things are getting more difficult because people want you to move faster. I started getting what they would call advocates. Basically, [advocates were] wardens who would kind of help write things down, but I still had to do most of the work. Even though I had that student advocate, sometimes it would be difficult 'cause some classes I didn't like. Sometimes I would fall asleep in those classes. It just wasn't easy. Sometimes where I would have a HTS. I had my godmom, as a HTS, and I'd stay up until 2:00 or 3:00 in the morning to get paperwork done just before getting up the next day to go to school. So it just wasn't easy at all, but I did go through it.*

*I had some good days at school where I would go to my art class. And, sometimes I just can't see. So, like, when we did, like, graphing papers, then we had to measure the lines, I couldn't see it. So when I went to junior high, and I had laser and eye surgery and that was kinda the moment where I was, like, maybe this is going to be able to help, and maybe some things would be able to improve. But at first, I had to be out of school for three to six weeks and had to do homeschool a lot because surgeries and then, going back to school. But, I had a really willing heart to still do school, do what I needed to do.*

*When I was in junior high or middle school, I was dating this girl, but before I started dating her, she literally asked me "Well, are you a girl?" I said, "Uh, no." Back then I had long hair down to my shoulders. It was always braided so my mom would do different braids on my hair.*

*When I got into high school, I think that was when my best friend and I got to work for [a local pizza place] during the school year. Those moments where I was folding pizza boxes and I would do the pizza shakers and doing different things, would be really, really cool.*

Isaac reminisced on his high school graduation as he worked hard to achieve his goal of walking across the stage. Isaac organized an inquiry with BW, the staff member at the location Isaac engaged in physical therapy to work on his goal, to gain BW's perspective of that journey. Isaac informed BW of his role in the inquiry:

*So the funny thing about the reason why I'm using BW in this illustration is because, in that half of the school year we were trying to get me prepared to walk across the stage. They were getting me strength-trained to be able to walk across there, and, it didn't seem like it was working. So when I had the ceremony, or close to the preparation, I went to BW's office and I said, "I need somebody from your office. This is just not working." So, BW comes out*

*of the office, and he was like, "Well, I think I could take you, but let me see what I can do, and I'll come out there and I'll meet you up there." So, [BW] goes out of the office, and he was like, "My wife is pregnant, and I've got to talk to her," and all this other stuff. I called him, told him this is when to be there. [BW is] dressed professionally. I am, too, because, you know, it's business attire. He walked up there, I don't really think we trained, actually. I think he was just like, "We'll do it." And so the day that I walked across there, he was the only one to walk up there that was strong enough to hold me to walk across there, and it was probably, I would say, probably about 50 to 60 feet, not very far.*

BW replied to Isaac,

*Your memory is much better than mine. I don't remember any of what you said about my life or pregnancies or kids or anything. I don't know anything about that. I didn't remember how I got involved, but don't let him fool you. He says I was strong. He pulled me across that stage. [laughter] I mean, he stood up, and he took off. I barely had time to grab onto that belt by the time the boy was gone. I mean, you talk about adrenaline kicking in. That whole place went crazy when he went across that stage, and I knew his body felt it 'cause he was just skipping across that stage.*

Isaac added,

*[BW] was kind of shocked and he was really hanging onto it, as I remember. He's like, "I was really hanging onto this," and he's like, "You're actually doing it by yourself." I think the way that my brain was thinking, I was like, "Oh, my gosh," like, "This is real," like, "I'm getting a standing ovation, and everybody's like, 'Look out.'" So I took a second, and I'm getting this standing ovation. I remember exactly. We took that picture. That was really just cool 'cause that moment was just like, "This is more than I would ever think." To be honest, I was shocked. I think B was shocked, too, 'cause I saw his face, and he was just like, "Oh, wow." It was worth it. I will never forget that day. And I mean, this had to take all semester. I mean, I've known B since he was working at the other facility, so I've been with him through this whole transition when he's gotten new buildings. It's cool. And he still deals with me.*

Returning to his conversation with just me, Isaac described how his life changed after graduating high school:

*When I was in high school, I was sort of grounded or sometimes my mama had to put her feet into me because we were not getting along so well. Sometimes, she would put me out of the house. That's just been my whole life. So, when I was about getting close out of high school, I worked a little bit, graduated. I realized that I'm gonna get out, and I remember like it was yesterday. That, like, literally I said to myself, "I'm going to get out, going to move to a studio apartment." I told her I was going to and I did. I remember having one of my friends carry these boxes to this studio apartment, because I was like, "I just can't do it anymore." None of [the studio apartments were] handicap simplified. I had to figure out how to crawl around. Sometimes I had huge accidents and people had throw things away because I had accidents in my clothes. Learning how to just crawl to get in the shower and to learn how to bathe in the shower when you don't have a shower chair and crawling in and try to get dressed every day.*

Isaac was asked what it was like for him to transition out of his mom's house and living with others.

*It wasn't easy, and I didn't have [pictures and decor] that were hung up sometimes. When I didn't have a job, it was living on social security and trying to pay the bills. One of the things that got me into trouble was a lot of my friends, they were always wanting to not pay the bills, and I ended up being stuck with the bills. Sometimes they would say, "Well, I don't have the money. Could you be able to cover this?" [My roommates] did their own thing and then sometimes they would leave dishes in the sink and the house would be a mess and that's what almost caused me to be evicted. My mom would come in and the house would be a mess. My mom would just have a fit, and we would get sick all the time, not knowing the house that we were in had lead paint and then it just was not working.*

Isaac added,

*I would like to mention, if you're going to live with roommates, you need to know them personally. I knew a few of my friends I went to school with. Like, I knew them personally, but at the same time, because of the friends that we chose, they were not as smart. I had someone shoot me in the foot with a BB gun because they were mad about something, and that wasn't even my fault. Things like that. And so just those processes, was it rough? Yes. There were times when things were rough. I've locked myself in a room and I have had [adult protective services] getting called and going through the [guardianship issues] that I'm going through now because of all of those situations. There are some things that I have to know when enough is being enough, and to tell people "No, you're not gonna run over me." And there are times when I didn't*

*have money because I was paying for everything. I even had roommates where they didn't pay their part of the bills, where I had to be stuck, and I've been evicted because of friends. There are hard issues.*

Isaac described losing his rights:

*I was my own guardian back when I moved out of my mom's house when I was 17, and I had that for a few years. Lost it because of how people have treated me and, I guess, because of the decisions I made that was not very smart. I will honestly say, I don't want anybody to go through what I was going through. I think it's rather hard on me, and I'm still paying for it to this very day. I remember when I got the letter. I had been with my mom for a year. I used to have to be at [a friend's] house every weekend because I was so depressed, I couldn't make any decisions. It was just really hard. Because of DHS and because of APS, they were allowed to put me in the housing place so that I could have my own place. I can make some decisions, but I can't say, "Well, I want to take this job." I have to go to my guardian for that. My mom wants to be protective, she's always going to be that way, I think. I think that's just something that most people have to understand that sometimes we make the wrong decisions early in life. This is the thing that you're going to kind of face because you didn't say "no" early. I've had my mom where she's been emotional sometimes and I've lived with her before, I said, "Look. If I could have a better guardian--" [but I understand] that it will hurt [my mom] in the long run if I decided to do something like that. I'm taking care of 90% of [my bills] by myself now, but at the beginning I couldn't. I'm still fighting now to be my own again. It's hard, because I can make decisions, but I can only make certain ones. Anything that has to do with medical, that's [my mom's] responsibility. Anything that has to do with me going out, I mean, I have that decision. But if there's something wrong, [my mom] wants me to tell her everything that's going on and I don't believe that she can handle it well.*

Isaac returned to describe the lessons he learned in his time living with roommates:

*Sometimes people don't know how to take care of their actions. Is it hard to have roommates? It can be if you don't know them. Like I said, if you're a disability person and you want to be as independent as you want, the idea is, ideally, you want somebody that you can trust, that you know that from the get-go, that they aren't going to burn you, like I've been through. I think that a lot of what people will look at is, "Oh, I want to get out and be free and be with my roommates, everything," but you have so much responsibility that you've got to be able to take care of, and making sure the people that you know are going to pay their responsibilities. I had to learn the hard way through that.*

*It was also family too. I mean, I thought this truly was going to be over after all of the perils and problems that happened. I moved to with my family, which were my cousins and they had a niece and a nephew. They were all, "Well, you're going to get your own room," and my mom gave me that opportunity to be able to go somewhere else. Well, this third time, I stayed with them for about three or four months, and I will tell you, it was one of the hardest things in my life because at the time they had a niece and nephew. I would still have to go to work, this would have been 11 years ago. I thought, "Well, I'm going to have my own personal room." Moved all of my stuff over there. It just didn't happen. So I would be going to work sometimes, but they would call me and they would say, "Oh, my electric's turned off, and I need some help." Not knowing that they were on social security, did not know that they were doing things. I remember getting my check out to pay for their electric. They were using my stuff and they had to do an investigation through APS because really, they were doing things that they shouldn't have been doing. They would say, "Well, you know, we want to go camping," and I told them. I was like, "Look, you have two kids to take care of," and most of the time I was paying most of the bills there. So I told them that I wasn't going to pay for their camping trip. I was paying for my niece and nephew that needs to be taken care of, not something that you want to do. You need to take that responsibility and handle that. But it was already too late. And so when APS got called because I didn't take care of myself, I was trembling. My skin and my hair didn't look great. When APS came by, they knew that I got taken advantage of. The reason why my mom is my guardian now is because when APS got involved. When I went to court, they said, "Well, either do you want a lawyer, or do you want your mom to be your full guardian?" And I said, "Well, I don't have a lawyer." So I've been fighting this since 2012 because of friends and family and me just being too nice, and a lot of people were taking advantage of me in many different areas.*

I pointed out that it seemed Isaac had to learn about being taken advantage of the hard way:

*Oh, yeah, I did several times and there was one time it caused me to get called by APS because I am so cared [about]. Sometimes you have to be really careful who you choose as your friends. It is very important that people understand that because the issue is, is that sometimes when we think that we know the person, and they don't do their part, I think it is super important to know that you need to know who your friends are, and you need to be careful who your friends are because it can turn into being very, very dangerous. And sometimes it's, it's not good. So, you need people that are going to respect you as a person, and when somebody's going to say they're going to do something, they need to do it. It's just what I believe, really. When you're kind of wanting to trust somebody that you think that you can definitely trust them doing what they're going to say they're doing and don't,*

*and it makes you look bad. So you just need to be careful on who you choose as friends. It's just things that you go through in life.*

Despite the struggles Isaac had being taken advantage of, he told me about the people who were there for him in the process:

*I remember one time, when I was living in my apartments, and I had people who would take advantage of me. So each week, somebody would bring me something. These were not, like, your normal group of guys. I mean, they worked. Sometimes, they would bring me food after they got off of work. And knowing that was kind of the turning point. Even though I'm being taking advantage of, there's people that are coming to help me. Even when I was feeling down, I'm thinking I was helping someone and I was helping my family and they were taking advantage of it, these guys came here and loved me. Even when I had bed bugs in a couple of apartments that I was in, they came in. They would love on me. They would help move stuff out. If I needed somewhere to stay, they were there. It was one of those moments where you could be, like, "Man, you should really pray about this because these people are really willing to help." Knowing those people have made a big impact.*

*And one [friend] in particular, this guy was a college wrestler when I met him. I remember when he started the whole thing with [a youth ministry group]. I remember he would help me and this group of students came together and loved me. One time [my friend] came on a scooter and brought me food and the people that were around him did the same thing. When I was going through bed bugs and things, I remember this girl. When I was down and out, and I just felt like nobody wanted to be around me 'cause I was dealing with these issues and it wasn't my fault, I mean, it happens to anyone. She was a student. She let me go to her breaks with her, the coffee house, and made me feel like I was a part of something better than just herself. Even when she had to study, I got to sit there with her and talk about things that I was thinking about, and she would still study. It just shows you how much people can really value you. It was just that moment right there that was just like, "This is, like-- the people you want to be around, because they want to build you up."*

Isaac explained what he had learned about what constitutes family through these experiences:

*Maybe you don't have to have blood to be a part of your family, but maybe if you get people that are connected in your life, that can change your heart and*



*maybe your understanding somewhat, that may change someone else's. Just being intentional with someone, I think that right there is huge. It doesn't matter if you're 30 or 50, as long as you're getting that brotherhood moment. I'm learning from somebody that's been around longer than I. I think that is just really, really cool. I couldn't get that with my own dad. I mean, I did, but, now since I'm older I don't see him quite as much, but having someone that comes hangs out with you once a week. And it's just like, that's so cool.*

In addition to learning the value of relationships and being able to set boundaries with friends, Isaac described having to learn how to balance friendships with HTSs. Isaac described an HTS as someone paid to make sure human services clients are meeting their goals:

*I had different staff that I would work with to work on my goals that I needed to work on, and some places we went. I always had to grow up with someone that had to be an HTS for me. I went through several.*

*As I'm an adult now, I'm working, with [my former HTS] so much. Knowing that he has a disability himself, I've had to learn to have respect for people that are working with me. We had some issues that weren't as good sometimes because when I would tell him, "Oh, we need to go do this," or, "We need to go do that," without asking him it just got overwhelming. I started being really personal and things that I went through, such as, for instance we kinda talked about my personal issues where I did wrong things. So, when you were supposed to be with men or women, and when I went through this different experience of not understanding, like, okay, well, maybe I'm being too personal because this person works for you. It was overwhelming and he was dealing with things himself. And at the time, I didn't realize that. So at the time, he asked me, "Am I doing enough for you?" or "You want to be with someone else?" because there was sometimes we would get into it. Sometimes we would sit and watch movies. Sometimes he had a car that didn't work, but I mean, he really did try and sometimes I didn't see that at the time. Sometimes you get hurtful and you can be hurtful. Sometimes when you think that it's all you, but when it's about each other and how you have to value each other's time. It's just knowing that sometimes it wasn't easy. Sometimes he would get frustrated at the drivers, he would go faster than normal because he's so frustrated. Like, this is the thing that I've experienced with the staff. It's something that I learned a lot and knowing that sometimes it wasn't very safe.*

*This was mostly recent. But, at the time I was trying to get ready to move out. Before this, I remember [my HTS at the time] D taking the time out his own day to go get this machine and doing the heating treatment at my house and going back and forth and trying to take care of his mom and family, and also trying to take care of me. There were times where I had to cover for him because he didn't have a car. I remember having my friend push me to get to [physical therapy] sometimes. And because I care about D so much, there were times where I had to, like, figure out ways to compensate for him because I knew that he cared. He was trying to do what he could do when his car didn't work. I remember my friend would walk over to my house, push me to this other house, stretch me, then go the store, if I needed anything, and then push me all the way home. I can honestly say, when you have dedicated people like that, it's huge. At the same time my mom would be like, "Did [your HTS] work today?" I'd have friends to cover for the person that worked for me. That's how much I valued him, but at the time it didn't seem like I did that. But through that process we still did a lot of great things together. We are still friends until this day. Then there were a times when we had to take three months away from each other because it had got so overwhelming. Sometimes I have to be ashamed because sometimes, I didn't see as much time that he was putting out. He would come and visit me, but he wouldn't work for the four hours. So it was just like, "Well, I'll come when I can," 'cause he's got family stuff to deal with, and I just feel like, this is not good. You know? So I'm sitting there talking with other people about what I should do, "Should I get rid of him or anything?" but I didn't want to because I knew—at the same time, he really did care. When he did want to do things, I mean, he did. Like, he went to Sonic. I mean, he took me to his parents' house when he didn't have to and he asked me to go running with him. I mean, and there was times where he would love me being with him. It was nice because I got to get out of [my hometown] and getting to see his friend's house. I think the hard part for me is when his parents lost their house. And he had to work with me at the time and still try to work on his parents' house. I mean, [my then HTS] is one of those where he is so independent, takes care of his family, and I have to applaud him for that and trying to take care of me at the same. But when you have your mom try tell you, "Well, he needs to be here for the four hours." Like, he's—required to be here for 4 hours. So I had to make up these different things to try to make it work even when it didn't feel like it. But this is, like, steps that I learned to deal with.*

Isaac highlighted relationships with others and the importance of valuing one another, specifically highlighting three of his people that were invited to and participated in inquiries: B, N, and D: B is Isaac's friend of 15 years. When B arrived to the inquiry,

Isaac asked B to recount his experience in developing a friendship with Isaac. B recalled,

*I got a degree in recreation management. One of those classes, we did different kind of therapy-type stuff and one of those components was aqua water therapy. It was with six or eight kids at [the high school Isaac attended]. So, that's where we kinda connected. I don't remember how we officially first met but started friendship that way. Obviously, Isaac is a super likeable guy, never met a stranger, so it was pretty natural. You know, when you're in college, everybody's kinda becoming friends with everybody. Then Isaac just kind of got brought into that group and he was still in high school at the time. I saw him pretty regularly, maybe, weekly for a semester or so. Course, he lived [close by] so that made it easy. Really from there, it just kinda snowballed. We just kind of-- just like my other college buddies, we spent time together. We talked about, not serious things. We talked about serious things. We held each other accountable to things that we wanted to do and things we didn't wanna do. It was really a pretty-- just a natural friendship.*

*Isaac's been probably the main driver in keeping that friendship going since [I moved away]. I'm terrible at long distance friendships, but Isaac's really, really good at that. Since I've moved away, we usually spend maybe, every Thanksgiving together just about, except for the last couple. Even a couple Christmases he's been around so it's been awesome. We've just stayed close friends over the years. Isaac actually sang at the rehearsal dinner [for my wedding]. He wrote a song for [my wife and I] and another one of my buddies played the guitar. He got up in front of everybody and he sang a song that he wrote for us. It was pretty special."*

Isaac added,

*So, one of the things that I prayed for was like kind of having the glue of what is it like to have kind of have a brother relationship. Long story short, my family is-- you know my story. I didn't even talk to them very much so, he was kinda like the person that we talked a lot. We were just like brothers I never thought I'd have. But after my brother got married, I literally was, like, "Oh my God. I'm not gonna sing to him again." So I called one of his friends. and I was, like, "Oh my God. He just got married." Like, I was sitting there crying and everything and because he just touched my heart so much. I was, like, "Well, he just got married and I won't see him again." I'm bawling, and he goes, "Wait. Wait a minute." He's like, "You are like a brother to him so you guys are always gonna have a bond and he's gonna call you when he gets back from his honeymoon. You can leave him messages, or you can text him and I'm pretty sure he'll read them even if he's gone on honeymoon. You bros have something." That just meant so much to me and made me feel better. A week or two later, B called me back after he had got back from his honeymoon, and we just started to hang out as bros. He would pick me up and take me to his parent's house. When I got to his parents' house, they are so genuine and his younger brother is one of those brothers you never*

*thought he'd have. One time, I guess his brother got attached to me too because one time he was outside with everybody and his brother was sitting in the room with me. I was like, "Why you didn't go outside with everybody else?" He was like, "What kind a brother would I be to leave you hanging and everybody else is doing something? I consider you like family as well." That moment, right there, it's just cool that they consider me like family, It's just a heart of gold, you know.*

B recalled,

*We also got to do, uh, Special Olympics all together.*

Isaac told me about Special Olympics after learning I had never attended:

*It will change your life. There is one moment that I can honestly say, I still remember it, till this very day. This would've been, like, maybe four years ago-- five years ago. I had a friend that I was doing Special Olympics with-- and had no idea what they were doing. Usually, they'll choose athlete of the year and they don't tell you, so I had no idea. I remember, going down the aisle and [my friend] goes, "Hold on." 'Cause I was getting ready to leave and I think B was either on the phone or we were doing two different things 'cause we got split up, somehow. The guy mentions my name and I got athlete of the year! I screamed and I remember my coach breaking down. The whole aisle-- and my whole face lit up and I was almost in tears because it was, like, a trophy. And B's, like, "What is going on?" 'cause everybody was in a whole moment. Everybody's just on the moment of silence and it was just-- that was so awesome. Very valuable experience.*

B described the progression of his friendship with Isaac:

*I feel like it's kinda like two sections of our friendship. One when I was [in college] and then one since [I moved away]. I feel like the main ones since [college] probably are the Thanksgivings. He comes down with my wife's family and myself. We switch Thanksgivings, so it'd be one year with my wife's family and one year with my family. So he usually comes down for Thanksgiving, so he kinda gets to know both sides of the family, so it's just really fun. I mean, it just didn't even skip a beat to have Isaac along, and it also means we get to have a road trip to and from [Isaac's hometown] on Thanksgiving Day, which is fun. In May is Special Olympics. August is [Isaac's] birthday. Those are kinda like those touch points throughout the year that even if we've been busy and hadn't keep good touch over the years, those are the points that we always come back to, to say okay, "Well, at least*

*we know these are established time that we'll connect or see each other over a weekend" or whatever, and so I just really like those over the years.*

*I've gotten to compete with Isaac. He has one event called the buddy walk, where I get to walk alongside of him, cheering him on, on the track. It's always awesome. Sometimes it's blazing hot as we stand out on the field waiting for his event and stuff, but kinda suffer through it together. Overall, Isaac is just one of those people that always rises above whatever circumstances he's in. He has a good attitude about it and he presses on. I mean, he could tell you a million stories. I could probably tell you half a million stories of times that he's been too generous, and people have taken advantage of him or he's been in a rough apartment and things aren't going good. Whether it's his neighbors or issues with the apartment facilities themselves. But I mean, all the time, he's just always talking about his prayers that help him keep perspective and just having a good attitude and just somehow, makes it through it. I just don't think I'd have as much mental and emotional endurance as he has. He's a friend to every single person he's ever met. So it's always really encouraging to me, is just his generosity and his kindness to everybody is really, really admirable.*

Isaac added,

*I wanted to almost, you know, give up. I would be, like, "Well, I need to be in a different environment and all those things." But through counseling and stuff it's kind of really helped. I think that what has holded us together is just God, foremost, but also just the fact that I've been with him growing-- where things can sometimes be difficult 'cause we would have conversations where he would say, "Well, you know, it's not as easy." 'Cause I would see his pictures, and I used to say, "Oh, man, you have a great life," 'cause he's always smiling all the time. But we all go through things in life, it's not always gonna be fun and glory all the time. But the cool thing is, is when we do talk, it may be 10 or 15 minutes and it's never 15 minutes. I mean he's gonna get value from and so, I think that's what keeps me going every chance we get.*

B responded,

*Yep. That's true. I think, too, something with, Isaac-- if I think over the last however many years-- 15-plus years, we've known each other. I feel like Isaac is, generally, a pretty consistent individual, but then the people surround him-- those tend to be the ones that make his life better or more difficult. So there've been times, you can imagine with the cycle of college students during the school year, and there's lots of college students there, he gets plugged in to some great people. He has good people around him, and*

*things are going well. Then during these off seasons or different semesters where he's not as connected, you know. I remember his last apartment he was in, it's kind of some lower income housing around that area and there was some people that he got involved with, which they're overall good people, but they had a lot of issues and struggles in their lives. They found this friend in Isaac. I don't know if they did it on purpose or just because they were kinda struggling in their own life. They kind of reached out to him and depended on him for a lot of things and he would give them money. He would let them stay at his place. He would let them use his Hulu account and all this different stuff. I mean, all the time. They're just endlessly asking for things. I mean, even though they're not doing as good of a job as he is in making their life decisions, that they can lean on him, for kind of that consistent person. I think it's something that really drew those people to Isaac was because I think in their life, there's a lot of chaos and Isaac was kind of this constant. Even if they got kicked out of their apartment because they were doing drugs, they know they could call Isaac and he would let them come crash on the couch until they got stuff sorted out. So, all the time I'm just, like, "Isaac what are you doing? You can't keep doing this." He's like, "Yeah. I let this person borrow this much money. They said they're gonna be paying me back." I'm like, "Buddy, they never pay you back." He's like, "I know but they just really needed it." I mean, just always generous, always kind. Always thinking the best of people and he's just like, "Oh, it's okay, God will take care of me." And that's true. He has. I mean, Isaac's in, probably the best housing situation he's been in, in a very, very long time and living independently. I mean, it's remarkable. It's really remarkable that Isaac can keep his perspective despite all that stuff."*

Isaac told B,

*I actually shared a moment [with the PI] where things were difficult between us for a little bit. I honestly did and I did grow from it. One of the things that I shared, I was dealing with a lot of like simple things that we talked about and they used to really, really bother my brother a lot and he used to say, "Well, I'm not gonna hang out with you again if you're gonna keep doing this sin." I kind of talked about that. But I think at the same time, there were times where I got really emotional through those kinds of situations, and I remember saying, "It's hard." Because I value him so much like a brother, I had to allow myself to be open to him kind of in that way, even when he felt like, "What you're doing is wrong. It's not okay." But he's learned over the years of growing up, he is my brother until the day we die. I can promise you that. But, we're all growing up and he was a student at the time and so a lot of when you're trying to follow Christ, and, I wasn't really following Christ very well at that time anyways. It was real hard for him. I got to see the hard moments in my brother's life of "I don't like you doing this but are you going to either change or I'm gonna not hang out with you." It stung me for so*

*many years. Eventually, I came down to [B's home] and I remember we were sitting in the car and there was something really bothering me. And B is like, "What's up?" I eventually opened up because it hit me so much where I had tears in my eyes because I always valued him as a friend. I really thought I was gonna lose that, I guess, through the process of him getting married and things changing in the heart. It was in that moment, he said, "That wasn't right of me to do that to you." I remember when he apologized he didn't realize it. Years went down the drain because I had that going on with me for a while. And he's like, "Why you didn't tell me?" It's one of the things, it bothered me so long. I've learned that it's better to have an open communication with people that really care about you, and to have that relationship because that is something that's really important. It doesn't matter. If you're honest with people that value you as any community, I think that is one thing that is always important. I think that's kind of thing that was also shaping me to be a better person to B. I think that was all in God's eyes and shaping me in a way that had brought us closer as bros.*

B added,

*I think that just shows how close of a friendship we had because there are only a couple people in my life that I would call out like that when they're not doing the things they should be doing. He's really probably one of my longest friends. I have maybe two other friends from college that I met around the same time. They live here in Tulsa now. But I mean, I maybe see them maybe once a year. We're not even that super close anymore.*

*Just thinking back all over those years, it's pretty remarkable to see Isaac grow up from a high school student to deal with just some things that are not easy cards that he got delt. And his faith-- I mean, obviously, his faith is probably the number one defining thing about him. I definitely think that's where his main identity is founded, in his faith. I've always just admired that his confidence in God and his love and hope for God to spite his physical situation. I always thought that was really, really profound. We read in the Bible, you can hear about different circumstances that, in modern times, where God heals people and people that were not able to walk, were able to walk. I know I prayed for that for Isaac for however long we've known each other-- 15-plus years-- that God would do that miracle in him and maybe still one day he might, but until that time Isaac doesn't seem to really hold it against God. I mean, maybe he does in his prayer life, which I would if I were him. [laughter] You know, be mad at God about stuff like that, but he just really kinda just takes it in stride, like all the other things in his life and it is not a part of him. I mean, it's not a defining part of him, really. I think if you were to ask anybody that's known Isaac for more than a week to define the top 5 or 10 things about Isaac-- the fact that he has to be in a wheelchair or use a walker, is not even gonna make that list. I mean, he's just such a*

*remarkable person. It's like the color of his hair, it's just not even something worth mentioning. I just think that's pretty remarkable. I have a lot of respect for him in that and the fact that his faith is so strong to spite that. I think that's kind of a common thing that people would assume-- is, you know, you kinda get mad that God isn't doing something you hoped He did and-- or hoped that He would do and, that would kind of build the separation between you and God but that's definitely not the case with Isaac. I mean, he prays for other people more than he prays for himself, I'm sure.*

Isaac replied,

*Well, one thing I have learned is that if you don't, worry about yourself and worry about others, the process of praying for them, it makes your life that much better because when you stop thinking about yourself that's when God glorifies you more. The process when you think about others-- because then it helps to build you up too.*

*If I get to meet Dr. Phil and if he got to ask me, "Why did you do something that was so remarkable and that was so personal about your own life?" I would honestly say, It's because people need to hear it." 'Cause some of our stories are not just because I'm disabled or just because people see me in a chair. But it is actually with everyday life, and I'm learning how to be independent, and learning how to grow every day when you think that it's not as easy. But what I want somebody to read the [story] and be like, "Wow. This is good. He literally did what he had to do to get where he's at."*

B commented,

*There's a million stories for sure. [laughter]*

Isaac responded,

*And there's a million more coming. I'm pretty sure.*

Isaac asked his friend and former HTS, N, to join an inquiry. When N arrived to the inquiry, Isaac told me how he and N met:

*So I actually met N through one of my friends, and he was a student at the time. I had asked [my friend], "Do you want to hang out?" He was like, "Yeah." So [my friend] picks me up in his car, I come over there and [my friend] ends up doing something or leaves and N is like, "Did he leave you*



*here or something?" So, N comes and sits on the couch and hangs out. He tells me about his story and about how he used to not be able to walk and he had to learn how to retrain his body to be able to do those kind of things. We became really, really, really good friends. I think it was either the second day or the third day [since we met], I said, "Well, I want to go to this wedding that's in Dallas." Of course, N doesn't even know me quite that long and I said, "Well, could you take me to this wedding?" So N's like, "I'm really not sure, but let me call Mom and find out."*

N added,

*Because I didn't own the vehicle. I was down to go, but I didn't own the vehicle, so I had to call and get permission.*

Isaac continued,

*Yeah, so I'm waiting for a good 10 to 15 minutes and he gets back in the car and tells me, "All right, I'll take you." So we get into his dad's car, and that's how we just kind of like kicked it off, is going traveling and going to Dallas. I'm serious, he didn't even know me from A. But, we're going on this major trip. So, we're going to this wedding and he's having the most fun of his entire life. I think we ended up going to the mall beforehand. We get going to this wedding. Of course, he didn't know at the time that I am one of the dancing fools at weddings and that's just how I am. I'm out there. He's out there with me having the most laughs, making sure I'm all right and everything. I am like the fool on the dance floor. N is just laughing with the biggest grin on his face. We just had a great time. Since then, we literally went on adventures together. Before N started working with me, I said, "I need a staff," N goes, "What do you mean?" I said, "Well, I need an HTS to work with me every day." And he was like, "I think that would be a good idea. Let me go and fill out this application." I'm telling you what, me and N was like those people that was unstoppable. We traveled every day. We went to go see his parents, from seeing his parents to going to a different wedding or to go into the city, into the mall. I mean, we were always doing something. We literally hit it off. I would go to his house or he would go to mine, and we would work every day.*

*N was one of those [HTSs], he saw me as a friend, so we were over beyond hours just to have fun. I would come over like almost every day and we would watch movies, eat popcorn, or whatever. I'm not saying that it was easy all the time, but for most part, that's the way we were. We just had it like that.*

Isaac moved to ask N the next question:

*So Tia, she's the one that asks my questions, but I'm changing it up. So what was kind of your first reaction when you got to meet me and kind of the idea of what was it like?*

N replied,

*It was fun. We had some good times. [Your friend] freaking ditched you. He just brought you over and then it was like, "Adios." So it was like, "Okay." So, we hung out for a bit and watched a movie, talked, and good times. I think it was the second day of knowing you we went out to the lake because you stayed the night and you wanted me to take you to Dallas, and I was like, "Shoot, yeah, absolutely." Partied up in Dallas. Dallas was wild. We got to run through the mall and through the parking garage. That was really fun. About lost you on the downhill. That was scary. [laughter]*

*But, yeah, Isaac, he hangs out with some characters, man. He's kind of like that person that takes stray cats or stray dogs, but stray people, the type of people that most people don't hang around, like [one of Isaac's old friends], for instance, somebody that has been on drugs their whole life or that deals with mental handicap or has just struck out a lot in life and doesn't have it going good for them. That's the kind of people that Isaac picks up off the street, and he'll hang out with them and just try and help them out. So we've met quite a few characters through knowing Isaac. We almost got in trouble with a local gang. That was interesting. We were going to approach the gang leader. It never happened, but we got into some hot stuff.*

Isaac added,

*Well, so, first of all, I already knew the gang member, He's like a cousin. And definitely, it was one of those moments where you're just like, "Why do you hang out with these people, and then why do you do the things that you do?" I explained to [the gang member] and he was all calm, and it didn't really escalate. So things went quite all right.*

Isaac continued,

*Well, and I guess the next question would be, what are some experiences that you had once you saw things that were going on with my family, and how did you kind of see the reaction of the different things that went on in my life?*

N responded,

*So because Isaac hangs out with such unique individuals, including his family, to a degree, there was a lot of drama at his house, man. And it was a contagious thing too, because I know I got caught up in it for a little while. It's just everybody's loud and obnoxious and everybody's in each other's business. And, boy, if they didn't like something you were doing, they'd let you know about it, and then they'd make a big deal out of it because then they'd go and tell this person and then they'd tell that person. And while they were living with you, it was drama, drama, drama all the time. So that was my experience with your family. It was constant just craziness in the house, and then they moved out and things chilled. But your friends still, I think, are quite dramatic, but not to the degree that it was when your whole family lived together."*

Isaac clarified "drama":

*So what he means by drama, because of how the family was reacting to some of the things that I would do or what they would do, it would cause him to kind of act more like them because of how they were reacting.*

N continued,

*Yeah. There was a lot with Isaac's independence and his mom trying to take control of his independence and not let him be his own man kind of thing. Then there was also like just every little thing in his apartment. "This could be better. That could be better. You should do this. You should do that," or, "You should hang out with that person," or, "You shouldn't hang out with that person."*

Isaac added,

*I guess it's like them lying because, like I said, when we talked about me having such a big heart for people that are into the whole drug scene and the whole idea aspect of things, I'm older now, so I have a little bit more common sense than I did a few years ago. But at the time, my idea was, "This person is really hurting so I should help them and not worry about myself." It was the same thing with my family, but the thing is I never had time to myself. Like they had like a dog we had from my grandma to my aunt being always in the house and they were all causing fleas. They wouldn't clean up after them. I had to do a lot of that, and it would get overwhelming because sometimes that's why N took off, because they were always there. The [human services] agency really didn't like it either, but because I am such a caring person that can cause me to be in trouble. A lot of what used to go on doesn't go on as much now as it was years ago. Since I moved and things like that, I'm further*

*out. So things have toned down a lot, and I think - and N can agree with it - sometimes when there would be points in our lives where the family would kind of motivate him in a negative way because of how they were treating me. That's the way that he started too, because of how they were acting. N also was my HTS. So when you have a friend/bro and then having to change kind of the direction because you're handling both, it becomes a little bit hard. And especially when you're in their personal life too and then trying to be an HTS, sometimes can be very, very hard at times.*

N responded,

*Well, too, Isaac is hyper independent. You wouldn't believe the things that Isaac can do. A lot of people look at a guy in a wheelchair with cerebral palsy, and they're like, "There's no way that he can vacuum his house or move furniture around or do the dishes or cook for himself or all that kind of stuff." And sure enough, Isaac gets around and he gets to it. So he's much more independent than people give him credit for. So he doesn't, I guess, know where that line crosses into the danger zone. But, no, Isaac's hyper independent and he has that mindset.*

Isaac added,

*It wasn't really glory all the time. There were times where we would be in heated arguments sometimes, because we're bros. And of course, when there would be certain things that I would be talking about, where it can be something small or we could be in a argument. Like, one time we were at my house and we were sitting in a car because my family's in there. And he would tell me, "This is so disrespectful, and all these people are doing this to you, and it does not make any sense. And you're allowing this to happen." I think a part of it, he was affected in a lot of ways because once you're an HTS and you get to see what's really going on, he was really concerned. At the same time, I was also trying to go to school, and that was really hard because I was going through a technical university, trying to get my Design for Computers. So it was really difficult. I would stay up late sometimes at his house to do the homework, or at least, the parts of it that I didn't understand. I was trying to be better off and do school and do all those things. But the school was causing me not to do what I needed to do because I took a lot of time to do that and not so much of my health and things like that. So N was one of those people that was always concerned. And if he didn't feel like it was right, he would let the PC know.*

N added,

*His mom had a house, but she spent a lot of time at Isaac's place instead. And then his uncle had an extra room or something, and yet his family chose to live with Isaac instead of the uncle. They had places to go. They could have gone elsewhere instead of living with him, and they disrespected his space. His mom knew absolutely no smoking in his house, and yet she would smoke in his house all the time. She would come over to his house to use the shower and then crank up the heating to like 80 degrees. And he had told her like, "Hey, it's hot in here. Why is it 80 degrees?" It's blowing his electric bill out of the water, and yet she's not paying for it. And these are things that we talked to her about, and it's like, "You can't do that. This is his house," and she would do it anyway. Then they brought a dog over, and the dog infested the house with fleas. Isaac had rules and they didn't follow them. And it's like, "You all could go someplace else." But Isaac wouldn't kick them out. Isaac wouldn't put his foot down and do that to them. I'd have let them have it. [laughter] Kicked them to the curb. "It's my house."*

I asked Isaac if he felt the same way N did. Isaac replied,

*Well, I think it was more of like he was getting angry because I would not tell them. Because, one, she's the guardian, but two, when my aunt and everyone was in the house, I really didn't have my own space, really. I was the one trying to take care of everyone and then myself. So it's we had these moments where N would be like, "Whoa." I'd come to his house just to get away from my own house. Sometimes when it was the weekend, I would literally stay at his house the entire weekend just to hang out."*

N added,

*We had to take him out of this house a lot just to get away from his family. And it's like, "That's his house. Why are we getting him out of his house to get away from people? Why can't they get away?" They were eating his food and not contributing. Can you imagine on his salary with his budget, trying to feed four people, including himself, and they weren't contributing? Like, what the heck? No. And they ask you for gas money and stuff. And it's like, "Dude, get a job. Don't ask Isaac for money." He'd give them money because he's got a tender heart."*

Isaac replied,

*Yeah. I was working at two jobs at the time to be able to make ends meet.*

I asked Isaac if family were the ones, in addition to friends, that he felt took advantage of him.

*Yes, mostly, it is my family. Because I'm in a different area now than what I was, it takes them a little longer. Today, my grandma's doing laundry because they have work now. But that's grandma. She's in her 60s. So I have respect for them.*

N added,

*That was another thing. They'd come over and do laundry, and that's another part of your bill that they wouldn't help with.*

Isaac continued,

*Well, and I think also one thing good that I could say is my grandma, she's the only one that's super supportive on a lot of things. I think a lot of it's so dramatic, but until my mom kind of steps away and has somebody else step in, it will help me in the longer process to do things that are better for my outlook because my mom wants to hold so tightly because she's afraid that people are going to take advantage. But until that time of letting freedom go so that life can change and life can happen, it's difficult.*

*I think the big thing- the reason why I brought N along is because he's seen where we've had different aspects of what happened and, well, we've had arguments because of what my family has caused or of the decisions that I make sometimes can cause a lot of that, and I think that is like his thing. But, yeah, the reality, I mean, there were some good moments like freedom for a little bit and something new would happen. I talk about you have to choose your friends wisely, and my mom didn't want me to go through anything hard, but anybody that I tell to read this book they have to allow themselves to get through the difficult to get through the good parts. But if you can't go through something difficult, they're not living life at all.*

N replied,

*Isaac's had a double life. He's had a very hard, very difficult life full of drama and hurt and pain. But he's also had an extraordinary life. You listen to his stories about all the things that we've done together and then Special Olympics, and he's been in a magazine. He was in the magazine [for the*

*place he works]. He was on the website [of the agency that provides disability services to him]. So he's got a crazy story.*

Isaac said,

*Well, here's the thing that you got to realize is that I want my story to matter and the reason why we take as much time as we're doing, and like, as much as I know N, he learned to value me and I learned to value him in such a way that we learned how to value each other's time and taking those moments very seriously. I'm just hoping that—through my story, I can make some differences because there are people out there that may be struggling, that may be far worse than I am, and in that respect of what should you do and what should you not do? I can be able to be very transparent with everyone and hopefully, change lives. That's the whole reason for it.*

D is Isaac's friend and former HTS. D, N, Isaac, and myself are in the inquiry. Isaac began to tell how he and D met before D interrupted,

*A little bit over a year ago I moved to Boomer, and my mom walked into the wrong apartment, which was his apartment. I moved in and I saw him with, at the time, it was his current HTS. I thought they were roommates. I didn't know the story. I'd just be, "Hey, man, how're you doing?" And I go my way. I didn't know who [Isaac's HTS] was. I guess he was quitting, and then [Isaac and I] would talk outside and then Isaac would tell me like, "Do want to be my HTS?" And I'm like, "Okay, I don't know what that is. Fine. Sure." I really wasn't at all excited about the idea because I had another job in mind at the time. I said, "Okay. Fine. We'll talk to these people whoever they are. I'm going to talk to them." I said, "Yeah, I guess we'll try for a little bit to see how I like it." I ended up doing that for nearly a year. And the other job that was in mind? Well, it didn't happen anyways because they just weren't hiring at the time. I did not know anything about HTS. I've been with him ever since, about what? Nine months?*

*When he went on his little break or something, his little trip, a lot of miscommunication happened with his ex PC. He said some things and I ended up without a job. I don't know what happened, but here we are now. To this day, I'm still not sure exactly what happened. So I'm not his HTS anymore, but I guess if you needed me to be one, I would be his HTS again if that was something, but I still come around. Still hang out with him, stuff like that.*

Isaac added,

*So he's done that for about a year. I would go travel with him. I got to go to his parent's house and I got to hang out with him a bit, just to get away from [town]. There were a few times when we went to the city, and I had to get my wheelchair fixed. D would take me to those places, and we would hang out. We went to Sonic all the time and did some awesome stuff there, and then kind of got involved with [a church-based group and it's just been really cool in just different moments.*

*Sometimes, it wasn't as easy, because we were all going through different changes and stuff. I was getting ready to move and all of this stuff. So it was kind of really chaotic because of the friends I've had. I've almost been [in my current home] for a year. I cannot believe it.*

*It's just been-- it was kind of like we were just going through ups and downs and all these people trying to tell us what to do. There were a few times when I wouldn't have very good friends or what you would consider role models. So when D was my HTS, when I had issues going on, he would go get things for us even when he was off duty, so just with those things.*

*Like I said before, we had points where things got super, super difficult, where [my human services agency] would say, "Where is your HTS? He hasn't been here today." I would call D and try to be the big man, trying to get everything to go right. Instead of asking somebody to do something, I would tell D to do something. Just because I was getting overwhelmed with my mom, and with the PC, with her trying to bug D.*

*I mean we didn't talk for about a couple of months after that because we just have a lot of distance with each other. I mean we needed a break just because there's so much going on. And a part of that was because, one, I was not respecting him when I should've been, and I should've been open about being more open with him on what was going on. And so that way, it wouldn't have happened the way it did. But we are stronger bros now than we ever have been now. I think that it's a learning experience. It's okay if your brothers are going through difficult things in your life, and you have to allow hard things in your life to be able to get to the good things in life.*

Isaac added,

*I remember one time, I had helped D. So I would hitch him [to my wheelchair] and try to help to get him going because even though you're not supposed to do that, he's my brother, so I'm going to do what's necessary to get him through. That's how we just care for each other.*



*Back then I was really in-depth with my personal life. I'm was going through so much stuff, but I was more about me at the time.*

D interrupted,

*I think the responsibility we had-- I almost think that sometimes I should have waited to be working with you. How do you know you're going to be in a rough spot? How do you even know that? That's with any job. You're working somewhere, you're going to hit a rough spot somewhere. Okay, so that's really no one's fault. Rough spots come up. Okay, there's no need to blame. It's just life. It's all there is to it. But not everyone is so understanding about that.*

Isaac continued,

*Right. I mean we had fighting words sometimes. I think that's with anything. We're gonna act like brothers and no matter what. That's just the way it's going to be. I consider him like my own brother anyway, even when he told me, "Well, you don't care and blah, blah, blah. You're thinking about yourself, blah, blah, blah." Well, it did affect me a lot because I'm just a caring person in general, but I should have done it in a different approach. The whole point of life is things aren't always going to be easy, but the harder things get easier as you go on in life because you want to grow with them. When they do go through something difficult, you'll know they're going to be there for you. You'll know it. I really knew it because I think through a point of being separated for a month and a half has taught me, "Well, you got to learn how to respect." It's better to listen to someone that's going through something, and so you should have asked them how are they doing. Before you just go on about your own thing, you should be really more worried about what's going on in their life. If I would have known that I think we would have been better, even if people would not have the best day, but me showing that consideration would have made our relationship stronger as bros and stuff. Even if things were hard in my life. I think it would have been a lot better to communicate because my communication was off.*

*He understands me better now. If I say something that does not make sense, he'll come to me and ask in-person and he'd be like, "What did you say?" or I'll come over. Because if it's something important, then I'll talk to him in person and say, "What were you trying to say? I didn't understand." Or he'll call me and say, "Hey, I didn't get it." We need people to-- actually, the best way I can put it, it's always good to have bros that seem to grow in relationship with you. But you have to have those bros that are going to be with you through thick and thin because, it gives you more confidence when*

*you have people that support you and more things in your life, when you support each other.*

D responded,

*I mean I don't just hang out with you just because the majority of it was not for a paycheck. It wasn't for pay, right? I mean if it was for the paycheck, and I can work with you now and I'm still over here. I don't just do it for pay, and I didn't do it for pay at the time either. I did it because I'm a generally caring person. I care for people. I mean I didn't get paid for the majority of the stuff that I did when I was your staff but I did it anyways.*

Isaac said,

*Yeah. So now I know when I'm going through something, I could text him no matter where he's at. And it might take him a little bit to respond but that's okay because I know that eventually he'll see it. But when I'm really frustrated, I can go to him. And I just know that that's when I was there, it just makes me feel better. I don't even talk to my case manager now, because every time I try to open up to him, he lets everyone know. And so just having that kind of personal person to be there, and my counselor-- He's kind of like my bro, my counselor, all of that. But it just enables the help, so in a way, I'm not feeling like I'm by myself. Maybe I did say things that were a little bit more personalized that my bro was not ready for it yet.*

D responded,

*Nah, you got to work a few things. Listen, there are some of the things that you kind of were dealing with. I understand why you did this, but I really don't agree with it of how you deal with this. There are certain things that you told me. Like yeah, I understand it, but I really don't respect it. It's how you deal with your business. Okay, so, like everyone deals with things in their own way, and you don't have to expect it, but you can understand it. Sometimes, you don't even understand it but you respect it.*

Isaac replied,

*Yeah. If people are talking about you, then you've done something right. But if people are not talking about you, there is something wrong. The reason why I say that is because you know that work is not done and you know you have work to do. So if people talk about you, it's always going to be like, "Okay." Well, there's reasons behind that. You just have to find your own people that care about you; you learn about them, and then they learn about*

*you. The more that you're around the person, the more that you also understand that person. So when everyone's having a hard time, they know that they can come to you and know that it's not going to anybody else, then that's the way it is. And that's something that I just had to learn from the ground floor to now.*

Returning back to the intimate inquiries between just Isaac and I, I asked Isaac what he looked for in a friend:

*One of the good qualities that I want to see as a friend is their positive attitude. Do they have the intentions of being a good friend? When I say that, it's like, do they have good morals about themselves? Do they have points of building you up instead of building you down? Do they respect you when you help them out and they opt to pay you back? Are they there when you're in need, and you really need that friend? When you're feeling your worst, do they build you back up?. I think what's important, is making sure that you have friends that value you as a person. Someone that's not gonna bring you down. I've had those friends where I've been brought down. I've been taken advantage of by friends that I thought were my friends and I helped people. Sometimes they overuse you. This is why you have to have morals for yourself, and you also have to have morals of people around. When you make those mistakes, your friends can be there to help you. 'Cause I mean, we're not here to be alone. We are here to build each other up and I think that is the greatest part about life.*

Isaac turned our conversation to another topic:

*This other topic I'm going to talk about is going to be very, very deep and is very personal-- let me see how I'm going to do this.. I'm going to say my dating life was kind of in both directions, I'll put it that way. Because I felt so depressed and down, I did things that were not right. I'm Christian, okay? And I didn't understand, like, who would judge this kind of category about this kind of topic. I will say mine started as I was a child. And when you don't realize what you're doing and when you're with your own siblings and they do things to you, and you don't realize, like, this is-- this is something you just don't do, it affects you as you're growing in that kind of area there. So, personally I'm still fighting this to this very day because, for a while, I used to be picked on, and the girls I used to date, I got beaten for. And so, the issues that I deal with on a daily basis people would consider as not doing the right thing. The reason for that was because for one, I was lonely, and I experienced both where I wanted to feel cared about and most people were like, "Well, people just do it just to do it." Mine was because I was living alone. I tried to get a girlfriend,*

*and then I also tried to date a guy person because of the fact that I was feeling lonely for many, many years, when I figured out that it just does not work.*

Isaac continued,

*I've been in that situation where, "Okay. Well, this person makes you happy. You did things that weren't all right. You got into sin and did things that you shouldn't have done." I've ended up being in a situation-- sometimes I'm still in that situation occasionally, because I think the part that I've dealt with, and even though I know God is still working and I'm still doing things that God wants me to do sometimes it's not easy to see that tunnel. And even though people think things are going good and you smile and things like that, but when you're alone, it hurts. Where I ended up being depressed and I was down for much of my life, I remember having a bro that used to come to my house at 6 in the morning to give me a hug because sometimes I wouldn't get up out of bed because I didn't feel that I was cared about. I mean, I had friends and stuff like that, but it was just not the same. A lot of people didn't know about this in my story because the only thing that people see is the good part, but not the central part, where, like, things are really hard. People will be like, "Well, he was this good person," and I mean, I am a good person, but, sometimes we go through situations in our lives where, it's not even our fault. Sometimes I'm like, "Well, why, God, did I have to go through this?" You know. "Are you still going to love me because of what I'm facing?" When I realized God still does, but I think over time, if you keep staying and you keep believing that God is going to change it, He's going to. Don't ever lose hope in that situation. I mean, I still go through the struggles, I do. Yes. I still deal with it, but, it is getting better because I am able to talk to someone about that. I've had to be personal. I can't tell my parents that. They would go ballistic, or they'd say they wouldn't love me. I've been told to have a sex change. I've been through all of that, but I feel that God still has a purpose for me, and has a purpose for your life. I feel like that my life is going to change for the better, and I may be going through this stuff right now, but it'll be okay because what I'm realizing, the more that you surround yourself with God and people, they start changing you. If you can find someone that you can be opened up to, you need to make sure that they're someone that wants to better your life, and don't go the opposite direction. And I think that's really hard for people to tell because they get judged a lot, and I think that is really the picture. That's why it's hard to open because of some of those things, but, I can relate to a lot of people that deal with that.*

*So the main thing I want to tell anybody that wants to be open to somebody, you need to make sure that they are ready spiritually, and also as mentally as possible because at the end of the day, you still want them to be your friend, and you want to respect that boundary. If they're not wanting to hear that, they need to tell you, "Well, I'm not ready right now. Can we discuss this*

*when I'm more mentally able to understand?" So that you don't do it to them. And you might have somebody else there.*

*I think if people knew the truth and knew that I was Godly and was with this person or a guy or whatever, it kind of just tears things apart with church, especially because even though they say, "Well, we love sinners," things like that, which they do, but their core value is "You want to follow Christ with your whole heart because God's intention is He doesn't want people to be stuck in sin. He wants people to be on a straight and narrow path. But then we go through the struggles, and we can overcome those." So they're the people that I'm with, and which I think that eventually-- like I said, I think this is just a stage in my life, where [one day] I can get a wife and be respected the way that I need to. I think once I realized that there's someone out there that is more important than doing the wrong thing - if that makes sense - then it brings hope because you have people that value you for you, and not so much of, "Oh, I'm doing this person because I'm feeling empty," or, "I'm feeling alone." God is supposed to fill those voids for you. I think that is where you learn through God that even if you're going through that struggle, and you find people that are loving you and that give you a hug and tell you that it's okay, and that I'm not the only one that's going through this. There's several other people that go through things like I do. I think that is where you find healing, is through being in discipleship and being open with that one-on-one person that values you and takes the time out to be able to work with you to work over the struggles. That's what [a local church] does, and I think that is the coolest thing because I could tell you, the churches that I've been to, they were nowhere near as loving as this church is. I mean, oh my gosh. Like, it's insane. I hope that other people realize, you may not be a church goer, but here's the situation. You're going this way, but it never works. That's the important thing.*

I asked if Isaac felt this was a phase in his life.

*I think it's just a phase because like I said, I want to have a wife and kids, and I want my wife to see the good thing in me. It brings me hope when you get out of those hard situations. It's not as easy sometimes because you want that love or that desire. That moment in your life where I was like, "Well, nobody cares. So I should go for it." And at the same time, you'll hear that kind of whisper in your voice, where it's like, "Jesus is still calling you for a purpose." Sometimes I'm like, "God's still using me, even though I'm going through this." Like, "Why is he using me?" But, like, [the Bible] talks about, God uses sinners. That to me is, like, "Oh my gosh. Well, God's still listening," but, like, I don't feel that way. It's a hard topic. You're going to go rile people. I'm myself because I don't want somebody judging me. Because if people will judge you, then that's when you start backing them off a lot. A lot of people don't want to listen. Like, some of my church members, but, when*

*I'm around them makes you want to be better because they value you as a person, and that makes it that much stronger. That you're not going to give up on yourself. It just shows you where God is putting people in your life to kind of look out for you, and it's huge. I believe that you may go through trials in your life where it may be difficult, but I pray that nobody judges this book.*

Isaac was asked if he had ever met a Christian who felt it was okay to love who they wanted and that God still loved them anyway.

*I think in a way it's one of the things where things are difficult when you're talking to another Christian, because I started sharing those things with my HTS, and I think that it got to a point where it got overwhelming for him and when you're having feelings for the same person, they kind of get away from you because you try to be open too much and they're not ready for that, it makes a bigger situation. They do have some different values for that, but, if they're loving enough, they shouldn't stop loving you because you're dealing with something. They should be willing to go beside you and to help you to get out of this and don't leave you hanging, but they're going through that situation with you.*

Isaac recalled,

*I think it was 2015, 2016, I met this guy, he was a [college] wrestler. He was just kind of a big time kind of a guy and we hung out. He's talking about [the Christian youth group he was in] and what he does and he would do this venture. Here I am, checking this group out and I was like, "How can I be a part of it?" And I'm not a student or whatever. He said, "That's fine." Well at the time, I was struggling with the Bible, and struggling with what it said at the time. And he would be like, "Well. You can't be a prayer warrior if you're going through that." But, I really wanted to because it was just a part of my life.*

*I'm a Christian that struggles with that type of sin, but it also says in the Bible that when we share, it kind of helps us to free ourselves. Sometimes you can't tell everyone everything, and I'm going to tell you that right now. I've tried to, but well, my mom kind of judged that in a lot of different areas. I'm talking about when she said that with a whole sex change, it was because when I was trying to be opened, did the sin things that were kind of like family members, which is not okay and I've kind of dealt with it when I was really, really young. Do I wish that I could change things? Because maybe that is a question that may be popping in your head. Um, sometimes it would be better not to change things because there's always greater opportunity somewhere else. You have*

*to be able to live life a little. You have to get into the difficult things in life to understand the easier things in life. If you couldn't handle something that is difficult, then it's kind of hard to understand the easier stuff. You can't just go through the cool stuff.*

I asked Isaac, "Would you say that any of these experiences have defined who you are? Have shaped who you are today?" Isaac responded,

*Yes. I would have to say so.*

Isaac was asked what he envisioned for his future in 5 to 10 years from now.

*I just pray that eventually I will get the wife of my dreams. But it doesn't have to be perfect. I think kind of like going through life together and experiencing the fruitfulness of that and then also having kids. My mom told me; she's like, "Well, if you get any boys, you know, I'm gonna steal them. Or if you get a girl, you're not gonna have it back." So I'm like, "Mom, they're not gonna be anything like me. They're gonna be completely different." Hopefully, I'll treat my kids the same things that I went through that I don't wanna go through.*

I asked Isaac to clarify what he meant by his mom would take his boy or girl and if she would take their guardianship. Isaac replied,

*It's just my mom wanted a basketball team. Mom was like, "You can keep the boys all right," because, 'cause my mom hasn't had any kids, and she's been wanting girls. So I think she's like, "The girls, they can stay with me." I'm like, "No, Ma. No." To be real honest, I want a girl that just loves to be able to do adventures together. I like to travel. I like to want to enjoy life, and I want her to be a part of the groups that I'm in and experience a life together where we have open communication. I want it to be a lot better than me and my mom were. That is something that I'm looking forward to, because maybe through that relationship, hope is something that could honestly change my life, but also it could change hers too.*

*I'm hoping that the girl that I get will be able to stretch me where I can't stretch myself. Knowing that she would be the rock to hold each other up. I mean, I would be that for her, too, but I think that would be just really cool. And that she loves working out and just gets me kind of motivated. When she doesn't feel her best, I can do the same for her. It would be a great moment. I want someone that would value the things that I like doing. I want to value*

*them and spend time together in that way because I feel like in this society today, that that doesn't really happen as much.*

Before wrapping up our inquiries, Isaac told me,

*I appreciate you for just meeting with me every week and doing this for me. Because this is the biggest opportunity ever. I said I've done with several students where they had to write a biography on me, but this is the first time it's actually going to be an actual published [story]. You get to be a part of that. I am looking forward to it. And I hope this last semester is gonna be worth it all. I'm excited. I really am. This is gonna be one of the most important [stories]. When people look at this, people can be like, "I know this kid worked really hard to share his story."*

*This is one of those things, I think that's gonna be one of those moments where I'm just gonna be like, "I have to give it to the Lord, because this is my real story and I get to share with the world I'm gonna be like thanks to Tia, she's got to be here with me. It's just an opportunity to show there are people with disabilities that are real and we lead real lives. It's not as easy. I've dealt with a lot of things where I was taken advantage of.*

Isaac continued,

*I believe that some of the things that I talk about in the [story] is my personal issues that I dealt with. Most people are not going to be okay with what I say, but I want people to understand, this is just the ground well of where God kind of had me, and they're going to be, like, "Well, it really wasn't God." I believe that it was because if it was God's choice, I wouldn't be doing what I'm doing in a church, I'm closer with people. I study. I do all of that. But I have problems too. Everybody does. I think that's what people will understand. I mean my story's going to be really important, and I think that most people are going to understand. I'm very independent, and sometimes being independent is not always easy, you have to understand, you have to do the hard stuff and pay bills and doing the things that people don't really explain to you. When you're in the real world, it means that you have to get real, you have to do that.*

Isaac described his desire to tell his story on the Dr. Phil show. Isaac expressed how much he hoped to impact others with his story.

*That's what I was literally saying. And when [Dr. Phil] asks you a question like, "When he wrote this book, did it kind of affect you in a kind of a way I believe that you would say, "Yes. It affected me a lot because he is so real and*



*so committed to share his story." Would I do it again in a heartbeat? Yeah. I would because this is what I've been drawn to do, and this is what people are scared to share and I think that it will change the perspective of people. The point is, if somebody else is, like, "Well, I want to be independent and be by myself." I want people to be able to read this book and I'm hoping that they can say, "You know, I don't want to go through this, but, I'm glad that he shared his story because maybe this could be a wake-up call for someone." I mean, you know, you really don't know.*

Isaac emphasized he will be professional during book signings and being on stage. Before closing out Isaac, again, emphasized the value of people in his life and sharing his story.

*I wish I would've met you long time ago. I love having so many people in my life too.*

I commented on the similarities among Isaac and myself to which Isaac replied,

*I know. I know. I can't wait until one of these days I will meet your husband, and I will make sure we'll go to a nice restaurant, and I'll be professional. I can't wait.*

I told Isaac he didn't need to be professional for my husband, to which Isaac responded,

*Oh yeah 'cause it's gonna be a moment where like, I feel really lucky. Me in a suit and a tie, walking in there and sitting down with him and being professional and, you know, just show we got what it takes like everybody else does. I think your husband would be shocked if I gave him a firm handshake. It's just because, you wanna show to [people] you are in the same class as them. It's kinda one of those things where he'll be like, "Man, you handled it pretty well. I mean, you came in here in the nice restaurant, and come to talk to me professionally." 'Cause maybe he's never seen somebody that's disabled that actually handles business on a professional level and enjoyed doing it. Well, I haven't seen very many people that are disabled that's professional. I think it's because people don't give people enough opportunities or give them the chance to kind of shine. Maybe if I do something professional, [your husband] may see something and be like, "You know what? I have something for you." It's just things like that.*

Before closing out inquiries, Isaac told me,

*I hope we get to keep [our relationship] for a while.*

To which I replied, “I hope so, too.”

## CHAPTER V

### DISCUSSION

As individuals share their stories and derive meaning from lived experiences, their identity is composed (Henderson & Bigby, 2019). Deriving meaning from life experiences also provides an individual with a personal sense of purpose (Singer, 2004). Employment of storying to examine meaning making and identity formation processes is a source of empowerment among adults with intellectual disability (Grove, 2012). Furthermore, sharing stories creates connection and builds trust (Brown, 2018). The current study was guided theoretically by storying and the socio-ecological model of disability which are grounded in accessibility. Amplification of voices requires that voices are listened to and heard within safe spaces (Phillips & Bunda, 2018). The current study presented the beautiful and unique voice of three adults with intellectual disability and demonstrated their ability to share their stories, combating biases that perceive otherwise (See Scior, 2016).

Chapter 5 describes the story construction and storytelling processes as they were portrayed and how they relate to the research questions; interpretation of general, thematic, and unexpected findings; implications for research and practice, and future directions; and my closing thoughts.

## Story Construction and Storytelling

To honor the voices of the adults in the study, each of their stories are presented in the manner of which the adults intended for their stories to be retold and heard by the readers. Furthermore, each of the adults in the study's full story is presented one after the other. This is because their stories are all unique and allows for greater amplification of their voices as entangling each adult's story with the other adults in the study would limit the critical meaning making processes demonstrated by each adult individually. Furthermore, disentanglement of the stories to present them thematically uses my voice in place of their voices.

Ella told her stories in a chronological format, starting from birth. Each story built upon the next based on the timeline in which she experienced them. Ella described the purpose she had for sharing her story and wanting her story to be heard to prevent others from experiencing the same lived experiences she endured as well as provide tips for getting out of similar situations. Ella said trusting me with her story was important as she had only opened up to a few people.

Fabulous shared her stories starting with the present and bounced back and forth between the past, present, and future, emphasizing the present and future. Throughout Fabulous's stories, passion was evident as she described her future with such detail. Many of Fabulous's stories that she shared were accompanied with life lessons. Fabulous confided in me with some stories that she did not want shared and were removed during member checks. Many of the stories removed from the study could provide the reader

with additional context; however, it is the privilege of the story receiver to hold such beauty sacred.

Isaac begun sharing his stories chronologically starting with birth, but also bounced back and forth between the past, present, and future. Each story told by Isaac was accompanied with life lessons for himself and others. Isaac found joy in inviting a few important people in his life to share their perspectives of Isaac's lived experiences.

### **Research Questions**

There were two research questions which guided the present study. The first research question was, "What shapes the identity of adults with intellectual disability?" The second research question was, "Is intimate inquiry through a storying lens a relevant method for understanding identity formation and meaning making processes among adults with intellectual disability?" Connecting the results to the research questions, within each participant's story are two categories: current identity, and identity formation and meaning making processes. The *current identity* sections present the chosen and current identities of the participant. The *identity formation and meaning making processes* sections present the stories of lived experiences shared by each participant which have shaped their current identity. The second research question is answered through the results as the storied results demonstrate intimate inquiry through a storying lens as an appropriate method for examining identity formation and meaning making processes among adults with intellectual disability.

## **Interpretation of Findings**

I asked each of the adults in this study to meet with me on at least three occasions for intimate inquiries and they all agreed. However, the number of times I met with each participant varied. Ella and I met on three occasions: two via Zoom and one in-person in her hometown. The two inquiries Ella and I had were not in total privacy as they were held via Zoom and Ella was using the computer in the common area of the group home in which she lives. During both inquiries, staff and roommates were present. The third inquiry was in-person. During the third inquiry, Ella and I went to lunch and toured parts of her hometown, stopping in the local Dollar General for Ella to purchase gifts for staff with the money she received from the study. As we drove around town, Ella made plans for what we would say to staff when we got home regarding how much she ate and how she got the money to purchase the gifts.

Fabulous and I met on five occasions for intimate inquiries in which she and I were the only individuals present. The first four inquiries occurred via Zoom communications and the fifth was in-person in Fabulous 's hometown. During the fifth inquiry, Fabulous and I toured her hometown and stopped in to several places she liked to frequent including Walmart, CVS, a nutrition shop, and a church recreation center. As we drove around town, Fabulous told me to start the audio recording before delving into a story about her experiences with independence.

I met with Isaac on eight occasions for intimate inquiries; seven via Zoom and one in-person, although the in-person visit was not audio recorded. Of the seven Zoom

inquiries, four included important people in Isaac's life to include: the physical therapist who helped him to walk across the stage at his high school graduation, and three of his friends. Two of his friends (N and D) worked as Isaac's Habilitation Training Specialist (HTS), but had developed a relationship with Isaac prior to being his HTS. One of his friends (D) lives local to Isaac while the other two friends live out of town (N & B). For our in-person inquiry, I picked Isaac up from his home and we drove to pick up coffee at a local coffee shop before going to sit at the lake near his home. D met us at the lake and we chatted for about an hour, getting to know one another off of a recorded screen. This in-person meeting allowed me to gain a deeper perspective of his relationship with D as well as his favorite local places to frequent.

### **Socio-Ecological Model of Disability**

Modeled by the strengths-based approach of the socio-ecological model of disability (Shogren et al., 2017), the adults in this study were the drivers of the intimate inquiries in that they decided how often we met, how many times we met, and the stories they would share when we met. Occasionally, the adults in the study would request that I ask questions about their lived experiences; at which point I would probe into stories they have already shared, stories they have eluded to, or stories that they had not yet shared. Placing the adults in the study inside of the driver's seat during intimate inquiries and data analysis demonstrated accessibility and personalized supports, recognizing the individual strengths of the adults, consistent with storying (Phillips & Bunda, 2018) and the socio-ecological model of disability (Shogren et al., 2017). Personalized supports came in the form of allowing the adults to make requests as necessary during data collection and retelling their stories in the manner of which the adults intended to share them. For

example, Isaac would often comment on his desire for me to “piece together” his stories in a manner that exhibited “more professional” approaches. By this he meant that he wanted me to add details to his stories as he retold them during different inquiries to provide additional context. Furthermore, using the unique languages and voices of the adults in the study throughout the findings demonstrates their own unique and personalized strengths in storytelling. Each of their stories were told and shared in impactful ways, but each in their own way.

While the intimate inquiries held via Zoom allowed myself and the adults in the study to develop deeper relationships, the in-person visits provided me with more insight overall as demonstrated above. In-person visits allowed me to see, first-hand, the lives of these unique and incredible adults. Using the socio-ecological model of disability as a theoretical framework was critical for guiding the individualization and accessibility within the study and challenging biases prior to entering the field. This lens also provided further context for the stories that were shared by the adults in the study as well as the environments in which they live during our in-person visits. As emphasized in the socio-ecological model of disability, disability exists at the intersection of human functioning and environmental demands (Shogren et al., 2017). Getting to hold space with the adults in this study, virtually and in-person, allowed me the opportunity to witness the worlds and communities in which the adults live. I was able to witness their sacred spaces and see first-hand that disability did not hold space unless and until the adults entered environments that did not meet the demands of their unique functioning. For example, when I was with Fabulous in her hometown, she took me around to show me how she independently lives her day-to-day life. However, when she is with her staff she feels



held back in that she is not free to be herself and instead feel obligated to meet the demands of her staff in her own home.

### **Normalization Principle**

Important to note is the concept of normalization that was presented by the adults in the study. Fabulous and Isaac expressed their desire to be “normal” and be seen for more than a disability diagnosis. These expressions are consistent with the normalization principle which emphasizes the importance of “existence as close to normal as possible” (Nirje, 1969, p. 19). As Nirje (1969) said it, “The normalization principle means making available to [individuals with intellectual disability] patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society” (p. 19). The adults in this study each lived independent lives, whether in a group home or on their own, and each had staff members to support their independence in the areas of daily life that they uniquely needed support for, such as transportation. The normalization principle closely aligns with the socio-ecological model of disability in that strengths alongside limitations are the focus of supports (Nirje, 1969; Shogren et al., 2017).

### **Intimate Inquiry Through A Storying Lens As Source of Empowerment**

Findings of the study clearly identify intimate inquiry through a storying lens as a relevant methodology for examining identity formation and meaning making processes as noted by the emphasis of trust by some adults in the study and each of the adults emphasizing the importance of relationships. Furthermore, due to the fluid nature of stories, having multiple opportunities to retell and rehear stories provides both the

storyteller and the story recipient with additional context to paint a clearer picture of the meaning making processes employed. Consistent with Grove (2012), findings identified storying as a source of empowerment for each of the adults in the study. While their purposes were unique, each of the adults in the study mentioned having always wanted to share their story and described the benefits they would reap as storytellers in addition to the benefits story recipients would reap as a result of having heard the accounts by the adults in the study themselves. As Ella put it:

*I've always wanted to share my story with people. Me and my counselor have always wanted to publish my story, write a book about this. Me and my counselor was actually talking about me going to church and talking about my story and going to schools and talking about how my story is, you know, talking to girls and groups about how I survived. I want molestation, prostitution, [and] sex trafficking to never happen to any girls. Like it never happens to anybody. It never happens to little girls that live with their grandparents. [For me personally], I think it would help a lot by getting a lot of things off my chest for one. And for others, if somebody has been touched, they could feel safe to tell someone. That's what I'm gonna tell them. 'Don't ever be scared to tell someone because that's gonna hurt you in the long run.' 'Cause I didn't tell anyone 'till I was 16 'cause I was scared. It hurt me in the long run. I just don't want it to happen to anybody else. Like I've always wanted to [share my story]. I'm really glad you came to me.*

Fabulous Erin Crystal (Fabulous ) described her desire to share her story with the world.

*I want to tell my story to the whole world. I want people to hear my account, get my book, and see what I've been through.*

Isaac (Isaac) envisioned his story as a possible “wake-up call for someone,”

*This is what people are scared to share and I think that it will change the perspective of people. The point is, if somebody else is, like, "Well, I want to be independent and be by myself." I want people to be able to read this book and I'm hoping that they can say, "You know, I don't want to go through this, but, I'm glad that he shared his story because maybe this could be a wake-up call for someone."*

The more time spent with each adult in the study, the richer the stories due to fluidity of stories and the nature of stories being built upon one another (Phillips & Bunda, 2018). For each adult, inquiries built upon the other, but did so in unique ways. Several of the stories told by the adults in the study were retold during more than one inquiry, each retelling providing additional context. Furthermore, with each intimate inquiry, the adults in the study appeared to be more comfortable and trusting by demonstrating vulnerability. For example, during the initial intimate inquiries with Isaac, he presented his stories and asked for me to write them “in a more professional way.” However, as the inquiries continued, Isaac’s sharing of stories appeared more relaxed and Isaac confided in me with some aspects of his identity that he shared were not fully accepted by his friends and family (i.e., sexual orientation). Fabulous trusted me with some aspects of her personal identity that she also trusted I would not share with others. Having the privilege to be trusted enough for her to open up and share such deeply personal-to-her facets of identity provided me with additional context of who she is and her lived experiences alongside this hidden aspect of her identity; however, these insights will not be shared to maintain my commitment to confidentiality as well as to Fabulous as my friend.

### **Thematic Findings**

Within each intimate inquiry and through the stories shared by the adults in the study, three overarching themes were evident: pathways to independence, relationships, and spirituality. Pathways to independence include childhood and adolescent experiences, transitioning into adulthood, challenges and successes in the journey for independence. Relationships include friendships, relationships with family, peer relationships, community relationships, and relationships with staff. Spirituality encompasses a faith

and leaning on God in their lives. Relationships and spirituality were entangled in current identities as well as the identity formation and meaning making processes of the adults in the study, thus cannot be disentangled. Pathways to independence were highlighted in the identity formation and meaning making processes shared by the adults in the study.

### **Current Identity**

Consistent with Strnadoná et al. (2018), the adults in the study maintained a positive sense of self, despite the stigma and oppression they experienced. By entering the intimate inquiries without the assumption of disability as central to identity, one participant never disclosed having a disability. Disability was generally presented as an ascribed identity by the two participants who disclosed having disabilities, although disability seemed to be a fluid aspect of the chosen identity as shared throughout their stories.

Ella described her current identity, highlighting her survival of a traumatic childhood, her transition to independent living, relationships that have shaped who she is today, and the role of God in her life. Ella emphasized her ability to overcome the hardships she experienced in her life. The role of the supports she has had in her life have led her to be the person she had come to be at the time of the study. Disability language was never introduced in intimate inquiries with Ella, neither by Ella nor by myself, which demonstrates that disability does not play a role in Ella's identity.

*I a survivor. If it wasn't for [the pediatric psychiatric hospital I aged out of], the [group home I live in now], my aunt, my sister, my husband, my counselor, and my [housemates], I wouldn't be who I am today. Right now, I'm a loving person. I'm a wife. I'm a survivor. I'm God's gift. That's what I am. I am a leader. I am a wonderful person. I am a roommate. I'm just a*

*wonderful person. That's who I am. I'm very thoughtful. I have a big heart. [I'm my best self] when I'm happy and when I'm around my husband, roommates, when I'm around people.*

Fabulous highlighted the role spirituality and God played in her life alongside family, friends, peers, and coworkers. She also described her desire and delight in independence, demonstrating ordinariness in her identity as described by Kittelsaa (2014). Fabulous described herself as:

*I'm young, beautiful and courageous through my own very eyes of my heart and soul. I will never forget the great Fabulous I am right now. The greatest Fabulous I've ever been through my whole wide world. It's not because of my family. God comes first in my life. God knows. I'm there for each other, and I'm here for my friends. I'm here for my family. God goes first, and then family, and then friends, then comes my peers, then goes my coworkers.*

*I'm so wonderful, having a great time by myself without my HTS. I love those moments. I don't want some HTS up here all the time because I can do things on my own without a HTS here. I can relax more. I can play more. I can clean more. I can do whatever I want to do in my life.*

While Fabulous described having Down Syndrome and Alopecia, she also highlighted that those diagnoses did not define her. Fabulous also emphasized the importance of others getting to know her on a personal level without passing judgement.

*If someone doesn't know me, they have to get a chance to get to know me. They need a chance to love me for who I am.*

Isaac described that his favorite thing to do was “enjoy life with friends,” highlighting the ordinariness of his identity by placing importance of relationships in his life alongside belonging with his church family.

*Like, when I feel great, I feel like I can take on the world, I guess you can say that. I think it's having really good friends; really good relationships with friends. I can say with friends I hang out with, to have the intentionality of,*

*like hanging out and wanting to get to know me and wanting to go to the movies, and doing things, to being a part. That's when I'm feeling my best. When friends wanna hang out with me and it's just feeling like a whole reunion and that I know that I'm not alone. I could call that friend when I'm feeling the worst, and they can make it 10x better.*

Isaac shared that he had been diagnosed with cerebral palsy (CP) during our first intimate inquiry. He also shared that having CP was also accompanied with many challenges with activities of daily living (e.g., daily hygiene), but emphasized the value he places on independence as demonstrated by his excitement to earn a higher paying job so that he,

*Can pay more things faster and doing that kind of stuff to be more independent.*

### **Identity Formation and Meaning Making Processes**

Similar to the study conducted by Groves and colleagues (2018), the current study identified different meaning making processes among all of the adults in the study. However, for all adults in the study, relationships and spirituality played key roles in the identity formation and meaning making processes. Furthermore, relationships and spirituality were heavily entangled as many relationships described by the adults in the study were connected through faith and/or faith-based organizations or structures. Ella described learning about God through her counselor with whom she has seen since she was 16 and has a strong relationship. Fabulous and Isaac described having been a part of a church since childhood and continuing to be members of church congregations at the time of the inquiries, describing many of their friends' involvement in church and faith-based organizations. Notably, both Fabulous and Isaac attend church congregations other than those attended by their immediate family members, but are attended by their friends.

What is unknown is the role that cultural and community contexts play in this entanglement as the adults in this study reside in communities that are heavily populated with religious or spiritual community members and families.

Pathways to independence were also critical to the identity formation and meaning making processes among the adults in the study, which is congruent with the work of Midjo and Aune (2018) finding adults with intellectual disability to highlight their active agency . Specifically, each adult described their childhood, transition to adulthood, and future aspirations. Ella described what I initially perceived as a traumatic childhood by the age of 4 years before saying,

*I had a great life until I hit 7 years old. Then that's when the bad stuff started happening.*

Remaining committed to my promise of challenging my biases throughout this study's processes, I had to reframe my mental models to match the experiences Ella was describing in her own perspective. My personal biases viewed Ella's entire childhood as traumatic; however, Ella did not perceive her life as traumatic or "bad" until she described being "prostituted out" from the age of 7 to 14 before finding herself in a pediatric psychiatric hospital and aging out of the foster care system. Her siblings were very important to her when she was young and still carry great value to her to this day.

In her transition to independent living, Ella described her experiences with group homes prior to the home she resided in at the time of the study. Ella credited her childhood and experiences in this transition to shape who she is today. In describing her future aspirations, Ella said,

*[My husband is] not his own guardian, so he has to talk to his team about that. So, as soon as [my husband talks with his team] and he [moves in] with his mom, I'm signing myself out, and I'm going to go with him.*

Fabulous described a few events in her childhood but focused mostly on her transition to independent living, recounting how important independence was to her in every inquiry, highlighted her newfound freedom.

*It was a good idea for me in a group home, but I like to have my independence and be in my own apartment to myself. I was young back then when I moved in. I was 18 at the time. Let's just say it was fun at first to live on my own and do things differently. Then I always had problems a lot back then. I'm the most independent of any girls in that group home. And in 2020, my mom finally decided to let me live on my own. I finally got my wish.*

*I have to say this is very great for me to live on my own and do things that I really care about doing that I've never done before when I used to be in the group home.*

After describing her plan to retire in the Bahamas, Fabulous expressed her desire to get married and start a family in the (near) future without her family worrying about her.

*My whole world, and our world, is just something I can really, really trust myself in faith to get married someday. If I get married, I would do a cut-out person between each of my family, if they are dead by that time. It just doesn't matter who I want to be with the rest of my life. I'm ready for that step to get married one day, and I can't wait that long because I'm almost in my 40s. I don't know if I'll have [a baby] or not. If I decide to adopt a baby, I have to take care of them and love them, feed them. And I know it costs a lot of money though, but I know I can do it with family and friends around me. I love my family. I know I want to cherish myself and I want my family to know, I want to take care of myself and I want to do this all by my own. I love my family dearly. It's just, it's my turn to take care of myself. And it's my turn to experience this opportunity to have a wonderful family.*

Isaac described his biological aunt adopting him from his biological mother when he was young. Isaac also described the 13 surgeries he underwent as a child. Much of his



childhood was spent in the hospital and rehabbing from surgeries in-between trying to stay caught up in school. Alongside these experiences in childhood, Isaac explained lessons he learned in his transition to independent living and having his legal rights placed in the hands of his mother, who is his guardian.

*I was my own guardian back when I moved out of my mom's house when I was 17, and I had that for a few years. Lost it because of how people have treated me and, I guess, because of the decisions I made that was not very smart. I will honestly say, I don't want anybody to go through what I was going through. I think it's rather hard on me, and I'm still paying for it to this very day.*

*I've been very independent. I had made a mistake recently where I had to, to pay some credit card bills and I got kind of in a scam. It's just different things, then I have to just face them and keep going. One of the things that I'm learning is that you have to pay the bills first before you can help other people. I'm very kindhearted, and I think sometimes it's really hard for me to say no. It's hard because you see somebody that's struggling, and this is why I don't have the rent. I'm one of those people-- I'm willing to give you everything on my back. I'm giving everything I have as long as I'm helping people. I'm learning that sometimes I have to tell people "No" because people will take advantage of that.*

Isaac explained his desire to start a family one day in the future.

*I just pray that eventually I will get the wife of my dreams. But it doesn't have to be perfect. I think kind of like going through life together and experiencing the fruitfulness of that and then also having kids.*

Notably, alongside childhood and transition to adulthood experiences, the adults in the study described their future aspirations, all of which included their desire to start their own family. Belonging contributed greatly to the identities of the adults in the current study, which is consistent with Shakespeare (1996). As noted in their descriptions of current identity above, belonging was grounded in relationship with others (Carter, 2021), and the adults in the study described the importance of valuing one another (Robinson, et

al., 2020). As Warr (2015) described in their study, belonging occurs when one is surrounded by and connected to familiar faces which was also evident in the current study as the adults each described belonging to others, specifically those with an existing or developed relationship.

Each of the adults in the current study described being supported by paid professionals in their daily lives (e.g., HTS, staff) and two of the adults described instances when these paid professionals took advantage of or overstepped their boundaries with the adults themselves. For example, Ella described being abused in her group home by the house manager. Isaac described having to “cover” for his HTS on several occasions which led to his HTS ultimately being fired. Isaac also described state agencies not supporting him in getting a higher paying job despite the agency’s claim that they support independence and job success.

The adults in the study also described events related to their self-advocacy. Ella described running away from her group home because,

*If no one was gonna do something, I had to do something myself.*

Fabulous demonstrated self-advocacy as she convinced her mother to support her in moving into her own home. Isaac described several instances of self-advocacy related to getting a higher paying job despite his state support agency at the time refusing to assist and seeking out those he trusted to be his HTS.

Identity formation and meaning making processes were evident throughout each intimate inquiry as the adults in the study described who they are and what had shaped their current identity. Generally, the adults in the study maintained a positive sense of

their identity. However, the pathways that led to their current identities were shaped by the meanings they applied to their lived experiences. Ella described being a survivor and having a story that can positively impact other young girls. Ella also described the support she received in a pediatric psychiatric hospital and her counselor as critical to getting sober from drugs and alcohol. Ella also credits one trusted staff member for being there for her like family, which she described as not being defined by blood. Fabulous heavily attributed God and spirituality to meaning making processes in her life, describing that “God gave me this way,” referring to her life of independence. Family was viewed as both a source of joy and a source of limitation in Fabulous ’s life as she described how important her family is to her alongside their tendencies to limit her independence and autonomy as she expressed that it was her turn to take care of herself. Isaac emphasized the struggles he experienced in childhood related to inaccessible homes and spending much of his childhood in the hospital recovering from surgery; however, he described these struggles as major contributors to his current identity in a way that led him to be more independent at the time of the study. Each of the participants gained additional insights as a result of their lived experiences, often times as lessons learned from past experiences. This was demonstrated by the adults in the study spending time teaching me about the lessons they uniquely learned in many of the stories they told.

### **Unexpected Findings and Lessons Learned**

In my time with each of the adults in this study, I observed what I believe to be their love languages despite not actively seeking this data. Love languages are the ways in which people receive and give love. There are five love languages: quality time, words of affirmation, physical touch, acts of service, and gift giving (Chapman, 2010). Through

my intimate inquiries, I noticed that Ella's love language is gift giving as noted by her using the monies she received from the study to purchase gifts for her staff. Fabulous 's love languages are physical touch and quality time as noted by her hugging and close nature when we would meet in person. Fabulous also expressed the importance of quality time throughout her stories. Isaac's love languages are quality time and words of affirmation. This is noted by Isaac describing the importance of spending time with others and seeking feedback on his stories and others' experiences of their relationship with Isaac. Isaac also provided many words of affirmation throughout our inquires.

I experienced some difficulty, initially, when framing the stories from the perspective of the storyteller. By this I mean that I took the coding and thematic analysis piece very seriously and by the time I had picked each adult's stories apart throughout this process and wrote their stories to fit my findings, I had lost their voice. As I am committed to amplifying the voices of adults with intellectual disability, presenting my version of their story was out of the question. If I had left their voices in the presentation as they were originally delivered, I would have saved myself the time of writing and rewriting the stories. Moving forward, I will keep the stories as they are, in their raw and beautiful form.

The adults in this study shared numerous stories in our time together. While I expected to learn more about them, I did not fully expect the amount and depth of the stories they shared. It was an honor to listen to and hear their experiences that they shared while demonstrating "mental endurance" as Ella so eloquently put it. As it relates to the importance of storying, one of my favorite exchanges came between Isaac and his friend, B.

B commented,

*There's a million stories for sure. [laughter]*

Isaac responds,

*And there's a million more coming. I'm pretty sure.*

### **Implications**

This study clearly demonstrates the abilities of adults with intellectual disability to be self-reporters, to share their experiences, and to use their own voices. This study extends the works of Kittelsaa (2014) and Robinson et al. (2020) by emphasizing the ordinariness of identities, as described above. For the adults in the current study, the importance of relationships was evident in this research, not only through the stories that participants told about their lived experiences, but also as participants shared more freely as our relationship continued to bloom. Closeness to the quandary is critical for understanding individuals (Laura, 2013) and this was particularly evident in the current study. Storying demonstrates meaning making processes that may not be otherwise evident, specifically when accessible (Phillips & Bunda, 2018). Building relationships and getting to know one another allowed the participants and myself to derive deeper understandings of one another.

Storying was shown to be a source of empowerment for the adults in the current study, and for myself. For the adults in the study, feeling heard and knowing that their stories and lived experiences would be shared with others empowered their feelings of making a difference. Each of the adults described implications of their stories for others

and highlighted feeling pride in being able to help others. The adults in the study also described feeling heard as a source of empowerment, knowing that others care. For me personally, I felt more empowered as a researcher and a human being, both for the same reason. In research and in the “real world,” often exists this notion of “staying between the lines” and following the structures that have been in existence for longer than I have been alive. This work alongside the adults in the current study empowered me to break the molds that I have been groomed to fit inside by being in relationship with “research participants” and others. I have been taught to hide vulnerability, professionally and personally. The adults in the study demonstrated the need for reciprocal vulnerability – in my work and my life outside of work.

Scholars have emphasized the importance of support in examining and understanding identity among adults with intellectual disability (Gallus & Jones, 2017), which is the basis from which I informed the adults that they could invite any important persons to inquiries. Of the three adults in the study, only one invited others to join inquiries. None of the important persons invited to inquiries were family members. One inquiry did include a Physical Therapist to describe, from his perspective, the impact of Isaac reaching his goal of walking across the graduation stage after high school. Inviting important persons seemed to be more of a source of empowerment and connection for Isaac than an examination of his chosen identity as some important persons expressed views of Isaac’s identity that Isaac expressed not holding true himself (e.g., sexual orientation). The current study’s results demonstrated that supporters’ voices may have misrepresented the adults’ true and chosen identities. This is noted by Fabulous’s desire for more independence and to start dating towards marriage, but feeling held back due to

her mother's desire for Fabulous to live alone for a while before dating. This is also evident in Isaac's stories of conflict among family members and challenges with guardianship by his mother.

The current study presents a relevant avenue for examining identity formation and meaning making processes among adults with intellectual disability. The current study builds upon existing research in the fields of intimate inquiry and storying by using the combined methodologies among an understudied population. Furthermore, the current study fills a large gap in the field of intellectual disability as much of the research is informed by caregivers and support professionals of adults with intellectual disability. The current study demonstrates the importance of understanding adults with intellectual disability at the personal level and accessibility in research.

### **Limitations**

While the current study adds great knowledge to the field, some limitations are noted. First, the current study has a small sample size. However, my intention was not to gain a representative sample as every individual has a unique and deeply personal story. Engaging more adults with intellectual disability in storying research provides more opportunities for them to share their stories and derive empowerment. Another limitation in the current study is that the results are inherently subjective, which is assumed in storying research. To the best of my ability, the stories are presented in the voices of the participants and were checked through member checking. Future research among adults with intellectual disability employing intimate inquiry through a storying lens may provide deeper understanding within the field. Notably, the adults in this study had

minimal support needs; thus support needs of the adults in this study are not reflective of the support needs of all adults with intellectual disability. Additional supports may be necessary in future research among adults with intellectual disability to include communication supports.

### **Future Directions**

In addition to developing trusting relationships with the adults they work alongside, practitioners may benefit from employing strengths-based approaches such as the socio-ecological model of disability and allowing space for fluidity of identity and meaning making processes. Participants of the current study shared experiences of discrimination among practitioners and feelings of not being heard. Employment of best practice communication skills such as active listening, attentiveness, and reverence for others is recommended.

For future work in disability studies, replication of the methodology used in the current study may expand on present work employing intimate inquiry through a storying lens as a relevant methodology for examining identity and other constructs within the theoretical framework of the socio-ecological model of disability. Methodologists may derive benefit by using the current study's methodology alongside use of ethnopoetic scores to determine whether the ethnopoetic scores provide additional context and insight not otherwise presented without the scores. Furthermore, researchers as a whole may benefit professional and personally by spending time with those they study, just as I described I benefitted from the work myself.



For all persons, professionals or otherwise, entering community and/or work alongside adults or other individuals with intellectual disability without assuming disability as central to disability can serve as a two-fold benefit. First, those entering community and/or working alongside adults or other individuals with intellectual disability may see the adults or other individuals as people first, with lives that may or may not be centralized on disability. Second, adults and other individuals with intellectual disability are seen as people first and have the opportunity to demonstrate their chosen, not ascribed, identities.

### **Closing Thoughts**

As I wrap up the writing of this study, I cannot help but reflect on the process and how much I have grown personally and professionally. Entering the study with a trained background in quantitative research, I had little experience with qualitative research and no formal training on the processes. With the help of my advisor, I developed the present study hoping to amplify the voices of adults with intellectual disability and I wanted to do so in a way that truly shared their voices. My advisor, who's work happened to inspire the methodology employed in the present study, was there to guide me every step of the way. Initially, I was surprised in how seamless the study development process came together as I intended to enter the field with great flexibility to allow participants to drive the data collection process. I was prepared to enhance the presentation of the storytelling processes by using ethnopoetic scores and a thorough inquiry protocol complete with what I believed would contribute to the identities and meaning making processes of these adults. Upon entering the field, I immediately realized I may have been overprepared and

utilizing the tools I entered the field with may have limited the ability of participants to share as freely as they did.

These adults and this work challenged me and taught me more than I ever imagined. These adults were so passionate about telling their stories and had clear intentions for storytelling. As each of the adults told their stories, there were times that I found myself drawing my own interpretations of their meanings to be immediately corrected by the adults themselves as they shared the meanings their lived experiences that they personally held. I found myself struggling to present the stories told by these adults in the manner of which they were intended to be told. I tried to reconstruct their stories to make it flow, in the Westernized way that I have been taught to tell stories. In this process, I removed their voices that I entered the field intending to amplify. I spent time trying to dissect their stories and pull out themes to be presented in the results as themes are often expected to be presented in the Westernized field of academia. It wasn't until I went back to the original stories that I had not dissected that I realized how important it was to tell their stories as they were told. I cannot advocate for amplification of voices while I am marginalizing them through personally held and socially taught biases.

The art of storying and my employment in this research opened my eyes to a new world of research, one that brings back those butterflies I once had when I entered graduate school. The beauty of relationships in research is in the freedom to share openly and with great vulnerability in safe spaces with safe and trusted people. Storying and intimate inquiry are founded in love and, throughout this study, great love is what I found.

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## APPENDICIES

### IRB Approval Letter



#### Oklahoma State University Institutional Review Board

Application Number: IRB-21-493  
Proposal Title: Identity and Meaning Making Among Adults with Developmental Disabilities: A Relationship-Based Approach

Principal Investigator: Tia Waldrop  
Co-Investigator(s): Larisa Callaway-Cole  
Faculty Adviser: Jennifer Jones  
Project Coordinator:  
Research Assistant(s):

**Status Recommended by Reviewer(s): Approved**

Study Review Level: Exempt  
Modification Approval Date: 03/04/2022

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The modification of the IRB application referenced above has been approved. It is the judgment of the reviewers that the rights and welfare of individuals who may be asked to participate in this study will be respected, and that the research will be conducted in a manner consistent with the IRB requirements as outlined in section 45 CFR 46. The original expiration date of the protocol has not changed.

Modifications Approved:

Modifications Approved: Title change. Add unnamed personnel (URA and expand participant population up to include adults up the age of 40 instead of 35.

The final versions of any recruitment, consent and assent documents bearing the IRB approval stamp are available for download from IRBManager. These are the versions that must be used during the study.

As Principal Investigator, it is your responsibility to do the following:

1. Conduct this study exactly as it has been approved.
2. Submit a status report to the IRB when requested
3. Promptly report to the IRB any harm experienced by a participant that is both unanticipated and related per IRB policy.
4. Maintain accurate and complete study records for evaluation by the OSU IRB and, if applicable, inspection by regulatory agencies and/or the study sponsor.
5. Notify the IRB office when your research project is complete or when you are no longer affiliated with Oklahoma State University.

Sincerely,

Oklahoma State University IRB  
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## VITA

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