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Narrative Inquiry into Postsecondary Transition Outcomes for Young Adults with Intellectual & Developmental Disabilities

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Walden University
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Abstract

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MPHIL, Walden University, 2020

MSOT, Virginia Commonwealth University, 2001,

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Dissertation Submitted in Partial Fulfillment

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Abstract

Young adults with intellectual and developmental disabilities (IDD) continue to struggle with community engagement despite decades of research and policy initiatives addressing postsecondary transition. Evidence shows that persons with IDD are engaging in employment, postsecondary education, independent living, socialization, and other roles at significantly diminished rates, yet little data exists describing this participation in the voices of those affected. The purpose of this narrative inquiry was to describe community integration of persons with IDD in the decade following postsecondary transition in their own words. Critical disability theory was used as a lens to explore the successes and failures of public policy guiding this process. Research questions focused on types and frequency of community participation, personal perceptions of the transition journey, and how public policy supported or inhibited successful transition. Seven collaborators shared their transition narratives by creating comic books which revealed that: (a) transition began much earlier than addressed by policy, (b) bullying and paternalism were major obstacles that were insufficiently addressed, (c) sexuality was often ignored as an adult role, and (d) continued siloed service delivery led to fractured visions of adult roles and goals. Future research should explore benefits of updating public policy to address the transition beginning in early adolescence, prevalence of bullying for students with IDD, impact of siblings on social skills development, and if role participation should be emphasized over community integration to respect self-determination. Findings attest to the complexity and abilities of collaborators to enable positive social change by empowering overlooked voices to participate in the conversations guiding their futures.

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Dedication

First and foremost, this dissertation is dedicated to Amy for supporting me throughout this journey including the long nights and grumpy days. It wasn't easy and it wasn't always easy on you. To Autumn who, unlike your mother, didn't choose this path. I hope I have provided a secure, happy home and a positive example. And to Savannah. When we found out you were on your way in 2019 my first quip was, "Well, this should make getting a Ph.D. easier!" But you have renewed my purpose and your smiles and curiosity remind me every day why I am doing this and give me the strength to continue.

Also, although I am pursuing a degree in PPA, I am an OT by trade and identity and wouldn't be here without the guidance of the VCU MSOT faculty that set me on this career path 20 years ago (that can't be right?!?), and so I would like to thank you all. Particularly, Dianne Simons for your humor and giving me a glimpse of the coming rigor as my thesis chair. Jayne Shepherd for inspiring me. I don't know if you remember that original recommendation you wrote me, but I do and have spent my career trying to live up to it. And Al Copolillo—in a career with so few male role models I would have been lucky to have any, but instead I got the best. I've spent my career trying to live up to your gentle wisdom and calm reason. You were a man of few words but every single one counted. You are sorely missed.

Finally, I want to use this space to offer long overdue gratitude to three teachers from Woodrow Wilson High School in Beckley, WV. The narrative that had been imposed on my life was that I was lazy, bad tempered, and a poor student, yet the three of you were instrumental in shifting the plot. I thought I hated school until Mr. Lilly showed this would-be novelist that math was just as interesting as imagination and that Trigonometry was a puzzle, not problem. You too are missed, and I hope your family knows how many young minds you set afire. And although I entered college an art (soon-to-be-English) major, Mr. Doman’s Physics class also challenged my mind and taught me that learning how the universe functions wasn’t a chore but a gift and a pleasure. I still remember your quotes of the day on the chalk board, my two favorites being (if you’ll pardon the paraphrase): “The lottery is a tax on those bad at math,” and “The only time you’re not stepping on someone’s toes is when you’re standing still.” While the former still makes me chuckle, I continue to remind myself of the latter when resisting pressure to go with the flow or against my conscience. And finally, Mrs. Doman—or Miss Collier as I knew you. (Oh, how happy I was when I learned my two favorite teachers had become one another’s favorite persons!) Despite learning that I really did love to learn, I entered my senior year an insecure wallflower unsure if I had much to offer. But you called me out and said: “I see leadership potential in you.” I was floored. Me?! I was supposed to be lazy and temperamental, not a future leader. Never underestimate the power of a single sentence to rock the very foundation of someone’s life. Despite having little true aptitude for visual art, I accepted your invitation to lead the art club and set about organizing, delegating, and planning meetings, homecoming floats, and set designs for the school play with purpose and gusto. It may seem a small and silly thing—leading an afterschool club—but without that first step and those few words I don’t know that I would have set off on the path I did. Teachers aren’t thanked (or compensated) enough, but please know that I am forever grateful.

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However, none of this would have been possible without the seven collaborators who shared their stories with me and allowed our narratives to intersect for a while. I hope that I afforded you the respect and consideration you deserve. Also, thank you to D__ and M___ from The Arc for helping coordinate and enable this research. I won't mention names due to confidentiality, but you know who you are and what you did.

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Chapter 1: Introduction to the Study

Due to advances in healthcare, children born with physical and intellectual disabilities today are overwhelmingly surviving into adulthood. As a result, tens of thousands of adolescents with special conditions exit American public schools every year only to discover that in adulthood they lose the extensive support and inclusivity provided by the Individuals with Disabilities Education Act (IDEA; Acharya et al., 2017; Ladores, 2015). With no comprehensive public policy existing to bridge this gap into adulthood, young adults with special needs and their families consistently report feeling anxious and abandoned (Asp et al., 2015; Franklin et al., 2019; Joly, 2015), an experience that Joly (2015) summarized in the theme *It's like falling off a cliff!* As a result, such research shows that the majority of young adults with conditions such as intellectual and development disabilities (IDD) are failing to integrate into their communities at the same rate as peers with less severe or no disability labels (Acharya et al., 2017; Benson et al., 2021; Eismann et al., 2017; Flippo & Butterworth, 2018; Honeycutt et al., 2017; Huang & Porterfield, 2019; Kruszka et al., 2012; Ladores, 2015; Oertle & O'Leary, 2017; Qian et al., 2018; Sansosti et al., 2017; Sawicki et al., 2017; Smith et al., 2021). Yet the voices of such young adults with IDD are often left out of this research about them (Bjornsdottir et al., 2014; Clandinin & Raymond, 2006; Flynn, 2019; McDonald et al., 2016; Nind, 2008; Sigstad & Garrels, 2017; Smith-Chandler & Swart, 2014; Sunderland et al., 2015; Woodfield et al., 2020).

This qualitative study employed a narrative inquiry approach to address this gap in the literature and provide rich descriptive data exploring the community integration and postsecondary transition outcomes of persons with IDD in their own words. Such data is vital to inform future research and policy initiatives because we cannot serve the needs of an entire segment of the population without first understanding their perspectives. Although persons with IDD are a protected population, the harm of exclusion far outweighs the risks of inclusion. Therefore, in addressing this research problem, Chapter 1 begins with a brief overview of research on postsecondary transition before presenting the problem statement, purpose of the study, and research questions. Next, I describe the theoretical framework and nature of the study and define key terminology before considering the scope, assumptions, and limitations of this qualitative inquiry. The chapter concludes with a discussion of the study's significance and its potential to promote positive social change.

Background

The 1975 Education for All Handicapped Children Act was a landmark civil rights victory guaranteeing access to free and appropriate public education (FAPE) for all children regardless of ability status (U.S. Department of Education, n.d.). Because merely opening school access to children with disabilities was not enough, Congress reauthorized this law in 1990 as IDEA to mandate that children with disabilities be educated in the *least restrictive environment* to promote greater inclusion with nondisabled peers (U.S. Department of Education, n.d.). Next, a 1997 reauthorization added a requirement for postsecondary transition planning in light of mounting evidence that students with disabilities were struggling in adulthood upon losing IDEA support (United States Office of Special Education Programs, n.d.).

In 2000 the Department of Education's Institute of Education Sciences (IES) launched the National Longitudinal Study-2 (NLTS2) to track postsecondary transition outcomes comprehensively. This decade-long longitudinal study collected data in five waves across all 12 disability categories identified under IDEA (National Center for Special Education Research, n.d.; Newman et al., 2011). Initial analysis revealed that persons across all disability categories were integrating into the community at lower rates than nondisabled peers, while those in categories that would fall under the IDD umbrella such as autism, mental retardation (MR), and some forms of orthopedic impairment (OI)—particularly more severe cases and diagnoses—demonstrated the largest gap compared to nondisabled peers. For example, Newman et al. (2011) found that:

- Postsecondary education rates were 62% for those with OI, 44% with autism, and 29% for MR
- Current employment rates were 35% for OI, 37% for autism, and 39% for MR
- Only 31% with OI, 17% with autism, and 36% with MR were living outside the family home
- Only 66% with OI, 48% with autism, and 58% with MR responded affirmatively to seeing a friend weekly outside the home (Newman et al., 2011).

Building on these findings, follow-up studies using more contemporary disability categories such as autism spectrum disorder (ASD) and intellectual disabilities (ID) further demonstrated the alarming rates at which these young adults are failing to integrate into their communities (Chiang et al., 2017; H. Lee & Morningstar, 2019; Nasamran et al., 2017; Smith et al., 2021; Tint et al., 2017; Wehman et al., 2014).

While the NLTS2 included broader measures of community integration, postsecondary transition studies have traditionally focused on three topics: employment, postsecondary education, and healthcare independence, for although healthcare is not covered under IDEA, persons with disabilities and their families experience this simultaneous loss of educational and pediatric services as a unified phenomenon (Acharya et al., 2017; Franklin et al., 2019; Joly, 2015). However, multiple authors have argued that we must expand our conceptualization of postsecondary outcomes beyond such utilitarian neoliberal definitions towards more broad inclusive notions of community integration that consider holistic life roles and responsibilities (Black & Lawson, 2017; Charlton, 2000; Lee & Morningstar, 2019; Liasidou & Symeou, 2018). Thus, in the wake of the NLTS2, multiple other quantitative studies have gathered data illustrating how persons with IDD are significantly struggling with all forms of community integration (Benson et al., 2021; Chiang et al., 2017; Honeycutt et al., 2017; Kester et al., 2019; Lee & Morningstar, 2019; Miller-Warren, 2016; Nasamran et al., 2017; Newman et al., 2011; Tint et al., 2017). A growing body of qualitative studies focus on both the transition process and its outcomes from the perspectives of parents, educators, employers, administrators, and healthcare professionals (Acharya et al., 2017; Benson et al., 2021; Franklin et al., 2019; Gabriel et al., 2017; Hirano et al., 2018; Joly, 2015; Poppen et al., 2016; Riesen & Oertle, 2019; Ruble et al., 2019; Stein et al., 2016). However, very few studies look beyond the immediate aftermath of postsecondary transition or include the perspectives of persons with IDD in exploring outcomes. Worse, Jacobs et al. (2018) found in an extensive literature review that most studies did not even justify excluding the voices of those they studied, as though their lack of valuable perspective were a given. The information gained from interviewing caregivers, professionals, and other support personnel is vital to such discussions; however, a critical piece remains missing. To remedy this problem, advocates are increasingly calling for empowering persons with IDD through greater research inclusion (Bjornsdottir et al., 2014; Clandinin & Raymond, 2006; Flynn, 2019; McDonald et al., 2016; Nind, 2008; Sigstad & Garrels, 2017; Smith-Chandler & Swart, 2014; Sunderland et al., 2015; Woodfield et al., 2020). In their quantitative analysis of community integration by persons with severe disabilities, Lee and Morningstar (2019) specifically noted the need for including the voices of those with significant functional impairments in conceptualizing community integration experiences upon postsecondary transition, revealing the research problem addressed by this study.

Problem Statement

Most qualitative studies on postsecondary transition focus on the process and immediate aftermath, ignoring long-term outcomes (Asp et al., 2015; Franklin et al., 2019; Huang & Porterfield, 2019; Joly, 2015; Kruszka et al., 2012). Those few studies that explore outcomes often fail to include the voices of the persons they study (Jacobs, 2018; Lee & Morningstar, 2019). Thus, a problem exists in that little descriptive qualitative data has been collected to empower persons with IDD to conceptualize their community integration experiences following postsecondary transition in their own words (Lee & Morningstar, 2019). This gap in the literature hampers both research and policy initiatives that seek to create more effective transition outcomes. Failing to include the perspectives of those who actually navigate the postsecondary transition process in research and policy initiatives hinders decision makers' ability to enable improved transition outcomes. Thus, this narrative inquiry study of postsecondary outcomes of persons with IDD can empower effective change by adding to a nuanced understanding of current community integration outcomes for young adults who have completed this postsecondary transition process.

Purpose

The purpose of this qualitative study was to describe the community integration experiences of persons with IDD in the decade following postsecondary transition in their own words. The central phenomenon explored was how their journey to adulthood led to both successes and failures in community integration. Although quantitative data indicates that participants likely will report integrating into their community significantly less than nondisabled peers, empowering participants to share their successes to provide a holistic picture and avoid hegemonic stereotypes of helplessness is essential. To collect such emic perspectives on community integration, this study utilized narrative inquiry to collaborate with subjects who (a) have a diagnosis that falls within the IDD category, (b) received transition services on their individualized education plan (IEP), (c) transitioned from secondary education within the past 10 years, (d) possessed basic speech or augmented communication abilities, (e) collaborated on postsecondary transition with a local vocational rehabilitation (VR) agency, and (f) resided in the North Florida region.

Research Questions

RQ1: How do persons with IDD conceptualize their postsecondary transition journey and its impact on community integration through narratives?

RQ2: What do these narratives of the postsecondary transition journey reveal about the current quality of life and sense of well-being of persons with IDD in relation to community integration?

RQ3: What do these stories reveal about policies currently guiding postsecondary transition and potential policy changes?

Theoretical Framework

This study was built upon critical disability theory (CDT), which is an emancipatory theory and methodology that seeks to reconceptualize disability as a social rather than personal failing (Hall, 2019; Linton, 1998; Mollow, 2004). Disability studies as a distinct discipline emerged in the 1970s and 80s along with the rise of the disability culture model which sought to redefine disability as the intersection of social, medical, and personal/contextual factors (Brown, 2002; Owens, 2015; Reid-Cunningham, 2009; Retief & Letšosa, 2018). This model set the stage for the emergence of CDT which *The Stanford Encyclopedia of Philosophy* defined as an approach to understanding the oppression experienced by persons with disabilities "through a critical, intersectional analysis" (Hall, 2019, para. 4). Thus, CDT theorizes that disability is a social, political, and cultural phenomenon influenced by personal characteristics but not solely defined by them (Linton, 1998). Prominent 20th Century theoretical approaches such as critical theory and feminism paved the way for CDT, which also borrowed heavily from Foucault's critiques of language in establishing social power dynamics (Ferguson & Nusbaum, 2012; Goodley, 2013; Hall, 2019; Linton, 1998; Mollow, 2004; Meekosha & Shuttleworth, 2009). In viewing disability as both an identity that empowers and a social construct that oppresses, CDT embraces the paradox at its core and seeks meaning from this tension (Hosking, 2008; Hughes, 2007; Mollow, 2004). Thus, CDT embraces how the individual disability experience has resulted in a distinct support and advocacy community while simultaneously challenging the limitations and restrictions created by such labeling.

The nuances of CDT are explored with greater depth in Chapter 3, but Hosking (2008) identified its six basic objectives as to (a) illuminate the multidimensionality of roles and identities (often referred to as intersectionality), (b) embrace diversity while affirming the disability experience; (c) openly advocate for disability rights; (d) empower marginalized disabled voices in research and policy; (e) illuminate the ways that language and labeling influence perceptions of disability, and (f) embrace the fundamental goal of critical theory to emancipate humanity. Ferguson and Nusbaum (2012) expanded upon this to argue that CDT and critical disability studies (CDS) must adopt an interdisciplinary, participatory, and value-based epistemology while Fox (2017) emphasized the importance to CDT of broad inclusivity, increased visibility of disabled perspectives, and promoting both empathy and creativity. Goodley (2013), in turn, suggested the need for CDT and CDS to adopt a global perspective while positioning CDT as a direct rejection of neoliberalism, which prioritizes free economic markets and personal responsibility over government regulation and social safety nets, thereby sparking a critical backlash accusing it of treating citizens as economic drivers over sovereign individuals with inherent human rights (Vallier, 2021).

Such conceptualizations of CDT as an emancipatory, inclusive, and value-based theory were purposeful in shaping it as an actionable tool for social change rather than an esoteric intellectual exercise for classroom debates that are ultimately extensions of privilege (Erevelles, 2014; Minich, 2016; Schalk, 2017). CDT also explicitly challenges hegemony in data collection and reporting through rejecting the ableist supremacy of fluent communication and fluid narratives in favor of working collaboratively to find meaning in preferred forms of self-expression (St. Pierre, 2015). Therefore, while one does not have to identify as disabled to engage with CDT, an able-bodied researcher accepts a mantle of responsibility in employing it (Erevelles, 2014; Minich, 2016; Schalk, 2017). In this spirit, this study explored and advanced principles of CDT in seeking how policy and social norms influence the lived experiences of young adults with IDD while acknowledging the intersectionality of their identities and respecting the authority of their perspectives. Applying this multidisciplinary theory to public policy and administration research can empower silenced voices to participate in larger social narratives and celebrate collaborators as heroes of their own lives while simultaneously illuminating societal and policy impediments to community integration of persons with IDD.

Nature of Study

Due to a need for rich, descriptive data exploring the lived experiences of subjects with IDD upon postsecondary transition alongside considerable quantitative data indicating lagging community integration, qualitative methodology was chosen for this study. While other qualitative methods such as case study and phenomenology were considered, the research questions—which sought a better understanding how persons with IDD experienced and conceptualized postsecondary transition experiences—required a methodology that empowered and respected collaborator voices; thus, this study engaged in narrative inquiry to explore emic perspectives of community integration of persons with IDD in the decade following postsecondary transition. Narrative inquiry is a relational research method that asserts humans make meaning from their lives by imposing story structure upon random events to create a distinct beginning, middle, and end; therefore, narrative researchers live alongside and collaborate with subjects while acknowledging that this intersection of their narratives affects both researcher and subject (Bell, 2002; Clandinin, 2016; Patton, 2015). However, the stock story structures that we draw upon are not explicitly taught or acknowledged, but rather are subconsciously passed down by cultures throughout history as a natural part of human experience starting with early mythology (Clandin & Connelly, 200; Kim, 2016; Lai, 2010; MacIntyre, 2007). It wasn't until the advent of narrative inquiry in the last decades of the 20th century, however, that researchers began taking stories seriously, collecting structured narratives to examine the ways themes, commonalities, and paradoxes reveal subjective human experience in relation to the time, place, and society that shaped the stories, for no narrative is born in a vacuum (Bell, 2002; Clandinin, 2016; Clandinin & Connelly, 2000; Clandinin & Huber, 2010; Kim, 2016). Such rich and prolonged data collection allows "participants to emerge as people not cases" (Nind, 2008, p. 14). Thus, narrative inquiry is particularly suited for capturing the complex experiences of persons with IDD, as explored further in Chapters 2 and 3.

To conduct this inquiry, seven participants were recruited who met the criteria described above. During and after two semi-structured interview sessions, collaborators in this relational interaction were asked to contribute photographs, drawings, and magazine clippings to enhance their story and embrace divergent communication styles per recommendations for empowering persons with disabilities during narrative research (see Nind, 2008; Sigstad & Garrels, 2017; St. Pierre, 2015). Over three to four additional sessions (with one outlier where narrative construction and final member check were performed in one lengthy session), these various data sources compiled with the collaborators were then shaped into a comic book format which served as the completed narratives and were returned to collaborators once analysis was performed. Analysis employed successive rounds of coding with narratives treated as holistic data sources in order to uncover patterns and themes which improved understanding of postsecondary outcomes of persons following the loss of IDEA services as influenced by current public policy, focusing on both struggles and shortcomings in order to create a holistic narrative. Such balance in data collection was employed to guard against the trap of crafting exploitative victimization narratives which describe persons with disabilities as powerless, and thus undermine the self-efficacy of person with disabilities, and will also be explored further in subsequent chapters.

Definitions

Ableism: Discrimination originating from a system of oppression based on the belief that there is a *normal* able-bodied human state and that deviations from this norm are undesirable (The University of Arizona Disability Resource Center, 2021).

Archetype: The original patter or model of which all things of the same type are representations or copies (Merriam-Webster, n.d.a)

Autism Spectrum Disorder: A developmental disability encompassing a spectrum of behaviors and symptoms typically diagnosed around age 2 involving difficulty with socialization and interpersonal relations plus restricted interests and repetitive behaviors to a degree that significantly interfere with life roles (National Institute of Mental Health, 2018).

Developmental Disability: A broad disability category encompassing physical and/or intellectual challenges that emerge during early childhood and generally last throughout the lifespan (U.S. Department of Health and Human Services National Institutes of Health, 2021).

Individual Education Plan: A written plan addressing the individual needs of a student with a disability receiving services under the Individuals with Disabilities Education Act created and updated by a team including the student, teachers, parents/guardians, and other related personnel and including (a) present level of performance, (b) measurable annual goals, (c) a report on progress, (d) statement of required supplementary aids or services, (e) a rationale for any time spent away from typically developing peers, (f) a list of accommodations and alternate assessment needs, and (g) frequency, location, and duration of services including postsecondary transition services by age 16 (U.S. Department of Education, 2017).

Intellectual & Developmental Disabilities: A broad disability category encompassing conditions that both occur during childhood development and include cognitive impairment, and which generally fall within one of four categories: (a) those primarily related to the nervous system, (b) those primarily affecting the sensory system, (c) those impacting metabolism, and (d) those which are degenerative in nature (U.S. Department of Health and Human Services National Institutes of Health, 2021).

Intellectual Disability: A condition arising prior to age 18 that impacts the intellectual ability to learn, reason, and solve problem and impacts adaptive behaviors like social and life skills (U.S. Department of Health and Human Services National Institutes of Health, 2021).

Neoliberalism: A political theory with origins in the writings of economists F. A. Hayek, Milton Friedman, and James Buchanan that advocates for supporting and spreading democracy by prioritizing unrestricted economic markets and personal responsibility over government regulation and social safety nets (Vallier, 2021).

Occupational Therapy: Per the American Occupational Therapy Association (2017): "the therapeutic use of everyday life activities (occupations) with individuals or groups for the purpose of enhancing or enabling participation in roles, habits, and routines in home, school, workplace, community, and other settings" (p. 1).

Postsecondary Education: Education acquired after exiting high school including vocational and career schools, 2- and 4-year colleges, and universities with graduate programs (U.S. Department of Education, 2011).

Postsecondary Transition: "The passage from secondary education to participating in postsecondary education, training, or both, engaging in meaningful employment, living within one's community, exercising self-determination, and contributing to society as productive citizens" (Office of Special Education and Rehabilitative Services [OSERS], 2015, p. 1).

Secondary Education: Public schooling following primary school for the purpose of preparing students for adult roles—typically Grades 6-12 in the United States (U.S. Department of Education International Affairs Office, 2008).

Assumptions

Multiple assumptions were made in developing this study which should be acknowledged. By choosing a qualitative methodology, this work was grounded in an ontology stating that we each experience unique but overlapping realities and an epistemology that asserts we can derive knowledge from these unique and subjective experiences by studying the human perspective (see Denzin, 2013; Patton, 2015; Ravitch & Carl, 2016). In employing a narrative methodology, it was assumed that despite persistent prejudices, the persons with IDD who chose to participate possessed sufficient self-reflection and understanding to choose to participate out of a sense of altruism, as supported by contemporary research and reflected in the study's epistemology of subjective reported truth. I have worked with both people of high IQ who lacked significant self-awareness and persons with IDD who had deep and often painful understandings of their abilities and the exclusion they perceived as a result of those abilities so it was assumed collaborators would possess similar capacity and experiences. This was not to discount or de-value the perspectives of caregivers and educators, but rather that since their voices are quite prominent in the research literature, that this study will allow the voices of those with IDD be heard as well.

Such emphasis on the value and importance of highlighting dispossessed perspectives reveals my axiological assumption that inclusion and being heard are basic human rights and that persons affected by research and policy possess the intrinsic right to participate in the processes governing their experiences (see Cresswell & Poth, 2018). This builds upon the axiological assumptions of empowerment fundamental to the theoretical framework of CDT (Fox, 2017; Hall, 2019; Hosking, 2008). Further, this methodology assumed that useful insights were gained by engaging in both deductive reasoning comparing results to existing knowledge and inductive reasoning seeking truths that arise from the data free of prior assumptions (Cresswell & Poth, 2018; Patton, 2015).

It was further assumed that respondents answered honestly and to the best of their ability and that caregivers in both personal and institutional realms did not interfere or seek to influence responses for personal reasons. The fallibility of memory in all humans is well-documented, yet this study was based on narrative inquiry which draws upon a methodology and epistemology asserting that we understand our lives and experiences through the stories we create, recall, and share. In a more pragmatic concern, it was also assumed that since all participants had qualifying diagnoses made in childhood that would mandate they receive IEP services under IDEA, that they in fact received special education services even when collaborators struggled to articulate or remember IEP participation.

Scope and Delimitations

The focus of this study was on postsecondary outcomes of young adults with IDD. This scope emerged from a general literature review based on my interest in the topic of postsecondary transition. While there is evidence that those in all categories of disabilities struggle with community integration upon postsecondary transition when compared with nondisabled peers, the literature highlights persons with IDD as both significantly falling behind those in other disability categories and as being grossly underrepresented in research. To place the focus on postsecondary outcomes, the decision was made to seek participants within 10 years of leaving school so memories would still be fresh as well as to target immediate outcomes, for it is assumed that the farther into adulthood one proceeds, additional experiences and factors will increasingly influence community participation. And though this study utilized a multimedia approach to empower a range of communication styles and cognition levels, the decision was made to focus on clients with basic verbal abilities. For this reason, participation in VR was chosen as an inclusion criterion since such services require a formal screening process for basic community integration abilities by a government agency. These criteria support transferability across populations through identified common experience.

This study was initially influenced by McDermott and Varenne's (1995) theory of culture as disability from the field of anthropology, but although this theory explains how culture can create disability as a phenomenon, it fails to address the intersectionality of personal characteristics with social and culture factors and thus was limited in its application to interdisciplinary disability literature. Instead, CDT emerged as a more inclusive and comprehensive theoretical foundation for understanding how personal disability identity intersects with cultural and social phenomena to impact the disability experience. I also extensively reviewed literature from the narrative policy framework which contributed to the conceptualization of how policy initiatives such as those guiding postsecondary transition are influenced by stories. The narrative policy framework asserts that policies are developed around narratives which highlight the archetype of a hero's journey as popularized by Joseph Campbell (2008); by doing so, the public will sympathize with the hero and thus be called to action (i.e., support public policy) through emotion over pure reason. This assertion connected with my desire to empower participants rather than perpetuate stories of powerlessness and victimization which become self-fulfilling prophesies when they dominate the public discourse (see Shanahan, et al., 2018). Ultimately, the narrative policy framework was rejected because of its use of deductive reasoning to dissect how policies are developed because this study applied inductive reasoning to personal narratives to influence future policy and research initiatives.

Limitations

Even compared to typically limited sample sizes of qualitative studies, the complex narrative inquiry employed here dictated a sample size, and this along with the study's constructivist epistemology centering on individual experience may limit transferability. This project was unique and ambitious in creating physical picture books for each participant and even with limited sample sizes this had the potential to prove challenging due to the limited resources of a dissertation project. Further, the very act of selecting a study topic creates and reinforces researcher investment in the topic which can challenge objectivity. To minimize my personal biases as researcher, I journaled and reflected on positionality prior to beginning data collection and after each collection session while constantly reviewing and discussing ethical concerns with my committee and peer experts.

Another ongoing concern was that participants would be reluctant to consent or engage in full disclosure due to the sensitive and revealing nature of discussing disability. Also, sampling occurred through an undisclosed branch of The Arc. This could have complicated sampling and data collection if agency administrators had attempted to wield undue influence on sampling or if family/guardians prompted and guided answers between sessions due to their own concerns for how their child/ward was perceived. To guard against this, careful attention was paid to sampling methods to make sure participants met selection criteria yet were not singled out for additional unstated criteria such as agency favoritism, and frequent member checks were employed to encourage participants to focus on their own memories and concerns. Finally, lingering disruptions due to potential and actual resurgences of the COVID-19 pandemic also proved a barrier in recruiting and meeting with participants and may have proved a factor influencing purposeful sampling due to attendance and availability in the light of continued and widespread disruptions experienced throughout society.

Significance

This study fills a gap in the literature of descriptive data exploring postsecondary outcomes for young adults with IDD. Studies such as those by Acharya et al. (2017), Eismann et al. (2017), and Lee and Morningstar (2019) illustrated that persons with disabilities are integrating into the community at rates significantly lower than the general population. Literature reviews by Joly (2015) and Ladores (2015) illustrated the amount of attention that has been directed at this concern. Yet a nuanced understanding of actual outcomes of the postsecondary transition process in the words of those who have made this journey is critical for shaping ongoing public policy initiatives and informing future research, for it is difficult to design processes improving future outcomes when current outcomes are poorly understood. Therefore, a descriptive analysis of how persons with IDD experience and conceptualize community participation in the years following postsecondary transition can positively influence ongoing research and policy efforts, thereby informing more effective solutions.

Summary

Despite decades of research and policy initiatives seeking to improve postsecondary outcomes for persons with disabilities, this population continues to struggle integrating into their communities equally to nondisabled peers. This deficit is particularly pronounced for young adults with impairments such as IDD that significantly impact multiple areas of physical, cognitive, and social functioning. Despite this growing body of research, the voices of these individuals have largely been excluded from the academic discussions and policy debates about them. Therefore, the purpose of this study was to employ narrative inquiry to empower young adults with IDD to conceptualize their success and failures with community integration as guided by the postsecondary transition process. Such data is significant in that it can spur positive change by providing researchers and policy makers a richer understanding of actual outcomes and ongoing needs of this population while empowering such individuals to conceptualize their own relationships to their communities.

Chapter 1 provided a general overview of how this study can empower disenfranchised voices to participate in broader societal narratives and better guide future policy and research initiatives. Before detailing how narrative inquiry will be utilized to collect such robust descriptive data in Chapter 3, Chapter 2 will look more closely at the policy history guiding postsecondary transition, review current research on postsecondary outcomes with a focus on persons with IDD, and broaden current definitions of postsecondary transition outcomes beyond traditional vocational and healthcare concerns to form a more inclusive and holistic vision of community integration.

Chapter 2: Literature Review

Due to modern advances in healthcare, children born with disabilities today are overwhelmingly surviving into adulthood (Acharya et al., 2017; Ladores, 2015). As a result, tens of thousands of young adults with special needs are exiting American public schools each year where they are afforded extensive support and inclusivity under IDEA (Chiang et al., 2017; Wilczenski et al., 2017). However, the vast majority of these young adults with significant impairments such as IDD are failing to integrate into their communities at the same rate as peers with minor or no disability label (Acharya et al., 2017; Benson et al., 2021; Eismann et al., 2017; Flippo & Butterworth, 2018; Ladores, 2015; Oertle & O'Leary, 2017; Sawicki et al., 2017; Smith et al., 2021). And despite ongoing efforts to improve the postsecondary transition process, no comprehensive public policy exists to support those with special needs upon aging out of IDEA at 22; thus, these young adults and their families report feeling anxious and abandoned—an experience that has been described as *It's like falling off a cliff!* (Asp et al., 2015; Franklin et al., 2019; Joly, 2015). And despite overwhelming evidence of lagging outcomes, little descriptive data exists exploring how community integration in young adulthood is experienced by those with conditions such as IDD. Thus, the purpose of this qualitative study is to seek narrative data exploring the postsecondary transition outcomes of persons with IDD in relation to how successfully they are integrating into their communities to inform ongoing policy and research agendas.

This chapter discusses the literature search strategy used to develop this study, its theoretical framework, and key concepts informing the inquiry. Topics explored include

(a) an overview of policies that govern postsecondary transition, (b) an analysis of data illustrating the failings of this process, (c) traditional goals of postsecondary transition, and (d) a more holistic redefinition of what constitutes successful postsecondary transition based upon a broader understanding of community integration. Chapter 2 then ends with a summary of current research and an argument for why it is important to include the narrative voices of persons with IDD in postsecondary transition research, thereby setting up a discussion of the proposed research method in Chapter 3.

Literature Search Strategy

As an occupational therapist (OT) and OT professor, one of my key interests in both practice and scholarship is how to better aid adolescents with special needs in navigating the daunting postsecondary transition process. Thus, during my doctoral studies my interest was piqued upon studying the U.S. Office of Disease Prevention and Health Promotion’s *Healthy People 2020* initiative which included multiple objectives targeting improved postsecondary transition outcomes for adolescents with disabilities. With this seedling of an idea, I began searching broad terms such as *postsecondary transition* and *disability* or *special needs* in Thoreau, a database aggregator provided by Walden University. As a gap in the literature slowly emerged indicating a need for self-reported narrative outcomes of postsecondary transition for those with moderate to severe disabilities, I narrowed my search to the CINHAL, Medline, and Proquest databases, employing keywords including *postsecondary transition*, *vocational transition*, *healthcare* or *health care transition*, *adolescents*, *young adults*, *special education*, *special needs*, and *disabilities*. Analysis of literature from this targeted search illuminated seminal authors and articles, so the next phase of research focused heavily on mining these sources for seminal articles. One such critical article referenced was McDermott and Varenne's (1995) theory of culture as disability and a quick search of citations of this article in Google Scholar led to the disability culture model; thus, I returned to the above databases and searched the terms *culture as disability* and *disability* or *disabled culture*. Readings from this search then led me to critical disability theory which proved to fit the theoretical concerns of this study upon further review. However, in determining a theoretical foundation I also searched the narrative policy framework and identified seminal articles from this theoretical approach examining how narratives drive policy decisions.

Readings in both disability studies and qualitative research methods revealed a trend towards using narrative inquiry to empower persons with disabilities whose voices are often excluded from research, so the next round of searches focused on terms such as *narrative inquiry, narrative inquiry method,* and *narrative research* combined with previously searched terms such as *disability* or *special needs.* I then mined these articles for seminal works linking narrative inquiry to disability studies, as will be explored in Chapter 3.

From here I began outlining my literature review, and it became clear I would need to comment on public policy governing the postsecondary transition process. As an OT practitioner and educator, I am familiar with the major laws governing disability rights and my literature review uncovered additional minor laws relevant to this process, so I went directly to primary government resources for information on legislation such as

IDEA, the Americans with Disabilities Act (ADA), and the Rehabilitation Act of 1973. I then followed up with a Thoreau search of these laws combined with the terms *comparisons* and *differences*.

It should be noted that I did not search the term *intellectual and developmental disabilities* until the end of the literature review process. This emphasis emerged naturally, with the largest body of postsecondary transition research focusing on ASD, intellectual disabilities (ID), or IDD which includes both ID and ASD. Therefore, a final review was conducted with these terms in conjunction with terms such as *postsecondary transition* and *narrative inquiry* after data was collected but before analysis began to capture any critical studies that may have been overlooked and to ensure that the literature review was up to date after over a year spent in study development and approval.

Theoretical Framework

As an able-bodied White male, I approach this project from outside of disability and other broad categories of hegemonic exclusion; thus, I paid careful attention to both positionality and theoretical grounding to ensure this study empowers and uplifts the communities it seeks to represent. In recent decades, the literature on disability has increasingly turned to CDT to shift our conceptualization of physical, social, and emotional exclusion experienced by those with disabilities from an intrinsic (i.e., personal shortcomings) to an extrinsic (i.e., social and cultural failings in specific contexts) locus. Understanding the experiences of subjects with IDD through CDT will focus critique on policy and the social context in which policy evolves, empowering participants by celebrating their successes while exploring their struggles from an emphatic, holistic perspective that encourages awareness over indictment or exploitation.

The Stanford Encyclopedia of Philosophy defines *critical disability theory* as “a diverse, interdisciplinary set of theoretical approaches…to analyze disability as a cultural, historical, relative, and political phenomenon” (Hall, 2019, para. 1) while noting CDS and CDT are often used interchangeably. One important aspect of this theoretical approach is that it is viewed as a methodology for compelling activism and not an abstract theoretical construct meant primarily to spur debate within academic circles. CDT “necessarily refers to lived experiences and attempts to transform the circumstances under which oppressed subjects live through a critical, intersectional analysis” (Hall, 2019, para. 4). While it is difficult to note the exact moment a theory emerges, Linton (1998) presented one of the first distillations of what would become known as CDT in an article meant to define what should and should not be included in the emerging field of disability studies.

Disabilities studies came to prominence in the 1970s and 80s as an alternative to the applied fields of medicine and rehabilitation that focus on healing or preventing disability, instead offering a person-centered analysis of the disability experience and the social forces that spur alienation based on personal characteristics (Ferguson & Nusbaum, 2012; Goodley, 2013; Linton, 1998; Meekosha & Shuttleworth, 2009). Linton (1998), however, was one of the first authors to establish clear guidelines that would edge disability studies towards embracing critical theory. Per Linton, disability studies should explore disability as a “social, political, and cultural phenomenon” (p. 527), rejecting definitions centered on the individual that treat difference as pathology. Linton also spurned essentialism and called for greater inclusivity of the subjective voices of persons with disabilities in the field, citing a history of objectification where outside perspectives defined the social and personal reality of disability. While not directly using the term intersectionality, Linton (1998) noted the importance of building upon other theoretical perspectives such as feminism and race theory to understand the complex lives of those who experience disability. Thus, Linton concluded: “The need for a distinct field of Disability Studies is premised on the belief that disability has been socially constructed and that construction serves a variety of intellectual and social ends” (p. 536). Due to this grounding in social critique, Meekosha and Shuttleworth (2009) noted that it was widely assumed disability studies was emergent from critical theory long before explicitly noting this connection. Thus, while CDT was refined in the ensuing years, the term itself did not emerge for another decade.

Mollow (2004), an early voice in what would become known as CDT, expanded the theoretical underpinnings of this approach by challenging constructivist arguments that rejected disability as an individual identity, aspiring for greater inclusion by arguing that all humans are at times disabled. While disability may be a social construct, Mollow argued that denying the existence of disability as a unique identity by claiming universality and temporality of the disability experience was a misguided effort that negated the real struggles of persons experiencing disability throughout the world. Hughes (2007) concurred, asserting that “If we collapse the particularities of disabled lives into the abstract concept of humanity we end up claiming that disability doesn’t matter" (p. 678). Thus, tracing back to Linton's (1998) conceptualization as an action-based methodology grounded in lived experiences, these authors reject convoluted and abstract rhetorical debates in light of "the vast amount of empirical evidence that indicates, with unquestionable clarity, that disabled people live lives marred by discrimination and exclusion" (Hughes, 2007, p. 676). Thus, CDT embraces the individual nature of the disability experience while also providing a path for shared identity and advocacy.

Brown (2002) noted that an awareness of disability as a group identity emerged in the 1990s as a result of the disability right's movement (DRM) which modelled itself on other identity-based movements such as civil rights. Historically, disability evolved from being seen as a moral failing or curse from God to a medical issue to be treated and/or erased. In the 1970s, the social model of disability emerged from the U.K. to argue that disability was solely a social construct created by excluding certain individuals based on personal characteristics; yet this swing from a fully intrinsic to fully extrinsic understanding of disability was insufficient in understand the complexity of the experience, leading to the disability culture model around the turn of the century which viewed disability as the intersection of social, medical, and personal/contextual factors (Owens, 2015; Reid-Cunningham, 2009; Retief & Letšosa, 2018). Therefore Brown (2002), who identified as disabled, described *disability culture* as a method for subverting oppression through empowerment while indicting mainstream society for exclusion based upon personal characteristics:

> It is absolutely not our job [to] fit into mainstream society. Rather it is our destiny to demonstrate to mainstream society that it is to their benefit to figure out that we come attached to our wheelchairs, our ventilators, our canes, our hearing aids, etc. and to receive the benefit of our knowledge and experience mainstream society needs to figure not how we fit in, but how we can be of benefit exactly the way we are. That is disability culture. (p. 48)

Charlton (2000), another prominent voice in the emergence of disability culture, documented how disability is created throughout societies—both developing and industrialized—through such exclusion and objectification, thus necessitating cultural unity to combat oppression. Charlton also extended the critique of capitalism and neoliberalism beyond merely rejecting disabled bodies as non-productive to complicity in exploiting bodies viewed as disabled for economic means through institutionalization and medicalization. From here, it was a natural next step for Hughes (2007) to connect disability studies with a social ontology based upon critical theory. This shift placed the focus onto ableism over disability, thereby critiquing those outside of disability culture for their role in creating it (F. K. Campbell, 2008; Hughes, 2007).

Critical disability theory as a separate construct was first introduced in a 2008 paper by Hosking that established a baseline definition by incorporating earlier work influenced by critical theory. Critical theory emerged from Germany in the early 20th century where a school of scholars combined Marxist critiques of capitalism with Freudian notions of the unconscious mind to develop a richer analysis of societal oppression that moved beyond Marx’s binary and prescriptive class-based diagnosis that ignored the multiple identity categories through which social oppression operates (Hall, 2019; Hosking, 2008; Hughes, 2007). Building upon other critical theory influenced traditions such as feminism and queer theory, Hosking (2008) laid out seven basic elements of CDT. The first was to establish a more holistic understanding of disability by synthesizing medical and social models with the World Health Organization's (WHO) biopsychosocial model that defines disability as arising from the intersection of social and contextual factors with individual impairments and personal responses (similar to the more commonly cited disability culture model). Per Hosking, CDT should also (a) illuminate the multidimensionality of roles and identities of which disability is only one (often referred to as intersectionality), (b) embrace diversity while affirming the disability experience; (c) openly advocate for disability rights; (d) empower marginalized disabled voices in research and policy; (e) illuminate how language and labeling influence perceptions of disability, and (f) embrace the fundamental goal of critical theory to emancipate humanity. By adopting these seven tenets, CDT seeks to challenge hegemony and become an agent for social change while acknowledging that there is inherent paradox in embracing disability identity while challenging the limits such labels impose.

Hosking (2008) argued that CDT must embrace and analyze the paradoxical tension created by competing understandings of disability. For example, in both critiquing the harm of socially constructed disability labels and embracing disability as a cultural identity, Hosking welcomed the tension between the constructivist ontology of the social model and the postpositivist ontology of the disability culture model which defines itself in opposition to constructivism as a creative force. This bridges the ontological divide by accepting the paradox that two contradicting truths can coexist in a CDT version of Schrodinger's cat, paving the way for CDT as an action-based methodology that can embrace law as both a source of and solution to oppression.

Meekosha and Shuttleworth (2009) were amongst the first theorists to explicitly connect CDT to the intersectionality of feminism, critical race theory, postmodernism, and queer theory while asserting CDT to be an emancipatory approach built upon multidisciplinary eclecticism that counters binary conceptualization of disability (e.g., medical vs. social models). Going further, Meekosha and Shuttleworth also associated CDT with Foucault, drawing on his theory of how societies use language and institutions to control and oppress, ultimately compelling the oppressed to participate in their own subjugation through internalization of language and social categories. In the case of disability, they argued, this has largely been performed through charity, medicalization, and classification—often for purportedly benevolent ends. Carlson (2001) also applied Foucault to disability studies in a way particularly relevant to this study by arguing against cognitive ableism which has led to multiple forms of oppression including "marginalization of persons with cognitive disability from mainstream scholarship in philosophy and disability studies" (p. 141). Later authors such as Feely (2016) built upon Foucault's influence to further explore the paradox of disability labels as both the vehicle for creating oppression and a method for combatting it, arguing that this reveals the intersection of discourse with the material world. By embracing these conflicting forces, we "acknowledge the context-dependent limitations of bodies without accepting the impairment as brute truth" (p. 872). Various refined conceptualizations of CDT soon followed.

Ferguson and Nusbaum (2012)–though not explicitly citing CDT—emphasized the importance of disability studies as a socially focused discipline centered on exploring the concept of disability utilizing methods that are interdisciplinary, participatory, and explicitly value-based in social change. Taking a more economic approach, Goodley (2013) argued that at its core CDS must reject neoliberal notions of materialism that view the body as primarily a means of production to instead promote a view that persons with disabilities have *bodies that matter,* thereby challenging the notion of the disabled self as *other*. He also expanded upon the importance of intersectionality by arguing that CDS must take a global perspective.

The next wave of voices in CDT was instrumental in conceptualizing the theory as a methodology that carries intrinsic social responsibility, advancing and expanding Linton's (1998) argument that the goal of disability studies is active change in the community and not scholarly debate within the classroom (Erevelles, 2014; Minich, 2016; Schalk, 2017). These authors acknowledged that one does not have to identify as disabled to explore CDT, but such researchers are accountable to the disability community in how they employ the methodology—an assertion at the forefront of my approach to this study. Fox (2017), in turn, argued that the three primary aims of CDS are broad inclusivity, increased visibility for disabled populations centered on including their voices, and promoting empathy and creativity. And St. Pierre (2015) advanced an aspect of CDT particularly relevant to this study by arguing for the benefit of *cripping* *communication,* which is rejecting the ableist supremacy of fluent communication and clean, coherent narrative to instead *embrace the noise* and work collaboratively towards meaning construction. When such cooperative steps are taken, “[t]here is perhaps much to gain from resisting the straight and most direct communicative and discursive path” (St. Pierre, 2015, p. 338).

This study explored and advanced these principles of CDT, seeking how policy and social norms influence the lived experiences of young adults with IDD while considering the intersectionality of their identity and respecting the authority of their perspectives in seeking an understanding of how their perceived journeys were influence by public policy. Hosking (2008) explicitly drew a connection between CDT and policy change, arguing that CDT both:

> (1) identifies the overt and covert sources of oppression within the law and legal institutions and, by means of exposure, seeks to relieve disabled people from that oppression and (2) identifies the potential positive role of law and seeks to create law, use existing law and enlist legal institutions in the struggle for the emancipation of disabled people which is the rationale for CDT itself. (p. 16)

This second aim most directly supports this study in seeking the voices of those with IDD to identify the positive influences of existing postsecondary transition policy while exposing areas where policy could be improved, for Hosking acknowledged that existing law is both oppressive and emancipatory—an embrace of duality missing from earlier theorists and rigid approaches such as the social model. Applying this multidisciplinary theory to public policy and administration research embraces the paradox between postpositivist and constructivism ontologies to empower silenced voices and celebrate collaborators as heroes of their own lives while simultaneously illuminating societal and policy shortcomings that impede a better path forward.

Literature Review Related to Key Concepts

Merriam-Webster (n.d.b) defines *transition* as the "passage from one state, stage, subject, or place to another" (Definition 1a) or "a movement, development, or evolution from one form, stage, or style to another" (Definition 1b). The human lifespan is marked by constant periods of such passage or evolution, though perhaps the greatest transition a person experiences is from adolescence to adulthood—leaving the protection of home to find one's way as an autonomous actor responsible for their own survival and well-being. Joseph Campbell (2008) argued that human culture is built around such transitions where we see ourselves as the hero of our own journey, and entire bodies of fiction, poetry, movies, and music explore this fraught process and most cultures mark this rite of passage through an array of rituals such as graduations, sweet sixteen parties, rumspringa, bar/bat mitzvahs, and—in a sense—weddings. Yet for children and adolescents identified as having a disability, this process can be exponentially fraught and frightening. Thus, what is an unstructured and naturally unfolding journey for most adolescents is a carefully planned and monitored process for students served under IDEA guided by decades of public policy and research initiatives. Therefore, any discussion of postsecondary transition must begin with an overview of the public policy that frames this process, starting with the history of IDEA and other major federal laws before considering more recent although less global federal initiatives and concluding with a brief discussion of the regional transition policy landscape.

Policy Overview: Historical Perspectives on Postsecondary Transition

One of the least heralded but most significant moments in United States civil rights history occurred in 1975 when President Gerald Ford signed the Education for All Handicapped Children Act into law establishing the right to FAPE for all children regardless of ability status (U.S. Department of Education, n.d.). This monumental victory for families of children with special needs meant that no longer could schools bar their doors and claim they were unprepared to meet the needs of students who did not fit a certain mold. Instead, they were required to develop IEPs that explicitly spelled out how educators would meet the needs of students who required extra support to participate (U.S. Department of Education, n.d.). But getting in the door was only the beginning.

In 1990 President William Clinton signed a reauthorization of this law, now titled the Individuals with Disabilities Education Act, which established the concept of *least restrictive environment.* This provision ended the wholesale warehousing of students with special needs in segregated classrooms, placing the impetus on schools to educate these students with non-disabled peers to the maximum extent possible while still meeting specialized individual needs. As a result, in the 2018/2019 school year 64% of children with disabilities spent 80% or more of their day in general education classrooms where they benefitted from peer modeling and normalized expectations (U.S. Department of Education, n.d.). Yet while this mandate greatly expanded access to regular education classrooms for those with disabilities, it was becoming increasingly apparent that an exit strategy was also necessary to help these students better integrate into their communities upon graduation.

To address the growing need for assisting with the transition to adulthood a 1997 reauthorization of IDEA required that IEPs for all students 16 or older include a plan for:

> identifying appropriate employment and other postschool adult living objectives for the student; referring the student to appropriate community agencies; and linking the student to available community resources, including job placement and other follow-up services. (United States Office of Special Education Programs, n.d., p. 4)

This mandate reflected the growing acknowledgement that merely navigating 21 years of school was not enough. Students with disabilities must be prepared to function as adults in a cultural landscape where civil rights laws such as ADA bar their exclusion but do not mandate their inclusion like IDEA—a critical distinction.

In 1990—along with IDEA—President Clinton signed the more widely recognized Americans with Disabilities Act. While IDEA opened America's schools to children with disabilities, ADA was an all-encompassing civil rights law ensuring broader societal access to all persons with disabilities. Per the United States Department of Justice (n.d.) ADA is:

> one of America's most comprehensive pieces of civil rights legislation that prohibits discrimination and guarantees that people with disabilities have the same opportunities as everyone else to participate in mainstream of American life—to enjoy employment opportunities, to purchase goods and services, and to

> participate in State and local government programs and services. ("Introduction to the ADA," para. 1)

Such sweeping protections were the culmination of decades of advocacy by the DRM; thus, ADA remains the United States' flagship law for promoting community access for persons with disabilities.

Titles I through III of ADA most closely influence postsecondary transition. Title I promotes vocational transition by barring discrimination by employers, governments, or labor unions while requiring reasonable accommodations on the part of employers upon self-disclosure of a disability by the employee. An employer is not, however, required to alter fundamental job requirements. Further, little guidance is provided on what constitutes a reasonable accommodation and specific disabilities are not identified in the law (U.S. Department of Justice, n.d.). This leaves much room for interpretation and litigation, and employers largely resisted such accommodations leading to a 2008 amendment seeking to strengthen these protections (Basas, 2008). Title II of the ADA promotes postsecondary education transition by extending the concept of reasonable accommodations to colleges, universities, and vocational schools receiving federal funding while Title III addresses private educational institutions receiving no federal dollars (U.S. Department of Education, 2011). Additional legislation has also strengthened these provisions, as discussed later.

While IDEA and ADA are the most comprehensive civil rights laws protecting persons with disabilities in the United States, The Rehabilitation Act of 1973 was the precursor to both, and many of its most important mandates still in effect. While the

ADA mandated access for persons with disabilities throughout society, the Rehabilitation Act was an early move in this direction targeting only agencies receiving federal funding (including schools). Section 504 of the Rehabilitation Act of 1973 states:

> No qualified individual with a disability in the United States…shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance. (C.F.R. Part 104)

Section 504 covers adults with disabilities working for or served by organizations receiving federal funding including public and postsecondary schools, extending protections to school children not covered by IDEA to ensure access to reasonable accommodations and assistive technology. Further, Title I mandated the formation of VR agencies in all 50 states to serve those with the most severe disabilities (U.S. Department of Justice, 2020).

While these three civil rights milestones are the largest public policy initiatives influencing postsecondary transition, several recent minor laws have sought to increase inclusion and improve the transition process for those with special needs. For example, the Higher Education Opportunity Act (HEOA) of 2008, a reauthorization of the Higher Education Act of 1965, expanded postsecondary education opportunities for students with disabilities, particularly those with labels such as IDD who tended to be grossly underserved. For example, since its passage, postsecondary education (PSE) programs for students with ID have increased tenfold and enrollment by 500%—a remarkable feat for a population once excluded from even elementary education (Baker et al., 2018; U.S.

Department of Education, 2010; Wilczenski et al., 2017). In the vocational rehabilitation arena, 2014's Workforce Innovation and Opportunities Act (WIOA) sought to improve workforce integration by persons with disabilities. A key feature of this law was its mandate that 15% of dollars granted to state vocational rehabilitation agencies through Title I of the Vocational Rehabilitation Act now be devoted to transition preparation and coordination prior to gradation, working cooperatively with special education teachers to provide employment skills and job exposure (Kester et al., 2019; Riesen & Oertle, 2019; U.S. Department of Labor, n.d.). This law created a necessary policy bridge between IEP transition planning and adult vocational services. Nevertheless, significant barriers remain, for IDEA differs radically in mandate and execution from the protections provided in adulthood through ADA and the Rehabilitation Act of 1973.

IDEA weaves a comprehensive web of support and mandated inclusion through concepts such as FAPE and least restrictive environment that require schools and early intervention providers to identify and serve all students with disabilities while earmarking federal and state dollars towards these ends. As Chan (2016) explained, IDEA guarantees "a unique educational program that is customized to each specific child who needs special education services…and it offers due process when a family has disagreement with the school system" (p. 19). In stark contrast, however, ADA and Section 504 prescribe "equality of access and nondiscrimination" as opposed to requiring inclusion (Chan, 2016, p. 20). Thus, under ADA and 504 a person with a disability encountering discrimination must possess the skill and self-determination to request accommodations, file complaints when denied, and escalate to legal recourse if these complaints are ignored (Chan, 2016; Kelepouris, 2014; U.S. Department of Justice, n.d.). Further, while IDEA is a funded mandate, no state or federal programs comprehensively funds non-discrimination and reasonable accommodation mandates in adulthood. Instead, a nebulous and sparse patchwork of services are available through programs such as Medicaid or VR that fall vastly shy of the universal scope of IDEA. Thus, it is helpful to first examine this patchwork of services in the North Florida region where this study will take place.

Florida Policies & Services Serving Adults with IDD

The United States manages health and wellness policy at both the state and federal level, so any given region within the nation will be served by its own unique mix of government agencies and nongovernmental organizations (NGOs). The state of Florida has two primary state agencies focusing on community integration for adults with IDD. The Division of Vocational Rehabilitation (2020) describes its mission as “To help people with disabilities find and maintain employment and enhance their independence” (“Mission Statement”). Created through the Vocational Rehabilitation Act of 1973, the agency is primarily funded through federal grants, though it is administered and funded at the state level through Florida Statute 413 (Division of Vocational Rehabilitation, 2020; U.S. Department of Education, 2020). Qualifying applicants must prove a physical or cognitive disability that creates a substantial impairment impacting employment yet demonstrate the capability to benefit from VR, with priority given the more severe the disability (Title XXX: Social Welfare, 2020; U.S. Department of Education, 2020). Per agency statistics, in North Florida (Area 2), 5.4% of the population has a cognitive disability, however only 18.3% of persons with any disability were employed in 2018-2019 as opposed to 23.4% nationwide; nevertheless, this is in line with the statewide rate of 18.9% which is 12th lowest in the nation (Compton, et al., 2019). Florida VR accepts between 75-85% of applications annually (Compton, et al., 2019). As a result, they served 40,655 persons in 2019, half of which were transition-aged, and approximately 1/8th of whom achieved employment (Florida Rehabilitation Council, 2020).

Serving a broader mandate of community integration, the Agency for Persons with Disabilities ([APD], n.d.a) split from the Department of Children and Families in 2004 to focus on supporting adults with developmental disabilities (DD), and funds it services primarily through federal programs. The three-pronged mission of the APD is to support persons with DD "in Living, Learning, and Working in their Communities [capitalization by source]" (APD, n.d.a, "Agency Mission"). The APD accomplished this mission through 1) increasing access to healthcare, community, and residential services, 2) workforce integration, and 3) agency and provider oversight (APD, n.d.a, "Agency Goals"). The APD currently serves over 50,000 Floridians primarily through the state Medicaid waiver program which they term *iBudget* (APD, n.d.2). Medicaid waivers allow states to expand Medicaid coverage to populations that do not meet broad federal eligibility standards, and Florida's *Developmental Disabilities Individual Budgeting Waiver* provides home and community-based services for adults with DD to promote health, wellness, and self-determination (Agency for Health Care Administration, 2021). Currently, however, there is a waitlist of 22,000 Floridians seeking Medicaid waiver services (APD, n.d.1, "FAQs"). Florida was one of many states that rejected federal funding to expand Medicaid coverage under the Affordable Care Act (ACA), thereby leaving approximately 850,000 to 1.5 million Floridians without coverage (Chang, 2015; Florida Health Justice Project, n.d.). This has worsened the policy cliff in this region for young adults losing IDEA services, so many families rely on NGOs to fill the gap.

The Arc of Florida, the statewide branch of a prominent national organization, is the most visible service agency in the area. The Arc provides training, education, and day programs to promote community integration for persons with IDD through dozens of locations throughout the state, with funding coming from multiple sources, including Medicaid wavier and private donations (The Arc of Florida, n.d.). Smaller in scope yet perhaps more ambitious in its mission, the North Florida School of Special Education (NFSSE) was formed by parents of children with IDD to provide community-oriented education focusing on developing job skills and greater community independence. This school (NFSSE) is funded through private tuition, grants and scholarships, and donations as well as employing entrepreneurship through producing, marketing, and selling baked goods and dog biscuits during onsite skills training (NFSSE, 2021). In addition to a strong focus on transition, they provide postgraduate job training for adults with IDD ages 22-40+ (NFSSE, 2021). While these are the two largest providers of direct training in the region, other NGOs focus on advocacy and education such as the Florida Developmental Disabilities Council and Florida's Voice on Developmental Disabilities (Florida Developmental Disabilities Council, 2020; Florida's Voice, 2021). Similarly, the governor appointed volunteers of the Family Care Council (FCC) to work with the APD to advise and monitor program implementation and to advocate for and educate individuals with DD and their families (FCC Florida, n.d.).

In addition, multiple agencies support persons with specific diagnoses and their families in North Florida, many of which may fall under the IDD label such as the Autism Society of Florida (n.d.), United Cerebral Palsy of North Florida (2021), and the Down Syndrome Association of Jacksonville (2020). So, while there are many organizations and agencies assisting young adults with IDD as they integrate into the community, the vast body of research discussed below illustrates that such scattered and siloed services are confusing and difficult for families to access, resulting in a policy cliff that continues to hamper the postsecondary transition success of young adults with disabilities.

A Failure to Launch: Lagging Outcomes of Postsecondary Transition

The 1997 reauthorization of IDEA was a tacit acknowledgement that students with disabilities are struggling to transition into adult roles and occupations. In the decades since a growing body of literature has documented the continued failing of this process while calling for urgent action. While studies of individual transition programs have demonstrated incremental success and distillations of evidence-based practices abound, the problem persists. OSERS (2015) which oversees IDEA and VR funding under the Vocational Rehabilitation Act defines postsecondary transition as “the passage from secondary education to participating in postsecondary education, training, or both, engaging in meaningful employment, living within one’s community, exercising self-determination, and contributing to society as productive citizens” (p. 1). Per OSERS, over

3 million students were served under IDEA in 2013, of which 350,000 were ages 18-21 and thus beyond typical graduation age. Citing the comprehensive NLTS2, OSERS reported that by age 16 transition was addressed on 91% of IEPs and rose to 96% by age 18—though no reason was given for exceptions to this IDEA mandate (although some disparity may result from NLTS2 survey respondent error). In an encouraging sign, however, 75% of IEPs were already addressing transition by age 14. Of these transition plans, 53% addressed competitive employment while other common topics included independent living, postsecondary or vocational education, social skills, and functional independence. OSERS's report cites the NLTS2 because it is the most comprehensive data source examining postsecondary transition outcomes; thus, any conversation of transition should start there.

National Longitudinal Transition Study-2

Commissioned and funded by the U.S. Department of Education's IES, the NLTS2 surveyed over 11,000 students ages 13-16 in 2000, collecting data in five waves over the next decade. The purpose was to track these students through the transition process, examining data for students with disabilities in general as well as via the twelve qualifying disability categories under IDEA (National Center for Special Education Research, n.d.; Newman et al., 2011). This was accomplished by focusing on secondary education, transition, and outcomes (i.e., before, during, and after) using a variety of variables including "high school coursework, extracurricular activities, academic performance, postsecondary education and training, employment, independent living, and community participation" (National Center for Special Education Research, n.d., "Study

Design & Methodology," para. 2). The study also incorporated parent interviews, youth assessments, teacher and staff surveys, and analysis of school records and transcripts (National Center for Special Education Research, n.d.; Newman et al., 2011).

Per initial NLTS2 analysis, within 8 years of leaving high school 60% of young adults with disabilities enrolled in a college, university, or vocational school as opposed to 67% of the general population; 41% completed their postsecondary education as opposed to 52%; 60% were employed as opposed to 66%; and 45% were living independently as opposed to 59%. And while 91% of young adults with disabilities held a job, they worked fewer hours, accepted more part-time positions, and earned $1 less per hour than the general population. They were also slightly less likely to receive health care or vacation benefits. Yet it is significant to note that 63% of students who received IDEA services did not consider themselves disabled as adults—primarily in categories such as speech/language impairment, learning disability, traumatic brain injury, and emotional disturbance. When zeroing in on categories that would fall under the IDD umbrella such as autism, mental retardation (contemporarily referred to as ID), and some forms of OI, the gap between respondents and the general population widens (Newman et al., 2011).

In examining outcomes by category, Newman et al. (2011) found that only 62% of young adults with OI, 44% with Autism, and 29% with MR pursued postsecondary education—though a wide variety of majors were sought across all categories. Only 35% of those with OI, 37% with Autism, and 39% with MR were currently employed, while respondents in all three categories were more likely to reveal their disability and receive accommodations in both work and postsecondary education, indicating that these populations are more likely to retain their disability identity in adulthood. Independent living rates also lagged for these categories at 31% with OI, 17% with autism, and 36% of those with MR living outside the family home. The particularly low rates of independent living for young adults with autism emphasizes the importance of social skills and executive functioning for independence, and this theme recurs throughout the literature. Social inclusion rates were also significantly lower for these groups. For example, only 66% with OI, 48% with autism, and 58% with MR reported seeing at least one friend weekly outside the home as opposed to 84% with a speech/language impairment and 83% with a learning disability (Newman et al., 2011). All three categories were also less likely to drive, implying dependence in community mobility which also emerges throughout the literature. Sadly, many community integration markers such as volunteering, participation in activities outside the home, joining community organizations, and attending community-based classes were low for nearly all disability categories, reflecting how broad-based community integration struggles are despite disability label (Newman et al., 2011). And while this initial data paints a vivid picture, multiple studies in the decade since have drilled deeper into this data to further clarify postsecondary transition outcomes.

In their analysis of NLTS2 data focusing on the more contemporary ASD label which is more inclusive than autism, Nasamran et al. (2017) found that only 60% of respondents with ASD reported PSE success, 40% were employed, and 15% lived independently. On a positive note, though, they found that increased social skills aptitude correlated positively with desired outcomes. This aligns with other NLTS2 studies that found life skills training and vocational preparation were strong predictors for successful vocation transition and community integration outcomes across multiple disability categories (Lee & Morningstar, 2019; Wehman et al., 2014). But Chiang et al.'s (2017) NLTS2 analysis suggested that social skills were not being adequately addressed, finding that only 77% of transition-age students with ASD received life skills training as part of their IEP while 30% of parents whose children didn’t receive such training felt it was needed. Moreover, 80% of young adults with ASD continued to require life skills after transition (Chiang et al., 2017). Other NLTS2 studies addressed community participation more directly.

For example, Tint et al. (2017), citing multiple earlier NLTS2 studies establishing reduced community participation by young adults with ASD and ID, found that the presence of both diagnoses—a common occurrence that indicates more severe symptomology—compounded the likelihood of reduced community engagement. Yet Lee and Morningstar's (2019) study provided the broadest view community participation of those they defined as having severe disabilities. Per their findings less than ¼ of young adults with severe disabilities participated in outdoor physical activities while around 13% attended community entertainment events; 10% spent time in a church, coffee shop/café, or mall; and 5% spent time in bars or clubs, gyms, parks, and other formal outdoor settings. Alarmingly, despite the likelihood of medical complexities, less than 5% reported recently visiting a healthcare provider. Also of significance, Lee and Morningstar used linear regression to demonstrate that 83% of community involvement could be explained by functional life skills and participation in strong social networks indicating a strong negative relationship between community integration and severity of disability. But although the NLTS2 is the largest provider of data, evidence of postsecondary transition failures pervades the literature.

Other Indicators of Postsecondary Failure to Launch

In a survey of parents in one midwestern community, Miller-Warren (2016) found that only 17% of parents of children whose IEPs had addressed transition felt their children were adequately prepared upon leaving school. Through a nationwide survey of mental health professional, Poppen et al. (2016) identified that common transition barriers included limited information and resources for families, underdeveloped self-advocacy and self-determination skills in adolescents with special needs, limited stakeholder collaboration, and a need for greater family involvement. To address these problems, respondents called for increased education, collaboration, and empowerment. Stein et al. (2016) uncovered similar themes through a series of focus groups composed of youth with emotional and behavioral disorders (EBD), their caregivers, vocational and educational staff that worked with them, and supervisors. All stakeholders agreed that transitioning adolescents benefited from strong connections and a trusting relationship with transition staff, yet needs identified included increased community and family involvement, prioritization of self-determination skills, greater family assistance navigating complex systems, and reduced professional focus on deficits replaced by an abilities-based approach. Other studies that surveyed teachers and transition specialists cited the need for more clearly identified roles by all stakeholders, increased communication, improved training, and incentives to promote collaboration (Oertle et al., 2021; Plotner et al., 2020). Similarly, Benson et al.'s (2021) qualitative inquiry identified a similar need amongst the parents of transition age youth for increased services and communication. Such themes consistently emerge throughout transition literature.

Multiple systematic literature reviews echo how these concerns have persisted over time. In their exhaustive meta synthesis of qualitative studies targeting families of adolescents and young adults with ASD, Hirano et al. (2018) found that throughout the postsecondary transition process families reported barriers at both the school level and through adult services, with professionals from both ends of the transition spectrum failing to include them and their children sufficiently in the process. Transition professionals also tended to demonstrate a lack of respect, employ cookie-cutter approaches that neglected individual needs, and respond with hostility towards parent expertise. Such families also consistently reported lacking sufficient information of the transition process and that the process of qualifying for services was difficult and confusing (Hirano et al., 2018). Schools were singled out for racial and cultural insensitivity as well as waiting too late to plan while adult services were singled out for focusing on students' deficits as opposed to strengths and having low expectations of their clients. On top of—or perhaps because of—these challenges, families across all studies reported strain on their personal relationships and financial stress. Such stressors were compounded by a perceived lack of *cultural capital* or knowledge and power in social systems (Hirano et al., 2018). On the positive side, Taylor et al. (2020) demonstrated through a systemic literature review specifically targeting persons with IDD the strong correlation between inclusive education and a broad array of transition outcomes, although causation cannot be established. And although the NLTS2 and related studies have broadened our understanding of postsecondary transition outcomes, until recently the majority of postsecondary transition literature focused exclusively on healthcare, employment, or postsecondary education. So before expanding our definition it is helpful to first look at traditional focuses of this process.

Get Well & Get to Work: Neoliberal Aims of Postsecondary Transition

Healthcare Transitions

According to Gabriel et al. (2017): “Transitioning from pediatric to adult care encompasses preparation for managing one’s health and needed health care, transferring to adult-centered care with current medical information, and engaging in adult healthcare,” (p. 263). Although scarcely mentioned thus far, this process of taking charge of one’s own health is one of three themes dominating postsecondary transition literature. And while healthcare policy is an expansive topic separate from the civil rights and community integration approached taken in this study, disability—right or wrong—has historically been medicalized by our society; therefore, children with disabilities and their families experience education through a medical lens and thus tend not to differentiate educational, vocational, and healthcare transition concerns. In fact, multiple qualitative studies indicate that families experience the education and healthcare policy cliff as a unified phenomenon (Acharya et al., 2017; Franklin et al., 2019; Joly, 2015). As a healthcare practitioner, I too have traditionally approached transition from this perspective, having provided OT services in public schools through this combined educational and healthcare lens, and as a healthcare educator I teach transition from such a holistic perspective. Therefore, articles on healthcare transitions add substantively to this discussion.

Per Acharya et al. (2017), of the approximately 750,000 youth with special healthcare needs who transition to adulthood each year, only 40% receive the support they need to independently take charge of their own care. For example, in a survey of two large U.S. states, Sawicki et al. (2017) found that of adolescents with special healthcare needs, only 52% in one region and 33% in the other spoke to a provider about taking charge of their own healthcare without a parent present and only around 10% in each region discussed locating an adult provider. The most alarming finding, however, was that only 4% of transitioning youth with special healthcare needs developed a transition plan with their pediatric providers. Nevertheless, while stakeholders agree there is a problem, the cause is in question. Through a self-selected focus group of pediatric nurse practitioners, Lestishock et al. (2018) found that providers believed parents needed to be coached to relinquish control and allow adolescents to assume control of their own care. They also felt that adolescents with disabilities need to be better taught self-care, communication, and paperwork skills, which shifts the transition burden from providers to families and schools. Other stakeholders, though, provided a different perspective.

A literature review of healthcare transitions by Joly (2015) focusing on young adults with complex medical needs uncovered three major themes echoed throughout this discussion. The first theme, *It’s like falling off a cliff!,* reflected the universal sense of abandonment and disorientation upon the policy drop-off after losing both IDEA protection and healthcare from more supportive pediatric practitioners; *The Paradox of*

Independence illustrated how these young adults struggled with the need for extra support—i.e. dependence—in order to maintain their independence; and *It takes a village* articulated the need to be respected and included throughout the transition process. This study also found a acknowledged the need for better communication between siloed healthcare professionals, reflecting the common theme of poor communication and coordination. In their qualitative study of the healthcare transition from the understudied perspective of parents of adolescents with ID, Franklin et al. (2019) identified similar themes of *Inefficient and siloed systems* reflecting poor communication and coordination between professionals and *Left out here floundering* which is another iteration of the support/policy cliff. Their study, however, identified an additional theme of *Hope despite uncertainty* reflecting the resiliency of these families despite commonly cited dual feeling of isolation in their community due to lack of support and isolation of their children due to lack of successful community integration. Franklin et al. also illustrated how intertwined healthcare and education are, for parents throughout multiple studies on healthcare transition complained of frustration with the IEP process and stated a need to address healthcare on IEPs. And these problems are not specified to the United States. Asp et al.'s (2015) study of young adults with congenital heart disease in Sweden also found the need for better cross-discipline communication during the transition to adulthood, the prevalence of uncertainty arising from inadequate understanding of the process, and a universal desire to feel more involved throughout the process. Therefore, this portion of the healthcare transition literature points to bureaucracy, limited resources, and poor communication as universal barriers for persons with disabilities throughout the world, which seems to shift the preponderance of blame onto healthcare providers. However, legislators and administrators also carry a share of perceived blame.

Multiple other studies have established the persistence of bureaucratic barriers that confuse and overwhelm families in distress, thus thwarting well-intentioned policy aims (Asp et al., 2015; Franklin et al., 2019; Joly, 2015; Kruszka et al., 2012; Ladores, 2015; Sawicki et al., 2017). Gabriel et al. (2017) took it a step further and examined the efficacy of specific healthcare transition programs through the policy lens of the commonly cited healthcare *Triple Aim*: improving the population's health, improving patient experience with healthcare, and reducing costs. They found that 65% of studied healthcare transition programs reported significant positive findings, yet none stood out as supported by overwhelming evidence, and only 15 studies looked at programs that addressed all three aims. Thus, these authors too concluded there is a need for better communication and cooperation with families and amongst agencies. Ladores (2015), in turn, focused on nursing literature to better understand the how healthcare transition is defined, concluding that transition is a continuum which requires flexibility by providers, but—reflecting bureaucratic concerns—that the process consistently is seen as causing stress, uncertainty, and anxiety. Perhaps the most disconcerting finding, however, was that despite a 2002 joint statement by multiple professional associations advocating improved healthcare transition services, little evidence of progress exists, leaving plenty of blame for all involved parties (Ladores, 2015). Fortunately, there were positive signs. Huang and Porterfield (2019) demonstrated that there can be a positive impact from public policy. Their analysis of ACA showed that states that embraced Medicaid expansion as promoted by the law demonstrated higher rates of successful healthcare access by young adults with disabilities. And, surprisingly, Rydzewska et al. (2020) examined NLTS2 data and found that while few persons with Down syndrome report having ‘excellent health’ in surveys, there is not a measurable drop in perceived health status in the decade following postsecondary transition, suggesting that perhaps there is some semblance of continuity despite the obstacles. But regardless of pockets of isolated program success as demonstrated by Gabriel et al. (2017), there is clearly room for improvement.

Vocational Transition

Perhaps the most ubiquitous question asked of young children is “What do you want to be when you grow up?” Career exploration can be observed in play as early as toddlerhood—whether doctoring an ailing doll, donning a fire fighter costume, digging in the dirt with a toy bulldozer, or mimicking the moves of sports and music heroes. It should be no surprise then, that the largest area of focus in postsecondary transition literature is on vocational transition, as having a job and achieving financial independence is a major quality of life factor. In 2012, VR professionals adopted a 7-step transition model based on existing evidence that is a helpful entry point for understanding vocational transition policy and practice: 1) Provide planning and counseling, 2) Offer career experiences, 3) Promote job access and opportunity, 4) Emphasize program improvement activities, 5) Develop non-professional supports and relationships, 6) Analyze and improve allocation of resources, and 7) Nurture collaborative partnerships (Oertle & O’Leary, 2017, p. 413). These are echoed throughout the literature where the most common recommendations are to provide early career exposure and exploration, increase effective cooperation and communication between stakeholders, cultivate robust community involvement, provide early paid work experience, foster self-efficacy, and individualize services which emphasize strengths and interests over deficits (Daviso et al., 2016; Hoover, 2016; Kester et al., 2019; Oertle & O'Leary, 2017; Qian et al., 2018; Ruble et al., 2019; Sansosti et al., 2017; Wehman et al., 2014). More specifically, multiple recent studies have demonstrated a positive correlation between vocational goals and community involvement in the IEP process with successful vocational outcomes in young adulthood (Honeycutt et al., 2017; Hoover, 2016; Oertle & O'Leary, 2017; Qian et al., 2018; Rast et al., 2020). For example, in a study of impressive breadth, Honeycutt et al. (2017) analyzed nationwide data from state VR agencies for transitioning adolescents with mental health conditions over multiple years and confirmed a strong correlation between both pre-transition work experience and career planning/training by VR agencies and successful vocational outcomes. Flippo and Butterworth (2018) sorted through available evidence to demonstrate the effectiveness of community cooperation for predicting vocational success, arguing for cultivating broad-based community conversations to better educate potential employers and set the stage for successful transitions. Although when it comes to implementing these recommendations, the greatest hits of transition obstacles quickly rear their heads.

Both Kester et al.'s (2019) survey of VR professionals, educators, and other personnel in all 50 states and Oertle et al.'s (2017) survey of statewide education and VR supervisors across the nation identified frustration with the lack of sufficient communication, coordination, and education between stakeholders. Hoover (2016), in turn, demonstrated through an extensive literature review how increased community involvement is needed throughout the process as community integration is not something than can be tacked on the end of high school for vulnerable youth. Other authors have studied the problem from the community end. A study by Riesen and Oertle (2019) found that employers were willing to hire persons with ID, yet only 38% of these employers provided on-the-job training in conjunction with a community agency and all desired more education from VR agencies and closer coordination between VR and special educators to help ready these potential employees—another variation of the communication and coordination conundrum. In fact—supporting the view of disability as a cultural construct—multiple studies show that these support factors can be more influential than diagnosis for transition outcomes. In studying transitioning adolescents with ASD, Ruble et al. (2019) found that family engagement in the process, interagency cooperation, and effective program structure were more vital to predicting positive vocational outcomes than IQ or severity of the disability.

Rather than taking the broad view, there are many studies measuring the efficacy of specific programs that incorporate these best practice principles. Green et al. (2017) studied a model designed and implemented by Ohio State University that combined integration into university courses with specialized instruction promoting self-determination, career development, and campus participation. Early results boasted a 91% employment rate after six years. Other studies have demonstrated the effectiveness of specific techniques such as rehearsing job interviews, teaching job-related social skills like seeking feedback or apologizing for mistakes through Applied Behavioral Analysis, and targeting individually identified work readiness skills via video modelling (Grob et al., 2019; Landsiedel et al., 2021; Smith et al., 2021). However, other studies were aimed at VR professionals. For example, Joseph et al. (2017) examined how VR code of ethics for best practice were reflected in the 2014 WIOA legislation, emphasizing how both ethical mandates and available evidence point to a need for early work experience and career exploration tailored to individual interests as opposed to generic objectives. Instead of specific programs, other studies looked at the efficacy of these strategies based upon diagnosis.

Daviso et al. (2016) used quantitative analysis of three independent variables—career and technical training in high school, early work experience, and formal on-site work or training in the community—paired with dependent variables based on five disability categories and found that career training and paid work experience were primarily significant predictors for students with LD or other health impairments (OHI), while formal work opportunities was only a significant predictor for those with multiple disabilities. In a qualitative study exploring work experiences of young adults with ASD, Lee et al. (2019) interviewed six Australian young adults with ASD and six parents and identified heightened priorities for this population to learn employment-related social skills, develop specific job skills, and to identify and capitalize on personalize strengths and interests. Other studies, such as Olson's (2017) observation at a Jewish summer camp that taught job skills to persons with special needs showed how those with the best of intentions can be blind to the principles they espouse, for vocational trainees were ostracized and segregated from other employees by being barred from the employee lounge, talked down to like campers instead of staff, and excluded from inter-staff friendships. So, while vocational transition efforts continue to evolve, there is still progress to be made.

Postsecondary Education

The 1997 reauthorization of IDEA acknowledged the need for broadly defined postsecondary transition planning, and recent laws such as HEOA and WIOA have pushed for greater inclusion and smoother transitions of young adults with disabilities in PSE settings. This push for additional education is based upon growing evidence that PSE leads to greater career outcomes for person with disabilities just as it does with the general population. In a sense, then, PSE transition can be viewed as an intermediary step of vocational transition and yet, like with other forms of transition, persons with IDD are struggling to keep up. Qian et al. (2018) addressed this problem by studying a program developed under the U.S. Department of Education sponsored Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSID) model which defines a positive postsecondary education outcome as achieving work at or above minimum wage upon graduation (elsewhere referred to as *competitive employment*). The authors found the strongest predictor was taking only inclusive classes which increased the likelihood of vocational success by 4.65. The next strongest predictor was working while in college. Volunteering and attending campus events also result in 3.06 and 3.39 times increased likelihood respectively. In another study of TPSID, Domin et al. (2021) found that programs were more successful in leading to future employment when they engaged in outreach and engagement, were highly visible on campus, and cultivated community partnerships. Similarly, the Think College Transition program has proven effective in bridging the gap between high schools and colleges for students with IDD while ensuring their success at this next level through collaborative partnerships on both ends (Horn et al., 2022). And in a quasi-experimental study examining Think College Transition, Schillaci et al. (2021) demonstrated that supportive collaboration and communication between high schools and colleges significantly increased students' feelings of self-determination—an important factor for PSE success, obtaining employment, and achieving independent living. In turn, other studies have focused more on the general effects of PSE beyond specific program support.

Sannicandro et al. (2018) performed a quantitative analysis of Rehabilitation Services Administration data over a five-year period to demonstrate that persons with ID who attended PSE earned more on a weekly basis and were significantly less likely to require Supplement Security Income (SSI) benefits. Yet alarmingly Rast et al. (2020) analyzed VR agency data and found that students with ID and ASD received the least PSE training despite increased emphasis by the WIOA and persistent evidence of requiring more, not less, intervention. And even when necessary support is received, successful completion of PSE is not a panacea. Stewart and Schwartz (2018) found that students with physical disabilities who successfully completed PSE were still 10% less likely to obtain competitive employment than able bodied peers while in a study of PSE graduates with ID in Kentucky, Sheppard-Jones et al. (2018) found that while all respondents to their survey desired employment, only 37% were actually working (although 67% volunteer in the community), echoing the low rates reported in NLTS2 data. And these studies only consider those who are able to overcome obstacles to complete PSE.

As noted earlier, the move from IDEA to ADA results in the burden falling on the individual to self-disclose and request accommodations; thus, a large part of the literature on PSE transition focuses on when, how, and why (or why not) students request accommodations. Newman et al. (2016) examined NLTS2 data and found that both having a transition plan in high school and addressing the need for postsecondary accommodations early correlated strongly with students requesting and receiving access to accommodations upon transition. Shogren et al. (2018) found that during their first year of PSE 70% of students with IDD were included in regular education classes prior to transition, yet few received accommodations on the PSE level indicating a possible lack to knowledge or ability to access. On the positive side, this study found a strong correlation with engagement in social activities on campus and improved autonomy and self-determination, strengthening the evidence for early inclusion at elementary and secondary level. However, in addition to such quantitative data, disclosure of disability and accommodations requests is one research area where the voices of young adults with disabilities are frequently included.

In a familiar refrain, multiple studies from student, parent, and/or administrator perspectives indicate that students with disabilities struggle to both access accommodations and integrate into campus life (Bell & Zamani-Gallaher, 2017; Berg et al., 2017; Dymond et al., 2017; Hendrickson et al., 2017; Kramer & Davies, 2016). A narrative inquiry by Christian (2020) emphasized that disclosing a disability and requesting accommodations is a personal decision that must be understood as an ongoing and evolving process rather than a discreet act. This becomes apparent in several studies that discovered faculty and institutional attitudes can either encourage or discourage this decision. Bell and Zamani-Gallaher (2017) found that although students reported that all institutions needed to improve, they experienced greater ease of access to accommodations at two-year as opposed to four-year institutions, the latter tending to have larger, impersonal bureaucracies. Focusing on students with ID, Berg et al. (2017) also found that institution and faculty attitudes toward acceptance impacted disclosure decisions, although with this population access barriers were compounded by their poor understanding of the differences between the entitlement under IDEA and eligibility under ADA and 504. Kramer & Davies (2016) found similar struggles with understanding this distinction and possessing the self-determination to overcome this hurdle in students with traumatic brain injury. Other studies have examined the less clearly defined aspects of college life.

Authors such as Berg et al. (2017) and White et al. (2017) studied how students with IDD conditions such as ID and ASD struggle to navigate the abstract complex systems, expansive social networks, and unspoken expectations that are required to succeed in college, arguing that transition planning should address how to navigate these informal and undocumented but ubiquitous systems they dub the *hidden curriculum*. In interviews with students with ASD, their parents, and campus support personnel, Dymond et al. (2017) also addressed the need for heightened communication skills development to enable these students to cultivate both social and academic supports in their new, less inclusive environments. Interestingly, however, a survey by Hendrickson et al. (2017) found that parents of college students with ASD rated their social success higher than the students themselves, leaving two plausible explanations: parents have a broader view of how far these young adults have come or parents engage in wishful thinking and thus fail recognize how daunting the barriers remain for their children; the truth likely falls in between. Regardless of where the answer lies, such concerns demonstrate an understanding of postsecondary transition success involving broader social integration beyond mere academic and/or vocational success.

A Life Made Whole: Reconceptualizing Postsecondary Transition

Attending college, finding work, and taking control of one’s healthcare are all major milestones of adulthood, but no one grows up hoping they can see the doctor, go to work, and call it a life. So, although these topics have dominated the literature, there is a growing chorus of voices arguing that postsecondary transition should focus on broader concerns of community integration—creating engaged citizens as opposed to mere cogs in the economic machine. Admittedly, this study began with such a narrow vocational focus but was influenced by authors such as Liasidou and Symeou (2018) and Black and Lawson (2017) who offered impassioned arguments for expanding our understanding of educational outcomes for people with disabilities. In a searing critique of broadly embraced international educational reforms pursued by the World Bank, Liasidou and Symeou warned that “[n]eoliberal conceptualizations of inclusion concentrate on a meritocratic perspective and the ability of the individual to develop and thrive within a competitive educational marketplace" (p. 160). This marketplace approach, they concluded, reduces education to an investment and thus the educated to mere units of potential corporate profitability and competitiveness, leaving little room for less productive bodies thereby undermining broader calls for inclusion and human rights. Similarly, in framing their analysis of a transition program for students with severe LD, Black and Lawson (2017) established a broader definition of educational outcomes by rejecting the narrow focus on productivity promoted by neoliberalism. Conceding that despite the uplifting nature of work not all persons with disabilities will attain competitive employment, Black and Lawson reject arguments that less productive individuals are social burdens, arguing that instead we should cultivate and embrace their social contributions. Thus, building on the work of previous authors who sought to broaden educational aims, Black and Lawson arrived at three different aims of inclusive education: learning how to become a self-aware and self-directed individual, developing qualifications for work and/or volunteering, and socialization towards active and engaged citizenship. Similarly, in his seminal work of the DRM and disability culture, *Nothing About Us Without Us,* which heavily dwells upon the importance of employment in economic and social empowerment, Charlton (2000) too fiercely rejects what he perceives to be neoliberal hegemony, which he argued not only creates disability through exclusion but exploits disability by keeping certain populations dependent so that economies of scale can be built around serving and controlling them. Instead, he argues that self-actualization and not economic utility is the escape from oppression, reflecting early elements of what would become CDT. Subsequently, many authors working within

CDS and CDT explicitly called out neoliberal objectification of the human body as a productive unit, aligning with more inclusive conceptualizations of social belonging (Fritsch, 2016; Goodley et al., 2018).

The effects of these broader community integration arguments are increasingly represented in research, starting with NLTS2. Yet defining community integration and/or participation remains a challenge. In their comprehensive literature review of articles examining participation following postsecondary transition for young adults with IDD, Amado et al. (2013) found the terms *integration, inclusion, community participation,* and *community belonging* were used interchangeably but never clearly defined. In examining the ID transition literature, Dean et al. (2016) found that of 88 articles published between 2001-2015 addressing participation of adults with ID, only 7%—or six articles—explicitly defined participation. Of these, half used the WHO International Classification of Function (IFC).

The IFC "provides a standard language and framework for the description of health and health-related states," while placing the emphasis on "health and functioning, rather than disability," (WHO, 2002, p.2). *Participation* is defined as "involvement in a life situation" in one or more of nine categories: (a) earning and applying knowledge, (b) general tasks and demands, (c) communication, (d) mobility, (e) self-care, (f) domestic life, (g) interpersonal interactions and relationships, (h) major life areas, and (i) community, social and civic life (WHO, 2002, p.2). This function-based understanding of disability arises from the WHO's *biopsychosocial model* with its emphasis on the intersection of personal, social, and contextual factors (WHO, 2002). IFC was at the forefront of promoting community integration of person with disability, calling for “equity, inclusion, and the aim of all to achieve a life where each person can exploit his or her opportunities to the fullest possible degree” (WHO, 2002, p. 5). This inclusive language can be seen reflected in the United Nations’ (2006) Convention on the Rights of Persons with Disabilities which, in turn, has become an international touchstone of the DRM. Thus, IFC remains the most common reference point for defining participation and community integration for the disability community.

Perhaps the clearest distillation from IFC language comes from Rosenbaum and Gorter (2012) who sought to promote better conceptualization of quality of life for children and adolescents with disabilities by distilling IFC language into *six F words*: *function*, *family*, *fitness*, *fun*, *friends*, and *future*. Multiple authors have used this framework to expand our understanding of quality of life and community participation for persons with IDD diagnoses (Acharya et al., 2017; Davis et al., 2017; Fehlings, 2014; Murphy, 2016), while others have used the F words to guide healthcare practice such as in occupational and physical therapy services for children with disabilities or those struggling with obesity (Leite et al., 2021; Ross et al., 2016). In fact, according to Soper et al. (2019), since its 2012 publication *the six F words* has vastly increased the application of IFC language, referenced in at least 157 studies seeking to examine disability more holistically and effectively, measure quality of life for those with disabilities, develop more inclusive rehabilitation interventions, or conceptualize research projects. Other studies have employed qualitative research methods to better define and measure participation.

Taylor-Roberts et al. (2019) found that while there are currently 11 standardized assessments of community integration on the individual intervention level for use by healthcare and VR professionals, all lacked psychometric rigor, and none have been consistently applied. Other studies have examined community integration through the lens of Quality of life (QOL). For example, White et al. (2018) found a strong positive correlation between self-determination and QOL. In a more expanded view, Sheppard-Jones et al. (2018), defining QOL through successful employment, self-determination, social relationships, health & wellness, and community participation/inclusion, conducted a survey of 19 young adults with ID who had attended PSE and found all reported being underemployed and depended on volunteer experiences for productive engagement, though 80% reported being able to make their own schedules and all reported being active in their communities—though how was not defined. Alarmingly, most subjects reported struggling significantly with loneliness, another common concern to emerge throughout the literature. Amado et al. (2013) found that throughout community integration literature for adults with IDD loneliness and developing friendships was one of four common topics addressed along with measuring participation/integration, factors affecting degree of inclusion, and efficacy of intervention methods. They further found that integration tended to be measure in one of three ways: frequency, choice, and intensity. Lee and Morningstar's (2019) extensive study of NLTS2 data as discussed above showed that less than ¼ of persons with IDD related labels like MR, ASD, multiple disabilities, and deaf-blindness reported routine participation in their communities. But this is where the gap in the literature occludes our view, for we do not truly know how these ordinal measures are conceptualized and experienced by respondents because little data exists describing community integration outcomes in their own words.

The closest study to achieving a broader view of community integration from the point of view of young adults with special needs was performed by Hall (2017), who sought to “describe the community involvement of young adults with intellectual disabilities” (p. 861). The author focused on work, recreation, and leisure—though she did not make a clear distinction between the latter two—finding that the majority of her subjects were employed but none were full-time and all lacked work-related friendships which was particularly problematic since they frequently stated that being extended respect by typically developing peers and co-workers positively impacted their self-esteem. Compounding this lack of acceptance, outside of work participants predominately participated in segregated recreation and social groups based on disability. Desire for leadership opportunities was a common theme while lack of adequate transportation a common barrier (Hall, 2017). Similar themes of isolation emerged from a comprehensive review of qualitative studies focusing on community integration and QOL in which Jacobs et al. (2018) found that throughout the four predominant English-speaking societies (United States, United Kingdom, Australia, and Canada) parents of children with severe IDD consistently reported their children experienced exclusion from their communities and struggled forming adult identities. These studies confirmed that communication issues during transition and the policy/support cliff are cross-cultural issues. And Jacobs et al. (2020) employed a case study of three young adults in Scotland with severe ID to focus primarily on the transition to adult services, finding similar lack of involvement, lack of resources, and difficulty navigating complex systems after losing the support of school systems. Although different than the U.S. policy cliff, Jacobs et al. (2020) are relevant in arguing for embracing and understanding of interdependence rather than independence to promote maximum possible integration outside an alienating dichotomy of self-sufficiency which no human truly achieves—thus the very reason for humans coexisting in societies. However, the scope of these studies is limited compared to the expansive data that can be provided by narrative inquiry.

Amado et al.'s (2013) comprehensive literature review argued that there is an urgent need for outcomes to be described and understood in the voice of those with IDD, yet six years later Lee and Morningstar (2019) noted how this gap in the literature persists, arguing that the most significant future implication of their work is "the importance of extending current research to provide a deeper and more descriptive understanding of community participation among young adults with severe disabilities" (p. 196). It is clearly time to begin including the perspectives of persons with IDD in discussions about them.

"Nothing About Us Without Us": From Data to Discourse

Charlton (2000) published his seminal work *Nothing About Us Without Us* shortly before the WHO revealed the IFC with its similar melding of social, contextual, and physical factors, and this work has become a fundamental text of the disability culture model. Charlton borrowed the title from a commonly used refrain in civil rights demonstrations in Third World countries, and its influence is increasingly seen throughout the literature. Many authors who self-identify as disabled are not only conducting research but disclosing their disability in the process (Abes & Wallace, 2018; Andrews et al., 2019; Forber-Pratt, 2019; Hughes, 2007; Ingham, 2018; Linton, 1998; Sandahl, 2018). On top of this, there are rising calls for the voices of persons with disabilities to be included in studies, particularly persons with IDD who have been grossly underrepresented due to paternalism, condescension, and overprotectiveness that inadvertently reinforce hegemony (Bjornsdottir et al., 2014; Clandinin & Raymond, 2006; Flynn, 2019; McDonald et al., 2016; Nind, 2008; Sigstad & Garrels, 2017; Smith-Chandler & Swart, 2014; Sunderland et al., 2015; Woodfield et al., 2020). For example, Jacobs et al.'s (2018) literature review of postsecondary transition to adult services for persons with severe and profound IDD and found only 14 articles published in scholarly journals. Of these, most did not include the perspectives of the subjects with IDD and—more alarmingly—did not feel the need to provide any explanation as why their voices were excluded.

While I do not identify as disabled, there is also a growing body of research advocating the use of narrative methods in order to co-author research with the subjects and thus even the power dynamic (Abes & Wallace, 2018; Woodfield et al., 2020). And as stated above, one does not need to identify as disabled—but rather understand the responsibility of their actions—in order to employ CDT. In fact, such collaboration is vital if our understanding of disability and how it is shaped by policy decisions and cultural norms is to move towards positive social change through greater inclusion that bestows dignity and social capital. Charlton (2000) states that the idea of *nothing about* *us without us* “forces political-economic, and cultural systems to incorporate people with disabilities into the decision-making process and to recognize that the experiential knowledge of these people is pivotal in make decision that affect their lives” (p. 17). So, despite the vast body of postsecondary transition literature discussed in this review, the voices of persons with IDD have largely been excluded and little is truly understood about how they conceptualize community integration in terms of the three common measures: frequency, choice, and intensity. This study aims to address this critical gap.

How to Include ‘Us’: Considerations for Collaborators with IDD

As discussed fully in Chapter 3, this study was designed using narrative inquiry because disability researchers overwhelming recommend it is as particularly suited to disability research due to its relational method that embraces the various ways in which human communicate (Bjornsdottir et al., 2014; Clandinin & Raymond, 2006; Flynn, 2019; Nind, 2008; Sigstad & Garrels, 2017; Smith-Chandler & Swart, 2014). By rejecting ableist assumptions that competency is established through fluid speech, eloquent prose, and other dominant communication styles, the researcher can embrace adjunct communication methods that suit the participants rather than the researcher or audience (Nind, 2008; St. Pierre, 2015). For example, St. Pierre’s (2015) concept of *cripping communication* requires embracing noise, dissonance, silences, and the alternative styles of non-traditional communicators. This expansive approach to story construction not only allows space and freedom for non-traditional speakers but allows for other expressive forms such as photographs, drawing, poems, etc. to contribute to the narrative (Nind, 2008; Sigstad & Garrels, 2017). Therefore, this study’s methodology allowed such space and freedom while incorporating photographs, drawings, clipped images, and pictures found via internet search as both memory prompts and expressive contributions to the narrative. And to empower participants to tap into stock stories and shared mythology as identified by MacIntyre (2008), this study built upon the tradition of employing the superhero archetype to empower self-expression.

Lawrence (2006) traced the purposeful use of superheroes by professionals to the 1940s when child psychiatrist Dr. Lauretta Bender observed how hospitalized children were empowered by making Superman capes during OT. While initially controversial, utilizing superhero mythology has become widely accepted and applied. For example, Porter (2006) used superheroes to help children uncover their *secret identities* when "experience[ing] feelings of inadequacy or abandonment or…ridicule because of their secret thoughts, desires, and anxieties," because such feelings are often "based in overt rejection…because of differences in appearances and abilities" (p. 24). It is anticipated that this approach will resonate with young adults with IDD who have likely experienced similar ridicule and/or rejection. By providing an alternate reality where those who are different take control of their own destinies, superheroes appeal to those "overwhelmed with feelings of helplessness and negative judgement by other" (Porter, 2006, p. 24). Moreover, narrative psychology has shown that when people form positive narrative arcs, they report improved self-efficacy.

Narrative psychology sprang from similar epistemological roots as narrative inquiry and has amassed a vast body of evidence demonstrating that not only do people make meaning of their lives through stock story structures (e.g. *rags to riches* or *Icarus's* *flight and fall*), but that people who tend to adopt positive story arcs exhibit greater resiliency and success (Hoshmand, 2000; McAdams & McLean, 2013; Murray, 2003). Thus, narrative psychology uses stories not only as a tool for expression but of cognitive reframing that encourages greater psychological resilience. According to McAdams and McLean (2013), “A strong line of research shows that when narrators derive redemptive meanings from suffering and adversity in their lives, they tend to enjoy correspondingly higher levels of psychological well-being” (p. 236). So, by presenting a familiar and empowering story arc through the comic book format, collaborators instantly recognized the storytelling approach and benefited from participation through positive identity development as expressed during final member check and throughout the process.

This expectation of instant recognition was grounded in the enduring popularity of the superhero myth, reflecting the prevalence of Joseph Campbell’s (2008) concept of the hero’s journey. According to Rubin (2006), the enduring appeal of superheroes to children and adults alike centers on the paradox of the admiration and othering as social outliers they encounter after undergoing a process of radical transformation (i.e., transition). After this transformation, superheroes don a costume to flamboyantly celebrate their difference yet adopt secret identities to obscure it. Further, the superhero remains relatable due to a glaring fatal flaw, raising relevant themes such as exclusion, empowerment, adversity, and persistence (Rubin, 2006). Broaching such themes while having collaborators adopt their own secret identities helped to render such abstract concepts more concrete. Together, concepts such as cripping communication*,* stock superhero stories, and identity development through narrative psychology heavily influenced instrument development while simultaneously addressing potential ethical concerns. Yet Sztobryn-Giercuszkiewicz (2018) warned that along with victimhood, the other prevalent disability stereotype is the disabled person as histrionically heroic; thus, ethics and positionality are carefully considered throughout Chapter 3 in order to ensure that this study respected the spirt of Charlton's (2000) declaration and ultimately promotes positive social change over reinforcing exclusion and hegemony.

Summary

In this chapter I reviewed the literature surrounding postsecondary transition for young adults with disability with a focus on those identified with IDD, beginning by establishing a conceptual framework to guide my review and research design based on critical disability theory and the narrative policy framework. I then reviewed policy guiding the postsecondary transition process. Children from birth through age 21 who are identified in any of 12 disability categories are covered by IDEA which not only mandates coverage and inclusion in education and early intervention but requires local and state agencies to actively identify children with special needs. Upon graduation or reaching age 22, however, these young adults are primarily covered by ADA and Section 504 of the Rehabilitation Act. These laws require self-disclosure and self-advocacy, shifting the impetus on the individual to object to and prove discrimination. Whereas IDEA is fully funded by federal, state, and local governments, these other civil rights mandates go largely unfunded. The resulting shift creates a policy cliff that consistently causes stress and anxiety for transitioning adolescents and their families.

The 1997 reauthorization of IDEA led the way in recognizing the need for targeted postsecondary transition services for adolescents with special needs. Over the two and a half decades since, a large body of evidence has sounded the alarm that more needs to be done. While evidence exists that early job exposure, better communication between professionals, respecting the choices and needs of the transitioning youth, and encouraging PSE with proper supports help improve outcomes no comprehensive program or policy exists to adequately solve this social problem.

Traditionally postsecondary transition literature has focused on three areas of concern for young adulthood: health management, employment, and postsecondary education. However, authors such as Black and Lawson (2017), Charlton (2000), Lee and Morningstar (2019), and Liasidou and Symeou (2018) have made impassioned arguments for embracing a broader community integration based definition of postsecondary education outcomes. Such calls for inclusive justice are not only echoed in U.S. policy but the WHO's IFC framework and the United Nations' (2006) declaration on the rights of persons with disabilities. Disabilities rights pioneer Charlton (2000) summed up the need for inclusion in research policies and initiatives with the slogan *nothing about us without us* while authors from Amado et al. (2013) to Lee and Morningstar (2019) have documented the need for greater inclusion of descriptive data of postsecondary outcomes by young adults with moderate to severe disabilities such as IDD. Therefore, Chapter 3 will discuss the design of this qualitative narrative inquiry aimed at addressing this gap in the literature, discussing the research design and rationale, methodology, trustworthiness, and the role and positionality of the researcher.

Chapter 3: Research Method

The purpose of this qualitative study was to provide narrative data on postsecondary transition outcomes of young adults with IDD in order to inform policy and research agendas. Participants with IDD were drawn from the North Florida region having completed the postsecondary transition process within the past decade. In Chapter 3, I discuss the research design and rationale, the role of the researcher, the methodology and how it was executed, issues of trustworthiness, and ethical considerations to protect populations with IDD.

Research Design and Rationale

The literature review presented in Chapter 2 established that while there is abundant evidence that young adults with IDD struggle to achieve commensurate levels of community participation as those with less severe or no disabilities, little descriptive data exists exploring how—in their own words—this population conceptualizes community integration in the years following postsecondary transition. Therefore, this study sought to address this gap in the literature by giving voice to those with IDD who have undergone this transition in the past decade and are currently finding their place in their communities as young adults. To collect such rich descriptive data this study was guided by the following research questions:

RQ1: How do persons with IDD conceptualize their postsecondary transition journey and its impact on community integration through narratives?

RQ2: What do these narratives of the postsecondary transition journey reveal about the current quality of life and sense of well-being of persons with IDD in relation to community integration?

RQ3: What do successes and barriers in these stories reveal about policies guiding postsecondary transition?

To answer these questions, this qualitative study implemented a narrative inquiry. A qualitative study was warranted due to a gap in the literature indicating there is a lack of descriptive data exploring postsecondary transition outcomes for persons with IDD. Despite a multitude of quantitative studies that have established the presence of lagging outcomes, a need to explore the lived experiences of subjects led to the selection of qualitative over quantitative methods.

Other qualitative methods considered included case study and phenomenology. Like narrative inquiry, case studies involve subject interviews to create a story (Ravitch & Carl, 2016). Starman (2013) noted that a case study typically incorporates multiple data sources to verify the truth of a story, whereas my intent was to explore how subjects conceptualize their experiences rather than establish the veracity their claims. Moreover, a case study is conducted in a more structured and less relational manner than narrative inquiry and so I determined it was not ideal for this population which may require greater freedom to communicate and express themselves in individualized styles (see Clandinin & Raymond, 2006; Nind, 2008; Patton, 2015; St. Pierre, 2015). Employing a collaborative methodology was critical to this study because the top-down data analysis approach employed by a case study could have created power dynamics particularly problematic for vulnerable populations (see Patton, 2015, Ravitch & Carl, 2016).

Phenomenology was also considered for its focus on lived experiences and shared meaning as constructed by subjects (Patton, 2015, Ravitch & Carl, 2016). While such insights could have been critical to this study, phenomenology reduces stories to basic lessons or universal truths (Patton, 2015). While my data analysis sought themes and insights into larger social structures, ultimately the broad and collaborative approach of narrative inquiry was chosen to facilitate open-ended data collection in exploring an expansive topic like community integration. Yet, there are natural overlaps in the constructivist epistemologies of phenomenology and narrative inquiry, leading Kim (2016) to conclude that narrative inquiry is heavily indebted to phenomenology; therefore, there are phenomenological elements in how this study analyzed postsecondary transition.

Narrative inquiry was ultimately selected since it asserts that people make meaning of their complicated and ever-evolving lives through story structures that frame random experiences with a clear beginning, middle, and end (Bell, 2002; Clandinin, 2016; Patton, 2015). To gather such stories, narrative inquirers engage in a relational interaction where not only the researcher affects the subject's story, but the subject also impacts the researcher's life as their narratives intersect (Clandinin, 2016). Thus, narrative inquiry can only be understood through the researcher's place in relation to collaborators. Due to this relational epistemology, a growing body of research has advocated for employing narrative inquiry to empower persons with disabilities to take a more active role in research by enabling diverse communication styles. In response to a growing body of research proving that persons with IDD yearn to be heard, Clandinin and Raymond (2006) asserted:

> To give voice to individuals labeled developmentally disabled, research must be grounded in individual experiences. [And so] the intent of narrative inquiry…is to not silence individuals with developmental disabilities but to create an opportunity to reclaim and re-name their experiences. (p. 103)

Nind (2008) similarly argued that narrative inquiry enables "participants to emerge as people not cases, to reclaim their lives as their own, and to provide counter-narratives" (p. 14). And McDonald et al. (2016) argued that such inclusion benefits not only society but the subjects themselves by making them feel valued and thereby bolstering their self-esteem. Yet multiple studies have shown that researchers and IRB panels have consistently underestimated both persons with IDD's understanding of the social benefits of research and their desire to engage in such research to help those like them (McDonald et al., 2016; Sigstad & Garrels, 2017; Sunderland et al., 2015). In fact, Lessard et al. (2018) argued that the very act of labeling a population as *vulnerable* can infantilize and marginalize, while Smith-Chandler and Swart (2014) countered that the most powerful method for persons with IDD to counter oppressive stereotypes is through empowering their contributions. Thus, a chorus of disability researchers argue that exclusion presents a larger ethical concern than inclusion, and narrative inquiry is the most often recommended inclusive method (Bjornsdottir et al., 2014; Clandinin & Raymond, 2006; Flynn, 2019; Nind, 2008; Sigstad & Garrels, 2017; Smith-Chandler & Swart, 2014). The reason narrative inquiry is so highly recommended lies within its methods and assumptions.

Narrative inquiry is founded upon an epistemology that asserts “human beings make sense of random experience by the imposition of story structures” (Bell, 2002, p. 207). This epistemology traces its roots to MacIntyre’s seminal philosophical treatise *After Virtue* published in 1981 which synthesized ontological traditions built upon language construction and cultural cognition to argue social histories are maintained through stories dating back to early mythology (Clandinin, 2018; MacIntyre, 2007). The building blocks of such personal and cultural awareness are universally available *stock stories*—unconsciously understood and applied plots—to organize random events into a form that can explain both the individual’s life and the society in which it exists. As Lai (2010) stated succinctly: “human life is interpreted in stories” (p. 75). Because this study seeks to collect stories that explain how participants interpret their postsecondary transition journeys and resultant community integration, such constructivist epistemology best suits the study’s purpose. However, while narrative inquiry examines social context, it is also asserts that temporal and physical context are of equal importance (Clandinin & Connelly, 2000).

Clandinin and Connelly (2000) were amongst the first scholars to define narrative inquiry, highlighting the importance of time, place, and social circumstances on how humans understand their lives per MacIntyre's (2007) rejection of western notions of individualism in favor of collective reality. Therefore, these ceaseless forces continually reshape our stories like waves battering a sandy coastline. The narrative inquirer, then, recognizes that stories are not static artifacts replicated in the retelling but evolving constructs that change as we do (Clandinin, 2016; Clandinin & Huber, 2010; O' Toole, 2018). By embracing this truth, O'Grady et al. (2018) argued, "Narrative Inquiry, in challenging inherited dominant understandings of subjectivity and research methodologies as well as proposing emancipatory alternatives has the potential to give voice to often silenced knowledge" (p. 156). Thus, narrative inquiry eschews positivistic concerns for relating facts in a reproduceable manner and instead recognizes that creating and sharing stories illuminates how subjects experience and interpret their world (Clandinin, 2016; Leitch, 2018). This can be particularly freeing for those with cognitive impairments who will not be tested on the veracity of their memories, but rather will be enabled and empowered to share their perceived realities free of the judgmental constraints of hegemony, for challenging the veracity of one's stories means questioning their fundamental identity: "A person's lived and told stories are who they are and who they are becoming and that these stories sustain them" (Clandinin & Huber, 2010, p. 340). Our stories aren't about us—they are us. This does not mean data obtain through narrative inquiry is not dependable or transferable (as will be discussed in detail below). Because we make meaning of our lives through stories, analyzing their commonalities and departures can help us understand not only the subject but the time, place, and society that shaped them (Bell, 2002; Clandinin, 2016; Clandinin & Connelly, 2000; Clandinin & Huber, 2010; Kim, 2016). In other words, two individuals may not agree on the details of a mutually witnessed event, but the differing accounts reveal how each persons experienced that moment in that location in that society.

Because of this focus on the lived experience, Bell (2002) argued that narrative inquirers move beyond traditional outcomes-focused research to view the journey as important as the destination. In this study, then, the transition journey was viewed as intertwined with the resultant community integration. Through this approach, I built upon an emerging tradition of narrative inquiry in disability research by authors such as Abes and Wallace (2018) who examined how college students with physical disabilities were compelled to downplay their disabilities after experiencing *erasure*, Woodfield et al. (2020) who examined alternative communication forms, Tellis-James (2016) who explored how transition-age youth with disabilities viewed their futures, and Park et al. (2016) who used narrative inquiry to give voice to young women with learning disabilities in the criminal justice system. Regardless of topics, however, all narrative inquiries share a common is a focus on positionality and an awareness of the researcher to their effect on collaborators.

Role of the Researcher

As qualitative research methods matured, adherents realized they must examine their own role in the process in order to reduce power disparities between subject and researcher to limit the impact of bias on data collection and interpretation (Patton, 2015; Ravitch & Carl, 2016). This self-awareness—termed *positionality* in contemporary literature—is built into narrative inquiry so that adherents view themselves as co-researchers alongside collaborators (Clandinin, 2016; Clandinin & Connelly, 2000; Clandinin & Huber, 2010; Clandinin & Raymond, 2006; O' Grady et al., 2018; O' Toole, 2018). O'Grady et al. (2018) argued narrative inquirers "are not merely objective inquirers who study a world we did not help create…we are complicit in the world we study" (p. 156). Therefore, awareness of the researcher's positionality is woven throughout the narrative inquiry process. Such awareness is also critical in CDT which forms the theoretical foundation of this study, for—as stated in Chapter 2—while a researcher does not need to identify as disabled to engage in CDT, they must be aware of their own relationship to disability and acknowledge their responsibility to pursue its ethical mandate of promoting social change (Erevelles, 2014; Minich, 2016; Schalk, 2017). Thus, positionality was a guiding consideration throughout study design.

In examining positionality, I began with my long history working with persons with IDD. As an OT, I have served persons with a range of disabilities for nearly 20 years. OT is a client-centered profession emphasizing holistic health outcomes through collaboration with patients in identifying their goals and concerns, thus leveling the power dynamic of the elevated expert. Therefore, a collaborative approach to research aligns with my personal and professional values. Yet this does not mean that I am free of ableist assumptions or implicit bias. In fact, it was an experience wrestling with my own unexamined biases that led to my career in OT. Therefore, I began my reflection on positionality by revisiting an essay I wrote in 2000 when I abandoned a brief career as an English professor to pursue OT after spending the summer working at Camp Easter Seals. The essay, entitled *sUPERMAN* [sic], examines my naiveté in accepting a job at a residential camp for children and adults with disabilities with no experience, only romantic do-gooder notions. During my first week-long session, two adults with Down syndrome—one who perpetually adopted a Superman persona—exploited my inexperience to the point where I almost quit. Near the end of that week, however, I experienced an epiphany after I suddenly recognized my own childhood superhero fantasies born of deep and painful insecurities in the behavior of these two adults who had likely experienced rejection to an extent I could only imagine. A couple of years later I wrote *sUPERMAN* to process this career-altering revelation; thus, it has long served as the framing device of my current career narrative. Yet in revisiting it 20 years later, persistent biases despite my empathetic realization jump off the page, illustrating both how my understanding of disability as a concept has evolved and how I must continue to monitor for inadvertent condescension and implicit bias.

After returning to graduate school for a second Master's degree in OT I spent the first six years of my career working in public schools where, having learned of the need for improved transition services, I made it a priority to collaborate with high school special education teachers on postsecondary transition. Then in 2017 when I began teaching in a combined Masters/Doctoral program for entry-level OT students and developed the postsecondary transition lectures for the *Clinical Applications of OT in Pediatrics/Adolescence* course. Thus, my career has revolved around working with persons with disabilities including IDD with a particular interest in postsecondary transition.

I also have several close friends whose children have special needs, so this topic has touched me personally as well. I have watched these children grow and we consider each other extended family. But while I have experience moving in the orbit of disability, I also recognize that I identify as an able-bodied, heterosexual, White male. That does not mean that I have not experience alienation or exclusion. The epiphany in *sUPERMAN* rests upon my experiences as a shy, overweight child, and I grew up in rural West Virginia where, upon leaving, I often experienced snickering dismissals involving Appalachian stereotypes of poverty, ignorance, and incest. These experiences have rendered me sympathetic to the exclusion of others, yet I cannot claim the intersection of my identities pose barriers equal to those experienced by persons labeled IDD, many of whom are from racial, ethnic, gender, and sexual orientation groups that compound social exclusion. Therefore, I was careful not to see my professional or personal experiences as inoculating me against bias. In fact, many CDT theorists are critical of medical and charity professionals, going so far to dismiss them as primary agents of oppression (Charlton, 2000; Hughes, 2007; Linton, 1998). Nevertheless, fields such as OT have worked to level power dynamics while still providing needed support, and many contemporary authors acknowledge both the need for rehabilitative sciences and the emergence of more collaborative, empowering models (Ferguson & Nusbaum, 2012; Meekosha & Shuttleworth, 2009). Therefore, I constantly reflected on my motives and methods throughout this process. To maintain awareness of positionality, qualitative methodologists recommend reflexive journaling and careful self-reflection to minimize bias and power inequalities (Denzin & Lincoln, 2013; Patton, 2015; Ravitch & Carl, 2016). Thus, this reflection was only the beginning of my exploration of positionality. Part of my data analysis involved examining how my own journey intersected with those of collaborators, as this is a vital step in the relational epistemology of narrative inquiry (Clandinin, 2016; Clandinin & Huber, 2010). Because of this, data analysis began in a natural, iterative manner during collection before formal coding began. Further, by grounding this study in CDT and narrative inquiry and guiding the research design through concepts such as narrative psychology and cripping communication, ethical and personal considerations were woven throughout so that they remained at the forefront.

Another critical step to maintaining an ethical collaboration as co-researcher was continually reviewing the evolving narrative with subjects to ensure that I was faithfully telling their story, refining the final product through multiple iterations in what Kim (2016) terms *narrative smoothing*. I also sought guidance from committee members and peer experts to check for bias and power imbalances, while exploring these thoughts and observations of my performance through reflexive journaling. Thus, I embraced a role as facilitator and collaborator in crafting the stories of person with IDD rather than positioning myself as detached expert observer.

Another consideration of positionality stems from my dual role as educator and student researcher. I currently teach OT at the University of St. Augustine for Health Sciences (USAHS) which sends students for pre-employment internships at a local agency serving persons with IDD across multiple North Florida counties. USAHS faculty supervise these interns, although this is not one of my job duties. Such collaboration, however, has established trust between our institutions, and I gained insight into clientele and structure by mentoring a doctoral student performing a capstone project on site. Thus I was careful to avoid client contact during my few on-site visits. And though this connection may suggest convenience sampling, research into local resources pointed to this agency as the most natural venue for sampling as no other agency in this region serves this population so broadly. Further, the primary programmatic mission of the site where sampling began was to promote community integration. Therefore, this disclosure served to maintain ethical standards since neither entity stood to gain from this research beyond potential empowerment and self-esteem for agency clients and USAHS's general desire for faculty to advance their educations and produce socially beneficent research.

Methodology

Participant Selection

The population targeted by this study was young adults with an IDD diagnosis who received transition planning through their IEP during their public education and were a decade or less removed from postsecondary transition. Most persons with IDD are expected to maintain IEP services until their 22nd birthday as legally allowed, although some may graduate starting at age 18. Thus, the age range of the population spanned ages 18-32, depending on graduation date. Restricting the population to a decade from transition allowed a significant time period during which a broad array of outcomes emerged—thus meeting the study's purpose of looking beyond immediate transition aftermath—yet not so long a time period as to challenge memory or allow other variables to have greater influence, for it is not possible to isolate postsecondary transition as a sole variable and it is assumed the further one progresses into adulthood the greater the influence of other factors such as life experience, agency services, and other outside factors.

Purposeful sampling (Patton, 2015; Ravitch & Carl, 2016) was conducted in cooperation with two supervisors at The Arc based on this agency's broad mission serving persons with IDD, thus providing a sizeable sample population. Agency supervisors assisted in identifying collaborators based on the following criteria:

1. A diagnosis that falls within the IDD category per Chapter 1 definition
2. Receipt of transition services on their IEP in high school or sooner
3. Transition from secondary education within the past ten years (ages 18-32)
4. Basic speech or augmented communication ability augmented by visual media
5. Postsecondary collaboration with a local VR agency
6. Residence in the North Florida region

Receipt of VR was added as an inclusion criterion in order to target subjects that both desire to engage in their communities and possess baseline abilities to do so, for VR agencies screen for basic skills and communication abilities. Thus, this excluded severe and profound subjects which are beyond the purview of this study. Failure to meet all criteria resulted in exclusion from the study, although exclusion factors were also applied.

Any consenting collaborator that displayed hesitancy or other signs of possible incomprehension or involuntary consent would have been excluded. Participants would also have been excluded who demonstrated clear signs that they were unwilling or unable to relate information to the best of their ability (e.g., obvious exaggeration or confabulation) or if undue influence by family or agency personnel on story construction were detected. If the collaborator were unable to comprehend the narrative structure as provided by the superhero stock story or their communication level proved to be insufficient to capture data, then collaboration was to be discontinued. Fortunately, none of these exclusion scenarios arose during data collection.

Sample Size

Qualitative studies typically employ small sample sizes, though there is no uniform agreement on what is adequate (Patton 2015; Ravitch & Carl, 2016). A study by Guest et al. (2006) found that 12 subjects were sufficient in most instances for data saturation, though after considering other studies that found as few as four subjects could establish validity, ultimately recommending between 6-12 cases. Based on a literature review, Boddy (2016) concluded that a single case study can provide transferable results, noting that large sample sizes are only necessary under positivist epistemologies. Yet Mason's (2010) study of qualitative dissertations revealed a tendency to employ larger samples, n=1-95 with a mean of 31, hypothesizing that perhaps this was result of less confidence and maturity in research ability as well as playing it safe with IRB approval to ensure an adequate sample.

Baker and Edwards (2012) collected advice from multiple qualitative experts on qualitative sampling, although their findings merely illustrated the widespread lack of consensus. Amongst the experts they queried, several argued sample sizes of between 12-60 were necessary, justifying their recommendations through positivist assertions that large samples correlate with increased validity. In contrast, others argued a sample of one can be enough, for a study's sample size depends on purpose and design rather than predetermined benchmarks (Baker & Edwards, 2012). Thus, a small sample size will be used due to the breadth and complexity of study design.

Although most narrative inquiry manuals do not directly address sample size, Kim (2016) noted that the focus on life stories through lengthy relational collaborations necessitates smaller sample sizes. In an extensive literature review, Guetterman (2015) confirmed that narrative inquiries tended to use smaller sample sizes, with results ranging from 1 to 52. Because this study collected robust and thorough narratives while employing adjunctive methods tailored to collaborators with IDD, I sought no less than 3 and no more than 6 subjects to allow adequate space for full integration and analysis of these detailed narratives (Clandinin, 2016). However, I expanded to a seventh subject in order to provide two female voices to improve trustworthiness as discussed in Chapter 4, with all seven collaborators completing the process. This proved sufficient to triangulate themes and relate the narratives back to research questions to a degree that suggested reasonable saturation of data.

Researcher Developed Instrumentation

Of the three predominant interview formats—structured, semi-structured, and conversational/unstructured—narrative inquiries typically fall between the latter two, unfolding in a conversational style with enough structure to spotlight the research problem (Jovchelovitch & Bauer, 2000; Patton, 2015; Turner, 2010). Participants in this study, however, required more structure to stay on topic so a series of semi-structured interview scripts were developed (see Appendix A) to be used over multiple relational interactions to prompt and direct to stay on topic while still allowing narrative freedom to expand and explore (see Jovchelovitch & Bauer, 2000). Thus, the scripts were not followed verbatim but can be tailored to each collaborators' need. This is indicative of narrative inquiry's relational method which calls for situational fluidity and creative design (Clandinin, 2016; Kim, 2016; Patton, 2015). Such flexibility also allowed me to adapt to varying cognitive and communication levels. Thus, the scripts were developed per recommendations of Nind (2008), Sigstad & Garrels (2017), and St. Pierre (2015) described under *Additional Research Design Considerations* such as using simple language, restating concepts, checking for understanding, allowing increased processing time, and attending to non-verbal cues. The scripts also employed commonly recommended open-ended prompts such as *tell me about, describe,* or *explain why* (Jacobs & Furgeson, 2012; Jovchelovitch & Bauer, 2000; Myers & Neuman, 2007; Patton, 2015; Seidman, 2012; Turner, 2010). To ground the interview in a holistic view of life participation, I used Rosenbaum and Gorter's (2012) six F-words framework with its grounding in universally accepted IFC language to frame the script, and interview questions were then correlated back to research questions to confirm alignment. During this process, I sought feedback from committee members as well as peer experts familiar with this population to ensure content validity and appropriateness of language. My goal was to keep the language on a 5th grade reading level as confirmed through a Microsoft Word language review which reported a 5.1 reading level. The script is also designed to capture the hero’s journey stock plot via comic book format (see Campbell, 2008; MacIntyre, 2007).

While this comic book style narrative is unique to this study, narrative inquiry by its nature encourages practitioners to “play seriously” or engage in “aesthetic play” through approaches such as arts-based narrative inquiry (Kim, 2016, p. 87). The arts are increasingly being used to empower persons with disabilities to express themselves and form positive disability identities (Sandahl, 2018). Similarly, arts-based narrative inquiry uses images to empower participants to form their narratives in whatever medium they choose, although his differs from arts-based research which analyzes images in isolation for their intrinsic meaning rather than as part of the whole (Clandinin & Connelly, 2000; Kim, 2016). In narrative inquiry images are not interpreted separately but "accompany the narratives to convey the meaning of the stories told and retold" (Kim, 2016, p. 138). Thus, each completed comic book was considered a data point expressing a holistic conceptualization of each collaborator's postsecondary journey and resultant community integration.

CDT also embraces alternative communication methods, and so visual media (photographs, drawings, and/or magazine clippings) was used as both prompts and intrinsic pieces of the comic book narrative. As described above, superhero tropes have proven effective in facilitating expression—particularly for those who feel marginalized or excluded—and the comic book format both encouraged collaborative storytelling and provided a roadmap through culturally available stock stories (MacIntyre, 2007). The iterative process of developing these books was reflective of narrative inquiry which unfolds over time in a lived process that involves developing trust and revisiting the subject while working in a relation, collaborative manner (Clandinin, 2016; Clandinin & Huber, 2010; Kim, 2016). This is an important contrast to methodologies that employ single interviews. Yet to reinforce understanding and create an ongoing chain of consent, elements of a single interview script were included such as an introduction to explain and set expectations along with a conclusion to signal the session is ending (Jacob and Furgerson, 2012; Myers & Jacobson, 2007; Patton, 2015). Finally, the comic book format concretely framed the narratives with a clear beginning, middle, and end— growing up with a disability, receiving postsecondary transition services, and integrating into the community as a young adult (see Clandinin, 2016; Clandinin & Connelly, 2000; Clandinin & Huber, 2010; Kim, 2016; Patton, 2015). Completion of the book also established a clear ending point along with a final member check of the completed product.

Procedures for Recruitment, Participation, and Data Collection

Primary recruitment occurred through an undisclosed branch of The Arc where vocational training is provided for persons with IDD, and samples were drawn from two locations and three programs which proved sufficient for sample size and data saturation. Inclusion criteria was shared with supervisors who were familiar with program attendees and then a meeting was held to review potential collaborators. However, I emphasized the necessity of strictly basing recommendations on inclusion criteria to reduce the likelihood of sample bias. This collaborative strategy was preferred by the Director of Day Programs who felt flyers or announcements would have been a distraction and led to excessive non-qualifying inquiries. Ultimately all seven collaborators were consenting adults and thus able to grant their own consent, although contingencies were made to meet with families should legal guardian consent have been required.

Once identified, potential collaborators were approached to gauge interest, with one of the two supervisors making introductions to establish trust but then leaving to respect confidentiality. Benefits and risks were presented in clear, concrete language with particular care paid to ensure there was no coercion or expectation projected. The method was also explained so that they understand the original copy of the final narrative product (i.e., comic book as described below) would remain with them but that copies were retained to be shared. This collaborative model of narrative inquiry demanded greater sustained interaction than a structured interview process to build trust and allow for open-ended interactions that unfold alongside participants (Clandinin, 2016; O' Toole, 2018). Therefore, data collection was designed to be conducted over a minimum of five weekly sessions, with additional sessions added as necessary. Ultimately, no more than six sessions were required. Data collection was conducted in sessions of 1-2 hours per subject depending on attention span and was scheduled around agency training and programming, with collaborators sent a reminder prior to each session to bring photographs or drawings if they wish to share. The initial session was designed to focus on creating rapport and building trust while explaining the idea of a heroic narrative. Subsequent sessions addressed single parts of the narrative while moving non-linearly as topics occurred, using a combination of language and photographs, pictures, and drawings as provided by the subject with researcher guidance. Once a rough narrative was created, subsequent sessions were designed to employ data smoothing and a final member check of the completed book for accuracy and coherency (Kim, 2016; Loh, 2015).

Data Analysis Plan

Many qualitative approaches such as case studies or ethnographies analyze stories, but these methods seek hidden patterns during the multi-cycle coding process by chopping up the narratives with metaphorical scissors and then quilting together a pattern as conceived by the researcher (Patton, 2015; Saldaña, 2016). In narrative inquiry, however, the narrative is examined as a whole or *synthesized* rather than reduced to component parts (Bell, 2002; Clandinin, 2016; Clandinin & Connelly, 2000; Clandinin & Huber, 2010; Lai, 2010; O' Toole, 2018). Clandinin and Connelly (2000) explained: "An inquirer…looks for the patterns, narrative threads, tension, and themes either within or across an individual's experience and in the social setting" (p. 132). Yet in considering each narrative as an individual thread contributing to the holistic theme, the researcher not only stays true to the experiences of the collaborator but is forced to reckon with their own positionality. Much like a physicist acknowledging that the very act of measurement impacts studied particles, the narrative researcher acknowledges that by inserting themselves in the ongoing lives of their subjects they are contributing to and altering both their and their subjects' narratives (Clandinin, 2016; Kim, 2016; O' Grady et al., 2018). Thus, while first cycle excerpt coding was conducted, the emphasis of second cycle coding was on understanding and integrating the narrative as a whole by relating emerging themes to the research questions while considering how my own narrative as a researcher intersected with those of my collaborators.

More specifically, the postsecondary transition journey of each subject was examined in relation to place, time, and social context with an emphasis on community integration in the decade after transition. I then analyzed how these emerging themes related to public policy using a multiple coding and analysis approaches. Kim (2016) stated that due to the open-ended and iterative nature of narrative inquiry a researcher should flirt with the data through multiple approaches. So, while coding evolved in relation to discussion and feedback from expert methodologists, analysis was grounded in Polkinghorne's Analysis of Narratives as modified by Kim as well as Polkinghorne's Narrative Analysis (Kim, 2016). The former approach "attempts to fit individual details into a larger pattern" by seeking to identify "common themes or conceptual manifestations discovered in the data" while the latter approach emphasizes considering the narrative as a whole (Kim, 2016, p. 196). Polkinghorne's methods are grounded in an epistemology asserting that humans create order from experiences through self-identifying themes and common characteristics, yet Kim expanded this thematic analysis to acknowledge that interpretation is also influence and guided by the purpose of the study—in this case understanding postsecondary transition outcomes. Due to the study's constructivist epistemology, discrepant cases were not a concern. The very nature of individual journeys and subjective experience suggests that there may be disagreement regarding perceptions of barriers, successes, problems, and solutions. However, both CDT and narrative inquiry seek knowledge in the paradox rather than to explain it away.

To aid in consistency and ease of code application, Dedoose qualitative data analysis software was used. And since successive coding is the most common way to transition raw data into categories and themes, the entire narratives were coded in multiple passes (Patton, 2015; Ravitch & Carl, 2016). This was performed through two rounds of first cycle coding, provisional coding and open coding using concept codes, and two rounds of second cycle coding—narrative coding and pattern. Provisional coding allowed the researcher to relate data back to the existing literature concept coding allowed the researcher to look for emerging meaning in the words of the subjects and focus on their experiences as constructed in their words. Second cycle coding sought to cluster these concepts into patterns and themes (Kim, 2016; Saldaña, 2016). Due to the relation and iterative nature, however, themes and patterns began to emerge during the data smoothing process and through reflexive journaling. Therefore, extra care was taken to assure trustworthiness of results so that this iterative process did not unduly influence collaborator contributions.

Issues of Trustworthiness

Despite thoroughness of design and methodology, a researcher must assure readers of the study's inherent while ensuring that the results can be trusted. For quantitative research, validity demonstrates a study's quality and veracity in collecting and measuring targeted data while reliability demonstrates replicability of results (Patton, 2015; Ravitch & Carl, 2016). Yet, due to differing epistemological roots, these concepts are collectively labeled trustworthiness in qualitative literature and considered in the categories of creditability, transferability, dependability, and confirmability (Ravitch & Carl, 2016; Rudestam & Newton, 2015). From this study's constructivist perspective, rather than asking if this data represented easily replicable universal truths, I considered whether it captured useful information regarding ongoing postsecondary transition conversations in a manner that accurately and justly represented the experiences of collaborators.

Credibility

Credibility is similar to internal validity in considering whether the complexity of a problem has been considered and conceptually integrated (Ravtich & Carl, 2106). By grounding narrative inquiry in CDT this study exhibits strong alignment to both method and theory, as both are emancipatory methodologies promoting the inclusion of marginalized voices per a constructivist epistemology that emphasizes intersectionality and collaborative data collection. Moreover, a strong foundation in disability literature prevented oversimplifying or stereotyping the disability experience. Additionally, Loh's (2015) analysis of recent trustworthiness literature regarding qualitative recommended increasing credibility through prolonged engagement with subjects and persistent observation as performed. As core components of narrative inquiry these methods naturally aligned with my research design (Clandinin, 2016; Clandinin & Connelly, 2000; Kim, 2016). In addition, Loh recommended member checking of results with study collaborators. Such checks were built into the script at the end of each session, and the final session involved a final check of the completed narrative (see Appendix A). Also, due to the superhero stock story used to engage in narrative creation, extra care was taken to explain that while everyone is hero of their own life, stories must be honestly related to the best of collaborators' ability and—as discussed under exclusion criteria—data collection would have been suspended for any subject that displayed signs of purposeful exaggeration and/or fabrication or if undue family or agency personal influence was noted. Lastly, Loh recommended triangulation and peer debriefing. To these ends, I worked closely with the dissertation committee on design and instrumentation and also sought feedback from OT faculty peers who specialize in working with this population as described above to establish content validity and continued to seek feedback during data collection and analysis from seven different methodology experts.

Transferability

Transferability is associated with external validity and asks if a study can be generalized or holds meaning outside its individual context (Ravitch & Carl, 2016; Rudestam & Newton, 2015). Such transferability is achieved in narrative inquiry by its assertation that all narrative exists in physical, temporal, and social context (Bell, 2002; Clandinin, 2016; Clandinin & Connelly, 2000; Clandinin & Huber, 2010; Kim, 2016). Therefore, while each experienced reality is unique to the narrator, these experiences reveal hidden truths about the time, place, and society which shaped them. As stated above, narrative inquiry seeks not veracity in confirmable events, but consistency in thematic revelation. Therefore, to assure transferability collaborators were chosen based on inclusion criteria that broadly align with disability literature relating to postsecondary transition for persons with IDD while allowing freedom for individual conceptualization as narrative inquiry asserts that we understand society through the stories we share. To further support transferability, data analysis began with provisional coding to seek themes and topics present in the literature that transcend individual narratives to address the broader understanding of the transition and community integration process as described in the literature (Rubin & Rubin, 2012; Rudestam & Newton, 2015). Such purposeful sampling guided by current literature helped inform sampling criteria to identify subjects that represent transferable criteria so that their cases hold relevance beyond their own experiences while maintaining the individual integrity of each experienced reality. Loh (2013) also recommended thick description to promote transferability. Thus, by focusing on a smaller number of fully realized narratives while remaining transparent in both method and thought process, thick description was achieved through carefully rendered narratives created in a collaborative manner over time with frequent member checks.

Dependability

Dependability is similar to reliability in asking if data aligns with the research questions and purpose to deliver consistent results (Ravitch & Carl, 2016; Rudestam & Newton, 2015). To ensure dependability, alignment of purpose with theory and methodology was threaded throughout study design and execution. The gap in the literature this study addresses emerged organically from a broad literature review of postsecondary transition issues and then research questions and purpose were drafted to align with the identified need over time with feedback from multiple doctoral level instructors and peers. As the literature review progressed, CDT emerged as the most relevant theory and narrative inquiry as the recommended methodology, with theorists in the former strongly advocating for the latter. By following an organic inquiry process, dependability was strengthened through robust alignment, for no elements were retrofitted—in other words, the literature review revealed the research questions as opposed to having conducted a literature review to justify a preconceived agenda.

Polkinghorne (2007) argued that of all trustworthiness concerns, dependability relies most heavily on epistemology. Thus, a researcher wed solely to positivism may question the dependability of narrative inquiry, yet by explicitly embracing a constructivist epistemology with clear theoretical grounding, the narrative inquirer makes their case that they are portraying a valid worldview from the perspective of the subject's experienced reality. According to Bell (2002): "No matter how fictionalized, all stories rest on and illustrate the story structures a person holds. As such they provide a window into people's beliefs and experiences" (p. 209). Therefore, analysis focuses on what we learn from the narrator in relation to time, place, and society in which their story unfolds. There is truth in the mere telling. But, Polkinghorne argued, the narrative inquirer must clearly justify their interpretation of these transient elements, which was created through veracity in my interpretation of results by multi cycle coding and ongoing triangulation with guidance sought from five different methodology experts during the data analysis phase. Loh (2015), in turn, recommended an outside audit of the process to fortify dependability. This was achieved through oversight by committee and methodology experts and peer feedback as described above. Collaborators were also observed for signs of undue influence by agency personnel and family/guardians as discussed under exclusion criteria to maintain the dependability of collaborator stories.

Confirmability

While qualitative research eschews positivist claims of absolute objectivity, confirmability demonstrates that the findings of qualitative study are presented in a transparent method that reflects rigorous data collection that can be reviewed and verified (Ravitch & Carl, 2106). Loh (2015) recommended reflexive journaling which was used to augment confirmability. Notes were taken throughout the process and will be kept along with all data for five years, including copies of the completed narratives. And while confidentiality was maintained to the best of my ability, subject participation can be traced and confirmed on an as-needed basis by Walden personnel, while a signed research agreement affirms agency awareness of data collection as well as set ethical standards to protect participants as discussed below.

Intercoder Reliability

In addition to the primary categories of trustworthiness, intercoder reliability must also be considered. This concept examines if multiple researchers coding the data independently can achieve comparable results (Patton, 2015; Ravitch & Carl, 2016; Saldaña, 2016), although Ravitch and Carl (2016) noted that, particularly with unstructured interviews, interrater reliability can be a quixotic quest. For studies originating from a constructivist epistemology, exact replicability is not the objective. As stated in the analysis of narrative inquiry, the narratives we use to interpret our lives are forever changing and evolving. So, committee oversight and review from methodology experts guided the coding process in the spirit of interrater reliability, but I alone coded the data. However, committee and methodology specialist feedback was used to improve intracoder reliability, or *consistency* in coding by providing objective input (Ravitch & Carl, 2016). The use of Dedoose software also assisted in keeping coding terminology and definitions consistent throughout first cycle coding per accepted practices (Patton, 2015; Ravitch & Carl, 2016). Additionally, using specific approaches such as provisional and concept coding helped maintain stylistic consistency (Saldaña, 2016). Thus, through frequent checks and expert guidance, reliability in data interpretation was established in the absence of blind coding by multiple researchers.

Ethical Concerns & Procedures

In its infancy, qualitative research was often used to exploit vulnerable populations for the purpose of categorization and control, thus transforming the word research into a pejorative in these cultures (Denzin & Lincoln, 2013; Patton, 2015; Ravitch & Carl, 2016). Therefore, a researcher must always consider the possible effects of any study and minimize harm by considering possible adverse outcomes of participation including maintaining the privacy of subjects to protect them from embarrassment, exploitation, and even possible legal ramifications (Patton, 2015; Ravitch & Carl, 2016; Rubin & Rubin, 2012). Such concerns are heightened when working with persons with IDD who are haunted by a "dark history" of researcher abuse and exploitation (McDonald et al., 2016, p. 440). Therefore, greater care was given to ethical considerations to protect subjects of this study. To begin, I reviewed the research agreement provided by the partnering agency, and IRB approval provided additional oversight of method appropriateness, as is available to review through IRB approval number: 12-23-21-0971035. Once all permissions were obtained, enhanced informed consent procedures were employed throughout the data collection process.

Informed consent is the process of clearly and understandably providing information to a participant prior to data collection to inform them of the intents and possible consequences of research including the purpose, time demands of participation, how data is shared and stored, how results will be shared, any benefits and incentives offered, and potential harm from engagement in the process (Ravitch & Carl, 2016). For vulnerable populations such as those with communication and/or cognitive impairment, this process becomes more complicated (Nind, 2008; Patton, 2015; Sigstad & Garrels, 2017). Therefore, Patton (2015) suggested going beyond the initial legally required signatures with vulnerable populations by frequently seeking verbal consent throughout the project, while Nind (2008) recommended observing facial expressions and other non-verbal cues to collaborate written and verbal consent. Sigstad and Garrels (2018) noted the importance of using simple language (thus the 5th grade reading level), allowing time for processing, and repeating concepts as needed (as built into consent and scripts). And the researcher must explain and interpret the benefits and risks free of coercion, making it clear that there are no consequences for not participating (Nind, 2008; Patton, 2015). Thus, in addition to a detailed initial consent form, consent reviews using simple language and frequent member checks were built into the semi-structured interviews. These scripts will be stored with other research notes (see Appendix A).

Agency oversite served as another layer of consent, for data collection occurred on site where workers familiar with collaborators could observe for signs of reluctance or discomfort. A separate form was created for caregivers of those legally unable to independently consent, although this form proved unneeded. Nind (2008) noted that even for collaborators who can independently consent, agency caregivers can serve to heighten protections. In this case, agency supervisors served as this additional level of protection. Thus, throughout the research process consent parameters were thoroughly explained in simple, non-coercive language, and the triangulation of frequent checks, simplified language, and multiple levels of oversight wove an extensive web of ongoing consent to protect participants.

Failure to maintain confidentiality can also expose subjects to potential exploitation and other adverse outcomes (Patton, 2015; Ravitch & Carl, 2016; Rubin & Rubin, 2012). While no study can guarantee absolute anonymity, greater caution must be taken with this population to reduce risk of identification due to increased risk of adverse effects (e.g., if a collaborator is receiving Medicaid benefits and shares that they hold a side job for cash, this revelation could lead to an audit of benefit eligibility; see Nind, 2008; Patton, 2015; Ravitch & Carl, 2016). Typical methods for maintaining collaborator privacy include using assumed names, removing identifying information from descriptions, and securely storing data (Ravitch & Carl, 2016; Rubin & Rubin, 2012). Physical copies are being stored in a secured file cabinet in the researcher's locked office while digital data are stored in a 2-step verification secure computer. Actual names and identifying data are available only to the primary researcher, with any data shared with the dissertation committee altered for privacy. Thus, only the researcher, collaborators, and agency supervisors know the identities of participants, with the latter having no access to unmasked raw data. In addition, participants chose their own secret identities to promote privacy while engaging in the comic book motif. Photographs were altered to preserve privacy through the superhero theme by drawing masks on faces, with peer experts and committee members confirming that features are not recognizable. Further, per IRB approval no samples of the narratives were shared that possess photographs even when masked. Location identifiers such as signs or recognizable landmarks were also covered or removed. Member checks as well as committee oversite were also used to spot missed identifiers in the data. Such layered oversight also help observe for negative psychological effects (Patton, 2015; Ravitch & Carl, 2016). Signs of distress were only observed once when a collaborator wiped tears from his eyes while recounting painful memories and data collection was stopped immediately. Intervention was available through agency mental health counselors as agreed upon in the research agreement but not needed, and the subject demonstrated no ongoing affects or distress in subsequent sessions.

Despite enhanced the ethical safeguards and institutional review, a larger ethical concern to the larger IDD population emanates from the tendency of writers and researchers to inflict inadvertent harm by focusing on themes of exclusion and discrimination that perpetuate victimization stereotypes (Bjornsdottir et al., 2014). Perpetuating such narratives can disempower subjects by undermining self-determination, for, as this study's epistemology asserts, one's stories "are who they are and who they are becoming" (Clandinin & Huber, 2010, p. 340). Therefore, to coopt one's story is to steal the very essence of their identity. To guard against this the study facilitated positive narrative arcs per narrative psychology and heroic stock stories. Combining this idea of hero's transformation per Rubin (2016) with a story arc that explores self-efficacy per narrative psychology allowed for the emergence of traits such as perseverance and self-determination. Grounding the study in CDT and narrative inquiry further guarded against such usurpation. Yet, this does not mean that data was manipulated or unduly influence. An interview by definition is a directed conversation, and interviews in this study were built upon respect for the dignity and well-being of collaborators, empowering subjects to express self-determination while simultaneously exploring struggles and shortcomings in order to decrease the risk of psychological harm while promoting positive social change.

Additionally, the method of this study left collaborators with a physical manifestation of their story they can share if they so desire. Park et al (2016) noted that the most effective way to level power dynamics is to build relationships and demonstrate reciprocity—both of which will be accomplished by creating a tangible product. Sandahl (2018) argued using art to promote positive disability identity can "provide ways of imagining how we might re-think community integration, not only through the representations artists create, but through the art-making process and art presenting processes themselves" (p. 94). Thus, there is value in the making and the sharing, and collaborators may choose to share their narratives with other to promote positive identity formation although this decision rests solely with the participant.

According Clandinin (2018), narrative inquiries bring a unique perspective to policy debates because they "engage in policy and practice so much different[ly] because of thinking narratively" (Clandinin, 2018, p. 22). Thus, participation in this study also empowered collaborators to engage in social activism and influence policy discussions, fulfilling a widely identified altruistic impulse (McDonald et al., 2016; Sigstad & Garrels, 2017; Smith-Chandler & Swart, 2014), Nevertheless, even the most well-intentioned study risks condescension and exerting unintended power dynamics. Bjornsdottir et al. (2014) shared five examples from their own experiences of falling prey to stereotypes and misrepresentation when working collaboratively with persons with disabilities, thus reaffirming the ongoing self-reflection and awareness of positionality practiced throughout this study. Therefore, ethical concerns were not a final adjunct to design but the overarching context in which this study was designed.

Summary

Pervasive evidence in the postsecondary transition literature demonstrates that upon postsecondary transition persons with IDD continue to achieve significantly lesser levels community integration than the general population. However, missing from this evidence is rich descriptive data in the voice of this population, for often the voices such vulnerable collaborators are excluded out of fear or protectionism, in effect inverting a common civil rights motto to *Everything about us without us.* In Chapter 3, I described a research design used to collect such descriptive data using methods that embrace and enhance alternative communication styles while employing narrative psychology to structure these stories with positive plot arcs to minimize negative stereotypes and promote positive identity development during data collection. Empowering these voices can promote positive social change by empowering collaborators to participate in larger social narratives. To strike a balance between promoting positive story arcs and maintaining reliability of data, this chapter examined the study's design and rationale, methodology including the use of superheroes for narrative development, the role of the researcher in this relational method, issues of trustworthiness, and the heightened ethical concerns of working with persons with IDD. Chapter 4 will discuss the analysis of the mixed media data collected from this study, exploring what it reveals about the postsecondary experiences of collaborators, what their experiences may imply for the peers that navigate this process in the future, and what these experiences reveal about current postsecondary transition policy.

Chapter 4: Results

The purpose of this qualitative narrative inquiry was to explore postsecondary community integration outcomes for young adults with IDD as shaped by public policy. Literature on this topic reveals that this population is significantly struggling with participation in life roles upon losing IDEA services, yet little descriptive data exists exploring such experiences in their own words. Thus, research questions focused on how this population conceptualizes community integration through narratives, what these narratives reveal about their sense of well-being, and what these conceptualizations reveal about current public policy guiding the postsecondary transition process. To begin, two semi-structured interviews were conducted with each participant as adapted to respect various communication ability levels per CDT and narrative inquiry literature. Next, this information was refined through member checks and data smoothing and combined with various forms of visual data to form comic books telling the life story of collaborators through the transition process, ending with current life roles and community participation.

To ensure validity and veracity, member checks were conducted throughout each interaction and informed consent was reaffirmed prior to each session. Upon completion, the narratives were then analyzed through three phases of coding to identify emerging themes relating to the research questions primarily through the lens of Polkinghorne’s narrative analysis and Polkinghorne’s analysis of narratives, as modified by Kim (2016). Chapter 4 describes the setting of data collection, presents the demographics of collaborators, describes the method of data collection including changes from the methodology as originally conceived in Chapter 3, provides evidence of trustworthiness, and finally shares the results of data analysis. For confidentiality, throughout Chapters 4 and 5 all participant-collaborators will be referred to by the pseudonyms that they chose during the interview process.

Setting

All data sampling and collection occurred through a North Florida location of The Arc—a nationwide NPO that is singularly the largest provider of services and advocacy for persons with IDD in adulthood. A purposeful sample was drawn from three different programs housed at two locations to provide a greater breadth of sampling. Sampling was performed in conjunction with two supervisors per The Arc's Memorandum of Understanding and IRB approval to protect participants and ensure they met selection criteria. Arc personnel were highly cooperative and invested in facilitating this research, offering sampling guidance without indications of undue influence. They also made a private room available at each site for collaborator privacy.

During initial semi-structured interviews, both video and audio transcription recordings were made, while the subsequent data smoothing and narrative compilation sessions were recorded by video only. All clients who began the process demonstrated commitment to completing their books and expressed satisfaction at final member check. Only one environmental factor negatively influenced interviews. At one site, the only available space was a closed kitchen adjacent to a busy hall and active gym; thus, outside noise at times interfered with recordings and made it difficult to understand participants who tended to have labored or impaired speech patterns, rendering some parts of the transcript untranslatable; also, staff would occasionally interrupt session to retrieve supplies resulting in briefs halts to the process. However, due to the iterative nature of the comic book creation with continuous member checks, participants had ample opportunities to clarify and expand.

Demographics

Narrative inquiry requires ongoing and complex relational interactions (Bell, 2002; Clandinin, 2016; Kim, 2016), so the target sample size of this study was six participants with a minimum of three. In the first 2 weeks of sampling, six participants were identified although it was anticipated that not everyone would complete the process. Initially, only one female initially met selection criteria. Significantly more males than females are diagnosed with IDD so The Arc clientele skews heavily male, but out of a desire for greater gender diversity better matching population distribution, I chose to expand to seven participants when an additional qualifying female expressed interest in participating near the end of the data collection process. And despite contingencies, every collaborator who began the process finished, resulting in seven completed narratives.

All seven collaborators were legally capable of providing consent. One of the male participants was a first-generation immigrant with parents hailing from Southern Africa and India. All other participants were White, not Hispanic. Although a small sample size, this was roughly representative of the population served by The Arc in this region. Because exact age was not deemed necessary to narrative analysis, age was sorted into three categories to heighten protection of collaborator identities since they shared deeply personal narratives. Two collaborators fell within the early transition age period

(19-24), three fell within mid transition (25-28), and two were classified late transition (29-32). As noted in Chapter 3, persons with IDD tend to remain in school until age 22 per IDEA. For this reason, early transition covered a larger range than other categories and collaborators were included up to age 32 to fully capture the decade post-transition, whereas age 28 or 29 might be a more logical cutoff for the general population.

Per sampling criteria, all participants had an IDD diagnosis which serves as a broad category encompassing multiple more specific diagnoses. Two were diagnosed with ASD, one with Down syndrome, one with ADHD, and one with cerebral palsy. One collaborator was diagnosed with bipolar schizophrenia, one had a visual impairment, and another had an auditory impairment. Three participants had a history of seizures.

This sample also showed diversity in social characteristics. Although none of the collaborators lived independently, three still lived at home with their parents, three lived in a group home, and one lived in supported living, which is a step towards independence from a group home with intermittent as opposed to around-the-clock supervision. Only two collaborators currently were employed part-time. Four previously had been employed. One never held a paid position. No collaborators were competitively employed. One collaborator identified as LGBT; five referenced heterosexual relationships; and one did not address sexuality or relationships. Demographic characteristics are presented in Table 1.

Table 1

Collaborator Demographics (N=7)

Characteristic	*n*	Characteristic	*n*
Gender		Age	
Male	5	Early Transition (19-24)	2
Female	2	Mid Transition (25-28)	3
		Late Transition (29-32)	2
Sexual Identity		Living Situation	
Heterosexual	5	Independent	0
LGBTQ	1	Supported Living	1
Not Addressed	1	Group Home	3
		Parents	3
Diagnoses		Employment	
IDD	7	Full-Time	0
ASD	2	Part-Time	2
Seizures	3	Currently Unemployed	4
Cerebral Palsy	1	Never Employed	1
ADHD	1		
Bipolar	1	Race/Ethnicity	
Schizophrenia	1	White	6
Down Syndrome	1	Multinationality (non-white)	1
Hearing Impaired	1		
Visually Impaired			

Data Collection

Data collection occurred over a 6-week period with a slight delay between IRB approval and collection due to a COVID-19-related shutdown at The Arc facilities. Completing the entire multi-stage process took between five and six sessions per collaborator for all but one participant. No more than two data collection sessions were conducted in a week and sessions averaged around 45 minutes with only one exceeding 90 minutes. The final member check and debrief lasted only 15-20 minutes.

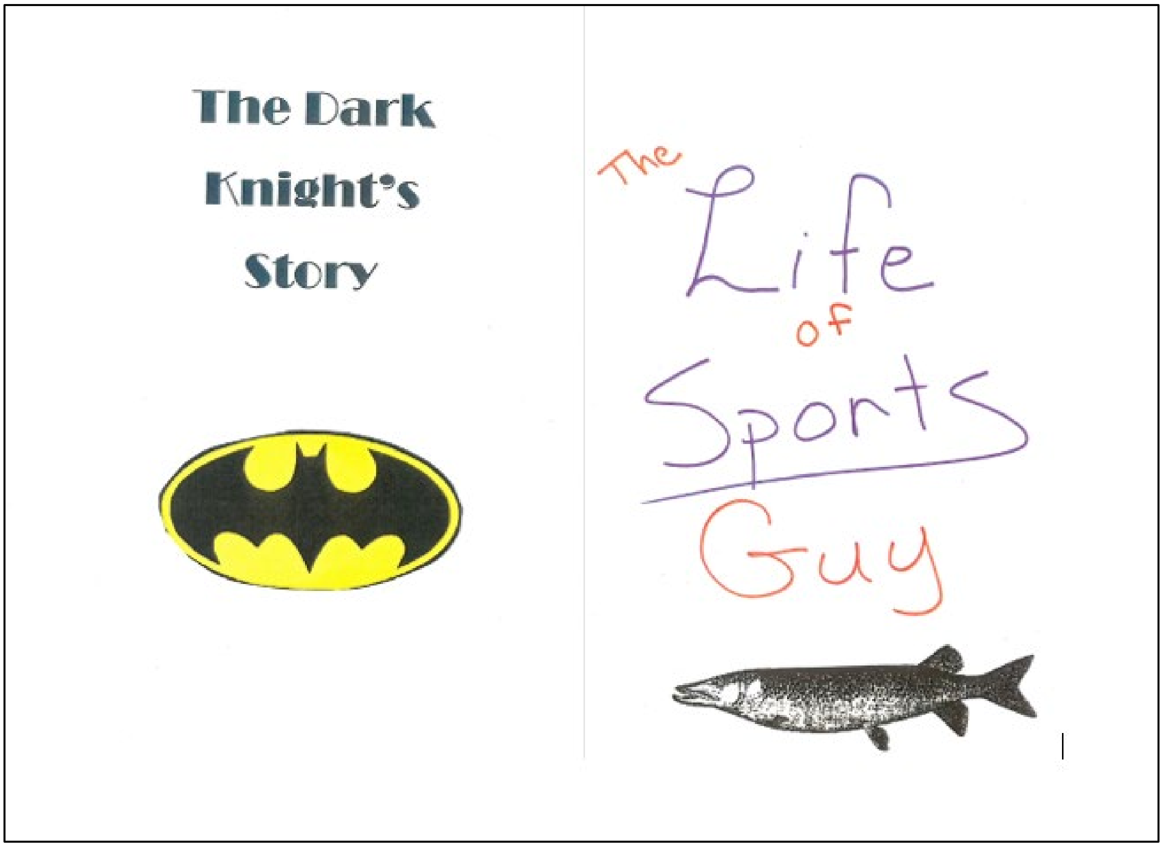
The semi-structured interview guide was designed to be administered over three sessions mirroring narrative structure: beginning (childhood and disability diagnosis), middle (adolescence and transition process), and end (current function and participation). Each interview began by prompting collaborators to choose their own secret identity to promote investment, empower identity formation, and reinforce the comic book hero's journey archetype as well as promote confidentiality. Upon commencement, it became immediately apparent that sessions one and two bled together as these topics spanned both phases of life; thus, the interviews progressed more rapidly than anticipated and these portions were combined, allowing all interviews to be completed in two sessions. After interviewing the first two collaborators, Bus Rider and Daredevil, I printed the transcripts and we reviewed them together during book construction, crafting the narrative as I handwrote text and prompted collaborators to choose pictures to align with the text—although they began this process during interviews. I had anticipated compiling the physical narratives would take one session with an additional session planned if needed, but this method of sifting through transcripts proved arduous, stretching over three sessions during which collaborators became restless and expressed boredom. This raised a concern of waning client engagement, so I revised the process for future collaborators. Fortunately, collapsing the interviews into two sessions allowed all collaborations to be completed within six sessions.

The Dark Knight was the third collaborator recruited, but because he declined all three image selection methods, I created a picture bank by searching internet images by topic labeled as holding creative common licenses. This proved successful so was adopted as a fourth image selection method for all seven collaborators, with multiple choices provided for any given concept. I also experimented with piecing the interview scripts into a rough narrative prior to The Dark Knight's third session to review and revise together to reduce frustration with the length of sessions. However, The Dark Knight abruptly ceased attending The Arc, so instead this method was successfully attempted with the fourth collaborator, Pudding, and thus employed going forward; however, I still handwrote Pudding's text which was slow and led to continued frustration. Nevertheless, we completed the process in five sessions—two interviews, two reviewing and compiling, and a final member check and debrief. So, for the final three collaborators—Sports Guy, Batgirl, and Diana—I employed this same schedule but further streamlined the process by printing the revised narratives after session three in a color chosen by collaborators, and then we cut and pasted text into the comic book template during the fourth session. This also led to a more readable and visually appealing product while enabling an additional member check during book assembly. We also chose images during session three to paste along with text in session four, and six of the seven collaborators used a combination of at least two image types, with The Dark Knight alone choosing only searched images.

The Dark Knight was also an outlier in finishing his narrative in three sessions, for during my penultimate data collection session I received a call from a supervisor at The Arc that he had returned. After completing that session with Diana, I drove to the site where The Dark Knight attended, and he stated that he was not sure when he would return again but insisted on completing his book that day. Fortunately, The Dark Knight was amongst the highest cognitive functioning participants and possessed a long attention span, so we combined session three through five into one two-hour session with The Dark Knight reaffirming his desire to finish throughout the process. Thus, data collection evolved due to collaborator needs and preferences, resulting in seven completed narratives verified through continuous member checks and iterative collaborations (see Figure 1).

Figure 1

Covers from Two Completed Narratives



Data Analysis

Data analysis was conducted through two first cycle and two second cycle rounds of coding guided by Polkinghorne's analysis of narratives as expanded upon by Kim (2016). Upon flirting with the data, Polkinghorne's narrative analysis approach was also adopted for its emphasis on comparing narratives holistically outside of deconstructive coding (Kim, 2016). Additionally, due to an iterative collaboration where interviews were transcribed, shaped into preliminary narratives, revised, and member checked multiple times, preliminary analysis began during data collection where I kept a running list of emerging themes as I engaged in reflexive journaling.

First Cycle Coding

Provisional Coding for Deductive Analysis

Provisional coding is a deductive method that applies preexisting codes derived from literature and theory (Patton, 2015; Saldaña, 2016). Beginning with existing literature allowed me to apply Polkinghorne's analysis of narratives through the lens of *concepts derived from existing theory* as well as through Kim's (2016) additional lens—*the predetermined foci of the study*. However, due to preliminary analysis while journaling, I required distance from the data to truly embrace a deductive approach, so I refreshed my literature review and updated Chapter 2 prior to provisional coding, creating a spreadsheet of codes as I went. Next, I entered these 30 provisional codes (see Appendix B) into Dedoose software, where I sorted them under five category codes and then coded the narratives in the order they were initiated, adding several more codes relevant to the literature review as I progressed. Once completed, the deductive coding was then assessed for what it revealed as well as what gaps and biases it exposed in the literature.

The most apparent result of this cycle of analysis was how the absence of codes such as *Altruism*, *Relationships & Sexuality*, *Positive Social Supports*, *Positive Policy Supports*, *Interpersonal Conflict*, *Bullying*, and *Adolescent Onset Turmoil* due to their absence from the transition literature. Thus, I reserved these codes for open inductive coding while making notes on these findings. Also, while none of the participants lived independently and all had limited community exposure, it became clear during this process that some participants were satisfied with their lives as they were. Therefore, I changed three of the five category codes to reflect role participation over community integration (see Table 2), for though community integration is in the title of this dissertation due to its ubiquity in the transition literature, I came to view this term as subjective and judgmental, much like examining an immigrant group through the lens of assimilation which imposes an expectation and burden to adopt the dominant culture. At this point, I set aside my notes and progressed to open coding.

Table 2

O*riginal & Revised Provisional Code Categories*

Original Provisional Category Code	Revised Provisional Category Code
Intrinsic Abilities Affecting Community Integration	Intrinsic Traits Affecting Community Participation
Community Engagement	Role Participation
Postsecondary Transition	Postsecondary Transition
Barriers to Community Integration	Barriers to Role Participation
Quality of Life	Quality of Life

Open Coding: Concept Coding for Inductive Analysis

Next, inductive analysis was applied using open coding to identify recurring concepts (Patton, 2015; Saldaña, 2016). This round of coding was guided by Polkinghorne's analysis of narratives lens *concepts inductively implied by the data*. During open coding, Dedoose software allowed for the creation of concept codes during the inductive readings. As new codes emerged they were also retroactively applied to previously coded narratives as appropriate, thus simultaneously initiating pattern coding through a constant comparative method (Patton, 2015; Saldaña, 2016). During this phase, code categories once again emerged so I sorted the codes into three emerging categories: *Intrinsic Characteristics*, *Quality of Life*, and *Supports & Barriers*. Additionally, the rich texts and specificity of open coding allowed three levels of sub-codes to evolve to better explore emerging themes (see Appendix C). Once open coding was completed through this iterative an expansive approach, a final review was performed, and codes consolidated and reorganized as necessary. Then the codes were compared for convergences and divergences and notes taken for later thematic development. I did not, however, analyze the codes with discrepant cases in mind but rather for how variances in data influenced emerging themes. In a constructivist epistemology each narrative is expected to be unique and deemed valid and per CDT insight lies in the paradox of conflicting experience. Thus, this data to was set aside for later triangulation of themes.

Second Cycle Coding

Narrative Coding

Next, each narrative was read aloud in its entirety for narrative coding and pictures reviewed for what they contributed to storytelling. Then the entire narrative was then analyzed for holistic themes and cross-comparison per Polkinghorne's narrative analysis method (see Kim, 2016; Saldaña, 2016). To express this holistic analysis of the narrative journey via the three-part story structure central to narrative inquiry analysis (see Bell, 2002; Clandinin, 2016; Clandinin & Connelly, 2000; Kim 2016), I created the following three-sentence plot summaries for each participant, written in first person from the participant perspective.

Bus Rider. I was born with multiple challenges and though I had a supportive and loving family, I struggled at school until adolescence when I moved to Florida to attend a special school. I made lots of friends there and had one serious relationship, but years of vocational training has led to only part-time work so I am working on my behaviors and life skills so I can become more independent and be allowed out of my group home more. Still, I am strong and determined which makes me optimistic for whatever comes next.

Daredevil. I was a happy child with a close, loving family and lots of friends, but I was bullied as a teenager so was happy to graduate. I learned job skills in high school and at a college and like cleaning and serving people at Wendy's, but I have to remember to work hard and unfortunately lost my job because of COVID-19. Yet I am proud to live in supported living and am happy being as independent as I can while seeing my family every week.

The Dark Knight. I was an only child from a good family and would like to help and inspire others, but I had no friends because I was 'slow' and have no social skills. I was constantly bullied at school and blamed myself when I was diagnosed with high functioning autism, so I was relieved to graduate and be free. I still live with my parents but have finally made a friend at the gym to shoot basketball with and am optimistic that someday I'll move out, get married, and maybe even help my dad run his business.

Pudding. Although my parents were always busy and I took lots of ADHD medicine, I had a happy childhood with lots of friends even though my brother bullied me. However, my life became tougher when I entered middle and high school where the bullying was so bad I dropped out and then I got kicked out of two special needs schools and a group home because I struggle with appropriate touching and sexual expression. Continued bullying has made it difficult to keep a job and my dad hates me because I am gay, but I am close with my mom, stay politically active, and hope to find a boyfriend and move out on my own one day, though I just wish people were nicer and understood my sexuality.

Sports Guy. I was an athletic child who still got bullied but was close to my family–especially my grandfather who took me to meet Tim Tebow and taught me to lay tile. Things got really bad in middle school when I started going in and out of psych hospitals until I got kicked out of the house for attempting suicide in front of my little brother and sister and dropped out of high school. I'm frustrated that I haven't gotten my GED to get a job, but although I've spent my life shuffling between group homes I am optimistic that someday I'll make something of my life, find a wife, and retire with my grandfather to the Bahamas—our favorite place.

Batgirl. I was a happy child who loved sports and was close to my parents and sister, plus I always had one best friend and got along with everyone. I did lots of chores at home and in middle and high school where teachers gave me lots of responsibility because I liked helping people and wanted to be a teacher when I grew up. I still live at home and don't think about moving out, but I am happy working at a thrift store and seeing my friends at The Arc though I'd like to work in a restaurant someday.

Diana. I loved pretending to be a Disney Princess when I was little and had so much fun with my brother, but I would get upset when my mom and dad would fight so mom would have to calm me down. But I love my family and had lots of friends in my special classroom, so I was proud to find out I had autism because it made me special and unique though I got bullied in high school and made new friends with help from my teachers. I was happy to graduate and get a job at Publix but lost it because of COVID-19 so while I love staying at home and having my friends visit, I want my job back and to go shopping with friends more.

Pattern Coding

Once narrative coding was complete, the constant comparative pattern coding that was initiated during open coding was expanded to synthesize all analysis approaches. First, I read over the seven narrative plot summaries and compared these to one another and to the inductive codes, calling up excerpts as necessary to clarify. Then, I referred back to my notes on the implications of provisional coding to seek connections between the various lenses. Next, I reviewed the preliminary codes recorded during reflexive journaling and compared these back to the narrative summaries and first cycle coding. As I toggled back and forth between these analysis lenses, I jotted down a list of emerging topics then tore the page out and rewrote these topics into categories. After continued triangulation through rewriting, I arrived at 12 preliminary themes and sought feedback from five different methodology experts to sharpen my focus and clarify my thematic conceptualization. On the strength of this feedback, four major themes emerged:

- *Happiness is a Friend: Social Support, Not Community Integration, Drives QOL*
- *The Adolescent Earthquake: Transition Begins Earlier Than Expected*
- *~~Dis~~Ability Identity: I Am a Complex Person and not a Disability*
- *Mountains of Exclusion: The Policy Cliff is a Slow Climb, not a Quick Fall.*

The other emerging themes were then sorted under these major themes as supporting topics, with additional supporting topics emerging through ongoing analysis and triangulation. These themes were then cross-referenced to the research questions as detailed below.

Evidence of Trustworthiness

Credibility

As described in Chapter 3, credibility was initially established through strong alignment between theory, method, and instrument design. Once data collection was completed, credibility was strengthened through deductive analysis that demonstrated connections between the data and existing literature while also exposing critical gaps and biases. Credibility was also strengthened through lengthy collaborations with participants over multiple weeks. During this time, data was recorded, reviewed, revised, and member checked multiple times, allowing ongoing confirmation that the emerging narratives were free from undo researcher influence. The majority of collaborators had impaired speech ability, so visual media was used to augment communication veracity. And though it often took multiple attempts to decipher meaning, collaborators demonstrated credibility through consistent and persistent expression when I struggled with intelligibility. For example, Daredevil possessed the most labored and unclear speech, yet he became animated and agitated when I would misunderstand, so we would persist until I correctly comprehended. For example, when discussing chores:

Daredevil: Take out the rocks.

Eric: Take out the rugs?

Daredevil: [Becoming frustrated.] No. The rocks. [Motions.] From Outside.

Eric: Oh, the rocks.

Daredevil: Yeah.

Eric: So out of the yard?

Daredevil: Yes. Pick up rocks.

At final member check the completed narratives were then read together and pictures reviewed, with all seven participants affirming accuracy and verbalizing satisfaction of results, such as The Dark Knight who simply said, “Perfect!” So, while it is acknowledged that recollection is imperfect, narrative inquiry is founded on the constructivist assertion that our perceptions reflect our reality, and the veracity and tenacity of collaborator contributions confirm high levels of credibility.

Lastly, the focus was kept solely on the perspectives of the collaborators without concurrent interviews sought from caregivers or professionals. While these other perspectives are valued and useful, they have been collected in previous studies, so this choice respected and enhanced the perspectives of collaborators who are from a population that is typically treated as if their experiences and perceived realities are untrustworthy. While in some instances such outside interviews may enhance credibility, per the epistemology of this study this would have served only to disempower the credibility of collaborator report. However, agency supervisors were consulted for basic demographic information regarding age, diagnosis, and living situation as necessary to ensure sampling accuracy.

Transferability

Transferability in narrative inquiry is first established by placing narrative in context of place, time, and society as well as through thick description, and each narrative explored the physical, social, and temporal environments where they occurred. Transferability was further enhanced by the emergence of consistent themes from existing literature across the narratives addressing universal concerns surrounding postsecondary transition as well as the disability per deductive coding. Moreover, although the sample size was small, a diverse sample was sought across age, gender, diagnosis, race, and sexuality, and sampling occurred at three different programs within The Arc to promote greater diversity. Ultimately, constructivist epistemology and narrative inquiry assert the uniqueness of individual experiences, yet the emergence of universal themes from a diverse and saturated data pool that related to relevant literature while providing new insights indicates that the experiences of collaborators support a degree of transferability to other persons of similar backgrounds and characteristics.

Dependability

Dependability was first and foremost established through design and alignment, although during data collection and analysis multiple methodology experts were consulted to review parts of data and/or thematic analysis to corroborate dependability. Per Chapter 3, dependability is closely tied to epistemology, and the constructivist epistemology asserts truth in experience and recollection. As described above, continuous redirects, prompts, and members checks were employed to ensure that data was dependable in capturing collaborator perspectives. And though data collection procedures were tweaked during the process, changes remained true to methodology design and were executed to support collaborators and thus increase dependability. Finally, dependability of results and conclusions was established by pattern coding that triangulated deductive methods, inductive methods, and narrative analysis which embraced a holistic narrative inquiry approach, and input was sought from five separate methodology experts during this triangulation process to strengthen dependability in conceptualization of themes.

Confirmability

Confirmability was established through reflexive journaling that sought to minimize researcher bias while documenting each collaborator contact. Notes were taken on the semi-structured interview scripts and reaffirmations of informed consent were noted as well. Interviews were recorded in both video and audio transcript formats and the transcripts were corrected and saved by the researcher. Multiple narrative drafts were also saved and final copies of completed narratives kept. All data has been secured per previously described standards and is available if needed. And while the participation of two Arc supervisors in sampling raised privacy concerns with IRB resulting in confidentiality agreements, their assistance with sampling and scheduling provided further confirmability that interaction occurred over multiple sessions; however, interactions were private and witnessed only by collaborator and researcher.

Intracoder Reliability

Finally, intracoder reliability was established through use of consistent coding procedures during each round. For example, provisional coding was consistently used for deductive analysis while concept coding was applied to inductive analysis, with Saldaña's (2016) coding manual serving as the primary guide and Patton’s (2015) text on qualitative research serving as a secondary reference. Further, multiple passes were made through each narrative to ensure consistency during each cycle of coding with codes added, subtracted, changed, or resorted to maintain consistency. Further, use of Dedoose software kept code nomenclature standard. Lastly, feedback was sought from multiple methodology experts throughout coding and conceptualization to maximize consistency and reliability. Therefore, coding remained both internally consistent to researcher observation and externally consistent with broadly accepted qualitative analysis concepts.

Results

Collected narratives yielded a rich data pool, but ultimately four overarching themes emerged relating back to postsecondary transition and community integration. Because of the emphasis on emic perspectives and inductive insights, results are presented below by theme and then related to research questions as indicated.

Happiness is a Friend: Social Support, Not Community Integration, Drives QOL

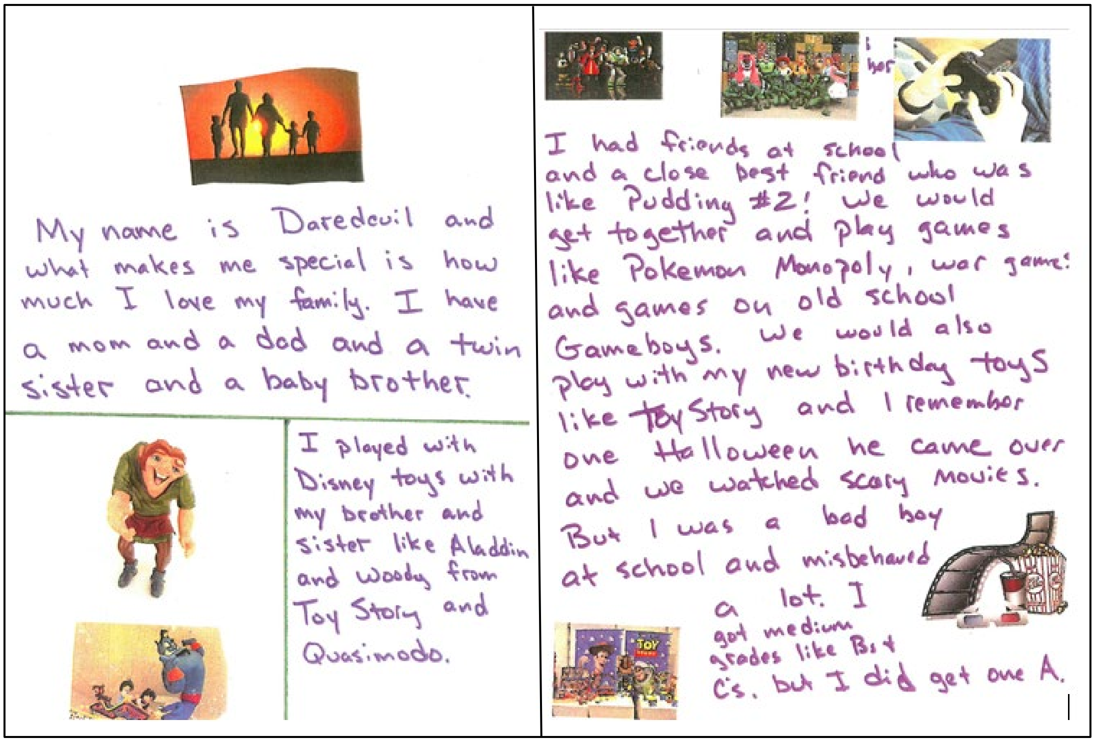
Because QOL is a major topic throughout transition literature and strongly correlated with community integration, it was used as a primary code category for both deductive and inductive coding. However, these narratives did not cite community integration as a primary indicator of QOL. Instead, social support emerged as a more significant QOL indicator for every collaborator.

In the Beginning…Friends & Happy Childhoods

All seven narratives opened with recollections of mostly happy childhoods before moving on to turmoil in adolescence. For example, Daredevil's narrative began: "When I was little, I played with Disney toys with my brother and sister like Aladdin and Woody from *Toy Story* and Quasimodo. I also went to daycare and passed ball with my friends." He continued, "My family would go out to all kinds of movies we would go to restaurants too…. I was a happy child" (see Figure 2). Pudding reminisced, "When I was young, I remember having different…. cool outfits like Pokémon. I had friends at school and a close best friend who was like Pudding Number Two" (see Figure 2). Batgirl recalled "I had a best friend, and we would play outside after class. I didn't have other friends, but I got along with everyone." Similarly, Diana stated, "In grade school I was in a special classroom because I had autism. I had five friends in class. We would play games outside at recess, and I got along with all the kids." And though Sports Guy was the only collaborator to experience bullying in early childhood he still recalled: "I was a very athletic kid and loved playing football, basketball, and a with other kids in the neighborhood." In a slightly different narrative plot, Bus Rider had mixed feelings due to rejection by his father and early awareness of his disability, but still conceptualized himself as a social child with many friends and strong family ties.

Figure 2

A Comparison of Daredevil & Pudding's Happy Childhood Memories



My name is Daredevil and what makes me special is how much I love my family. I have a mom and a dad and a twin sister and a baby brother.

I played with Disney toys with my brother and sister like Aladdin and Woody from Toy Story and Quasimodo.

I had friends at school and a close best friend who was like Pudding #2! We would get together and play games like Pokemon Monopoly, war games and games on old school Gameboys. We would also play with my new birthday toys like Toy Story and I remember one Halloween he came over and we watched scary Movies. But I was a bad boy at school and misbehaved a lot. I got medium grades like B's + C's. but I did get one A.

By contrast, The Dark Knight reported the most distressful childhood due to the absence of friends: "I didn't have friend at school or in the neighborhood. Nobody liked me. I wanted to make friends, but I was just a loner." To cope, he steered his energy into fantasy play and video games. Therefore, while he and other collaborators frequently cited preferred activities in these memories, it was ultimately the presence of friends that denoted happiness and positive QOL. But although true happiness was having a friend, this was the proverbial icing on the cake. All collaborators—even the Dark Knight—experienced stable childhoods due to strong family connections that served as the cornerstone of wellbeing.

Like a Rock: Family as the Cornerstone of Childhood Security

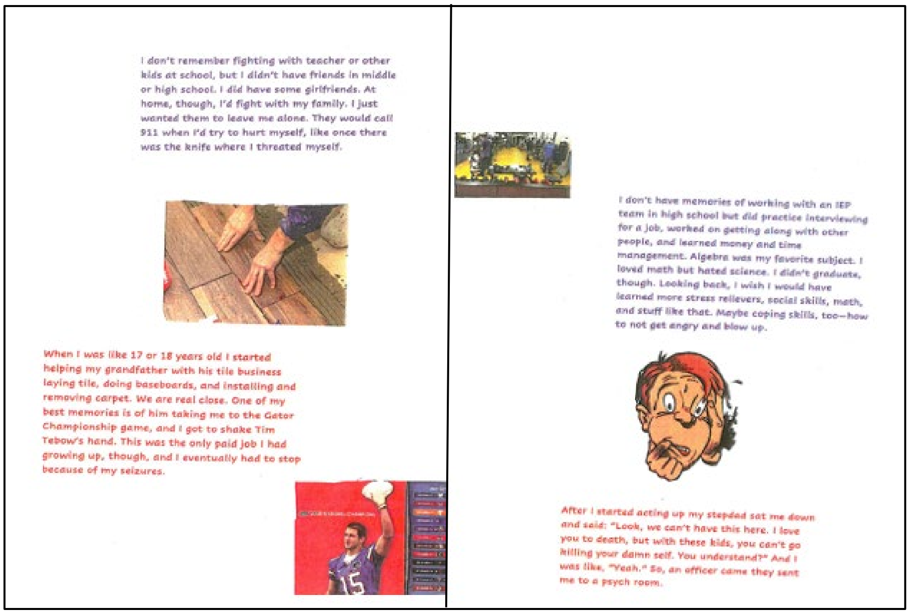
All seven participants reported at least one enduring close family relationship, and increased positive relationships correlated with anecdotes of happiness and contentment. Batgirl opened her narrative by stating, "What makes me unique is that I am a very happy person and that I spend big time with my family," while Daredevil began, "What makes me special is how much I love my family." Even the Dark Knight, who was friendless and isolated in childhood, spent more of his early narrative focused on positive experiences with his family such as going to Indian restaurants and movies, shooting basketball with his father, and traveling to the UK where he saw Big Ben. But the importance of family connections extended beyond just parents.

For Diana, Batgirl, and Daredevil, close sibling relationships were a key part of their identity continuing into adulthood. Diana smiled broadly when relating: "Me and my brother, we have fun," and chose to include more pictures of her and her brother than anything else. Of the three photographs Batgirl chose, two were of her and her sister whom she reported talking to every day on the phone. And though Pudding reported being physically bullied by his brother during childhood he speaks to him regularly as an adult. Taking a more indirect route, Sports Guy (see Figure 3) framed the importance his connection to his younger brother and sister through a sense of responsibility:

> After I started acting up my stepdad sat me down and said: “Look, we can’t have this here. I love you to death, but with these kids, you can’t go killing your damn self. You understand?” And I was like, “Yeah.” So, an officer came they sent me to a psych room.

Figure 3

The Sports Guy’s Happy & Troubled Memories in Gator Orange and Blue



I don’t remember fighting with teacher or other kids at school, but I didn’t have friends in middle or high school. I did have some girlfriends. At home, though, I’d fight with my family. I just wanted them to leave me alone. They would call 911 when I’d try to hurt myself, like once there was the knife where I threated myself.

When I was like 17 or 18 years old I started helping my grandfather with his tile business laying tile, doing baseboards, and installing and removing carpet. We are real close. One of my best memories is of him taking me to the Gator Championship game, and I got to shake Tim Tebow’s hand. This was the only paid job I had growing up, though, and I eventually had to stop because of my seizures.

I don’t have memories of working with an IEP team in high school but did practice interviewing for a job, worked on getting along with other people, and learned money and time management. Algebra was my favorite subject. I loved math but hated science. I didn’t graduate, though. Looking back, I wish I would have learned more stress relievers, social skills, math, and stuff like that. Maybe coping skills, too—how to not get angry and blow up.

After I started acting up my stepdad sat me down and said: “Look, we can’t have this here. I love you to death, but with these kids, you can’t go killing your damn self. You understand?” And I was like, “Yeah.” So, an officer came they sent me to a psych room.

Being told the negative effects of his behavior on his siblings resulted in willing acceptance of expulsion from his home. When later speaking of his goal to quit smoking, Sports Guy again alluded to this connection with tears in his eyes: “I would like to hear my brother say, ‘Hey, I’m proud you’re not smoking,’” By contrast, The Dark Knight was the only collaborator without a sibling and also the only collaborator to report isolation throughout childhood and adolescence and an inability to form early friendships.

However, in the interviews, the importance of family connections extended beyond immediate biological family.

Sports Guy’s narrative also demonstrated how critical stepparents could be for accepting a child despite their flaws and diagnoses, particularly when rejected by a biological parent. Early on he related: “My mom and my real dad split up when I was very young. I don’t remember seeing him much.” Yet despite relating how his stepfather kicked him out of the house, he begins by recalling how his stepfather began by stating how much he loved him. This connection held through the close of his narrative which concluded: “I am happy knowing that so many people actually care about me—my mom, my stepdad, family, but also everybody here at Arc.” Such stepparent support was also critical to Bus Rider, who experienced the most difficult early childhood: “I spent six to nine months in an incubator before I went home. This was hard for my mom. And my biological father was hardly ever around. They didn't get along.” But, “When I was five, I met my dad. Mom and dad met at a steakhouse where my mom worked. He taught me to do things like ride a bike and put on my socks.” Grandparents were also critical presences in most collaborator lives.

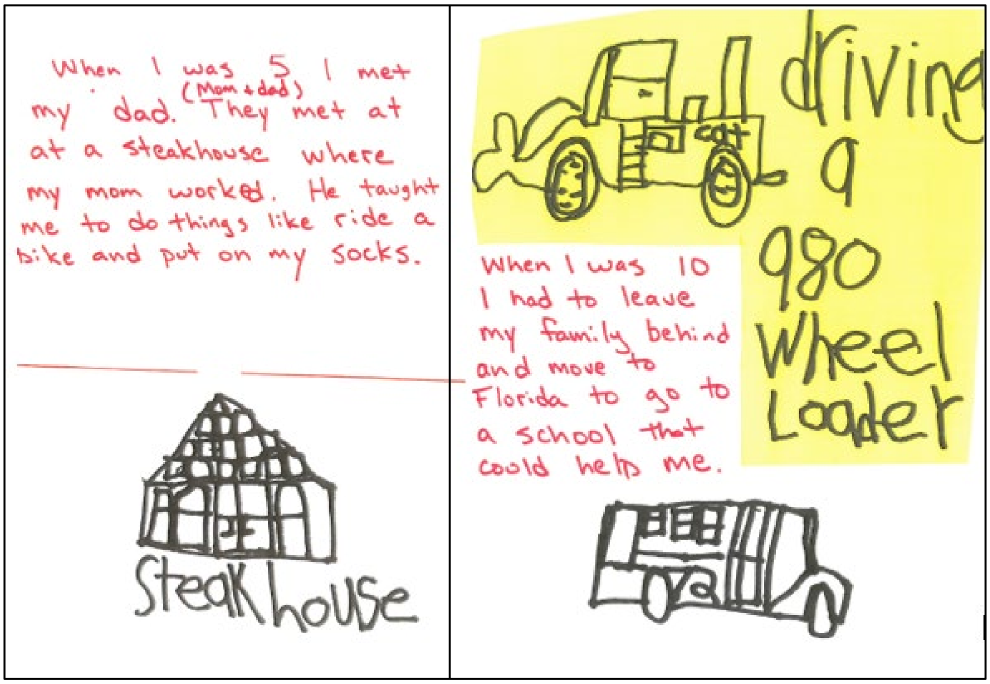
Bus Rider (see Figure 4) emphasized the importance of his grandfather in vocational exploration and building confidence:

> I have happy memories of me and my grandfather riding equipment together like a Wheel Loader 980. I used my left arm when needed. One time though he let me try and load the truck. I didn't see the edge of the bed and missed!

He also noted the importance of surrogate family: "I met the landlord of our duplex and he was there for all my life." Similarly, a grandfather was provided critical support for Sports Guy amidst mostly painful memories: "We are real close. One of my best memories is of him taking me to the Gator Championship game, and I got to shake Tim Tebow's hand." His grandfather, too, helped with vocational experience, hiring him to lay tile with him as a teenager. Batgirl, Diana, and Pudding also mentioned close relationships with grandparents. Aunts, uncles, and cousins also facilitated QOL through leisure and travel with Batgirl, The Dark Knight, and Sports Guy all traveling extensively to visit family.

Figure 4

Bus Rider's Family Connections



When I was 5 I met my dad. (Mom + dad) They met at at a steakhouse where my mom worked. He taught me to do things like ride a bike and put on my socks.

When I was 10 I had to leave my family behind and move to Florida to go to a school that could help me.

Theme One's Relationship to Research Questions

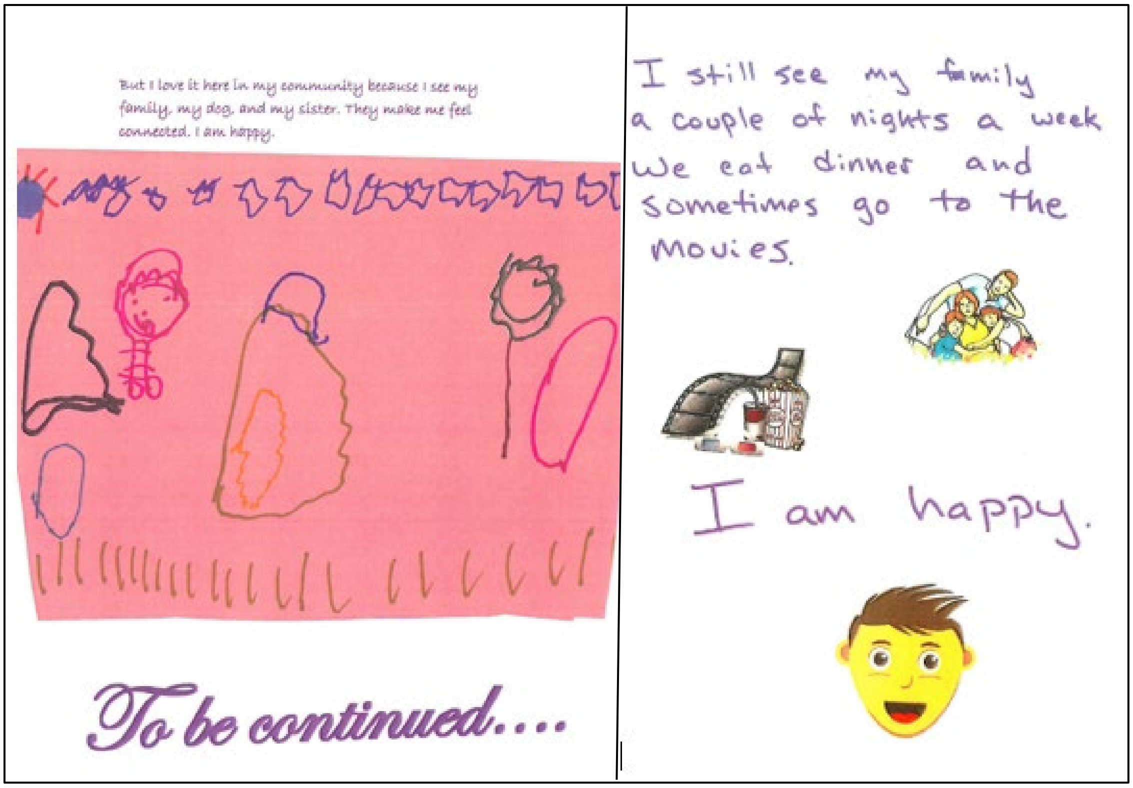
Social Support as the Vehicle for QOL & Connection. This theme directly answers RQ2: What do these narratives of the postsecondary transition journey reveal about the current quality of life and sense of well-being of persons with IDD in relation to community integration? The term community integration is often used as a primary indicator for QOL, yet connections to family and friends rather than places and community institutions were more significant for these collaborators. During interviews, it was clear that the abstract concept of community integration was difficult to comprehend and articulate. Thus, various prompts were used to uncover concrete examples. And it is likely that increased community integration would have improved QOL. However, the plots of these narratives were mostly influenced by interpersonal connections while linking these closely to leisure participation and self-determination.

Diana, Batgirl, and Daredevil consistently conceptualized their lives as happy and meaningful despite the fact that each would fall short on community integration measure compared to the general population such as independent living, community mobility, and employment. Nevertheless, each has maintained strong family ties throughout their lives. Additionally, they have all been able to maintain friendships and expressed self-efficacy in making and sustaining social connections. While QOL indicators related to community integration did arise such as underemployment, they were perceived as much less impactful than social supports. Batgirl and Diana both lived at home and expressed contentment at the certainty of this continuing well into the future, despite this being viewed as an indicator of dependence in the literature.

Batgirl is employed only part-time and sees her best friend socially once a week, while Diana lost her job due to the COVID-19 pandemic and only leaves the home to go shopping with her mom or attend The Arc. Both desire greater vocational engagement, but Diana still ended her narrative: “I like living in Florida. I am happy and part of my community. That is who I am.” Similarly, Batgirl ended her story: “But I love it here in my community because I see my family, my dog, and my sister. They make me feel connected. I am happy” (see Figure 5). Both women are dependent in their living situations and lack competitive employment, and neither volunteer nor votes. Yet they perceive themselves as fully integrated into their communities. Daredevil also lost his part-time job due to COVID-19 and, though he has achieved the most independent living situation—repeatedly expressing pride in residing in supported living instead of a group home. He only leaves the home intermittently with family or on supported leisure excursion organized for residents. Nevertheless, he too expressed high levels of QOL and community integration through connection to his family: “I still see my family a couple of nights a week. We eat dinner and sometimes go to the movies. I am happy” All three do desire greater vocational engagement, but strong family and social connections led to positive QOL. By contrast, those who felt less connected to their community experienced weaker connections and less social support.

Figure 5

Comparison of Batgirl & Daredevil's Happily Connected Endings



But I love it here in my community because I see my family, my dog, and my sister. They make me feel connected. I am happy.

To be continued....

I still see my family a couple of nights a week we eat dinner and sometimes go to the movies.

I am happy.

Pudding and Sports Guy described the most turbulent journeys, both being kicked out of multiple living situations. Both continued to deal with interpersonal conflict into young adulthood. Subsequently, they expressed less attachment to their communities and a greater desire to feel more involved. Sports Guy stated: “I'm trying to get a GED and get a job. I want to get an education…I don't want no bee in my butt and just sit here. I want to…be something with my life.” Similarly, Pudding related: “I wish I had more friends and that people at The Arc understood how I feel and about same-sex relationships.” This left him yearning for more: “Someday I want to move out, get my singing career going. Then I would like to get a boyfriend then get a big house....But I have never had a real relationship.” Bus Rider also described continued turmoil in his group home, and thus: “I feel like part of my community but not much. Volunteering would help me feel more involved.” In fact, all three of these young men lived in group homes which would quantitively register greater independence than living with family, yet all felt disconnected and complained about constant conflict. For example, Pudding stated, “I now live with five roommates, but there’s still bullying and I hate it,” while Bus Rider related, “I currently have five roommates. There's a lot of fighting and I do tend to instigate, so they teach us coping skills,” In these cases, struggles with interpersonal connection correlated with lower feelings of connection to their communities.

Perhaps no case illustrates the importance of family and stability in fostering a perception of community integration as The Dark Knight’s:

> In the future I see myself getting a job and moving out of my parents’ house and getting married, but I feel comfortable with my life in my community. I have a routine here with my family and have a good relationship with my mom and dad. I am happy.

Despite being feeling nearly universally rejected by society, strong family connections still provided The Dark Knight a sense of connection. He recently made his friends and has longed for friendships his entire life, but a stable living environment was enough for baseline contentment. Even Pudding and Sports Guy have been sustained through continued family connections and at least one close friend. As a young adult, Sports Guy has been continuously shuffled between group homes in a cycle of expulsion and re-hospitalized but still noted, “I have five roommates at my current group home. One is my best friend, and let’s just say he's been taking care of me.” He went on to end his story with a sense of optimism because so many people care about him. Pudding made one close friend at The Arc and he too ended on a note of optimism despite ongoing alienation: “But still I'm happy and optimistic about my future—a 10/10.” Despite mostly absent community connections in the face of ongoing turmoil and uncertainty, these two young adults experienced enough support to still form hopeful visions of the future. Nevertheless, their heightened struggles to connect and feel connected illustrate how vital social skill are for self-determination and well-being.

Social Skills as the Key to Self-Determination & QOL. Batgirl’s saddest memory was of her best friend moving away, but she remained confident in her ability to make friends, soon finding a new best friend and, upon postsecondary transition, found a new best friend in the community. Despite having IEP goals for making friends, Diana always made friends with her special education classmates, and even when bullied in high school, she simply moved on: “My teachers talked to them and made them stop, and I made new friends.” When she moved to Florida after graduation, she again confidently reported making new friends at The Arc that visit her every weekend. However, while Sports Guy, Pudding, Bus Rider, and The Dark Knight remain optimistic, they lacked such confidence with the social skills needed to develop true stability.

All three of these collaborators were thoughtful and verbally fluent, but still they recognized that their behaviors—or their efficacy with social skills—were holding them back from achieving greater independence. For example, Bus Rider stated:

> Once I met a friend and his mom at McDonald's. I would like to do that more in the future. Legally I am my own guardian, but my mom still makes a lot of decisions on who I can hang out with because she's worried about sexual contact. But I'm working with my house manager to be able to hang out more.

Once Bus Rider lost the support of a specialized residential school, he struggled to make friends as and experienced constant conflict in his group home. Thus, he lamented: “I would like to live in supported living…but I have to work on my behaviors.” Similarly, Sports Guy and Pudding struggled with conflict and behavior regulation leading to even greater instability, both having been removed from multiple living situations.

By comparison, Daredevil has a diagnosis of Down syndrome and demonstrated more restricted cognitive and verbal abilities yet has achieved the highest level of independent living of any collaborator. He has a strong sense of social self-efficacy and verbalized awareness of rules: “I now live in a supported living with three roommates…. One of my roommates breaks the rules but I do not.” This efficacy correlated with both increased independence and life satisfaction. The Dark Knight in turn displayed the highest cognitive, memory, and verbal skills of any collaborator, but his lack of social skills resulted in the lowest level of independence and participation. He lives at home, has never held a job, and has experienced near total social exclusion. So low self-efficacy with social skills led to less stability and independence for collaborators which in turn negatively impacted all areas of their lives.

The Adolescent Earthquake: Transition Begins Earlier Than Expected

While some collaborators faced childhood challenges, all conceptualized growing up as a mostly secure, positive experience. However, these smooth flights towards adulthood encountered significant turbulence with the onset of adolescence, and every collaborator except Batgirl confronted painful turmoil at some point post-childhood due to increasingly complex social relationships, emerging sexuality, and the predominance of bullying. Thus, for the majority of the collaborators, adolescence hit like an earthquake that proved to be a lifelong transition challenge dwarfing postsecondary transition.

External Tremors

For Pudding, the earthquake arose from external social conditions: “I started to have more troubles in middle and high school when other kids started picking on me.” Daredevil, whose narrative remained mostly positive otherwise, also felt the external tremors leading him to skim through middle and high school recollections, choosing only to share memories of bullying despite multiple prompts: “But at school there was a boy who would follow me and tease me about having a girlfriend. He was kicked off the bus and teachers at school told him to stop and leave me alone, but he wouldn't't” (see Figure 6). For The Dark Knight, passive social isolation also morphed into active aggression as a result of unrelenting bullying upon entering secondary school (see Figure 6):

> I was bullied a lot—mostly name calling. Because I was slow they used to call me like, slow and the A-word—a curse word. One bully used to spit ball—like with a straw. The teachers said to one of the bullies: “Just stop bullying him.” And they still didn't listen to the teacher. So they kept doing it even if they got in trouble a

> lot. So regardless, anywhere I turned—you know going to new classes—I basically got bullied….My saddest memory is the bullying and name calling.

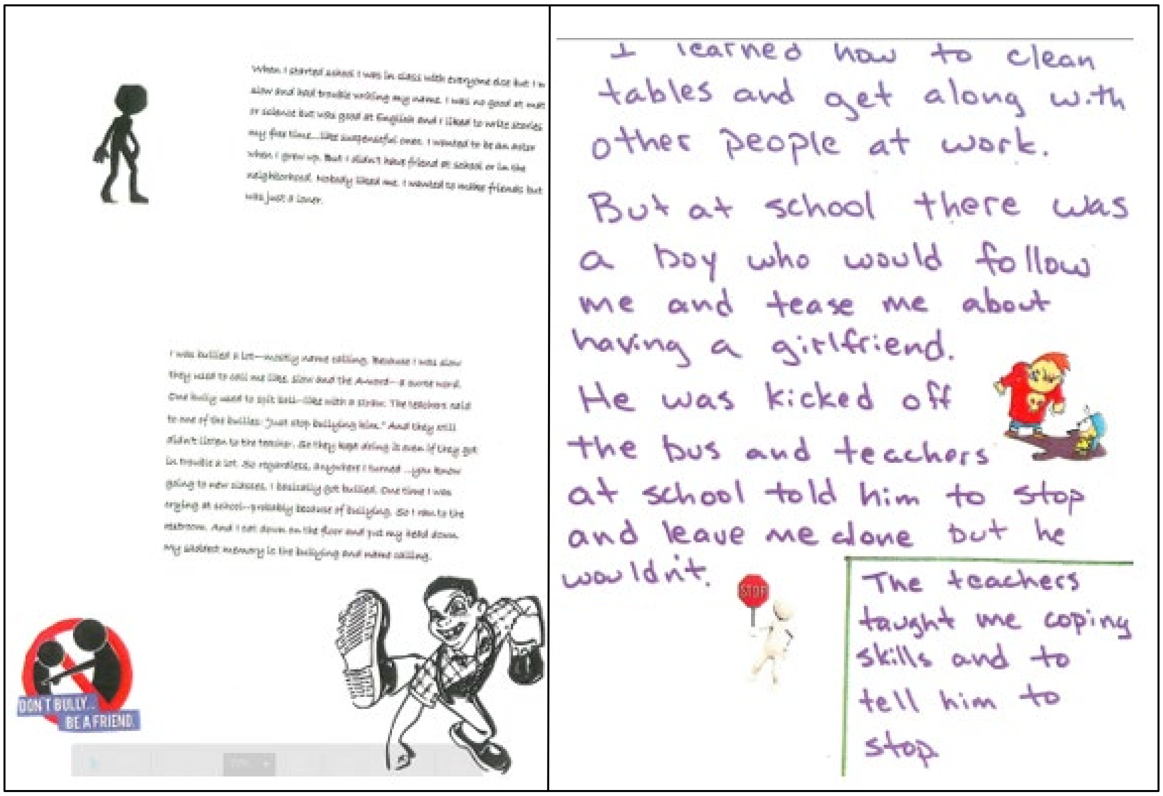
For Diana, bullying didn't emerge until high school:

> In high school… I was in class with new friends who said I am stupid, I am creepy, and that I am not beautiful enough. That made me feel sad and hurt. I talked to my parents about it. They said "They're mean and not good people. They're not your friends."

In this case, institutional and family interventions were successful, but for other collaborators, disruptive factors proved too complex to overcome.

Figure 6

Bullying As Described by The Dark Knight & Daredevil



I learned how to clean tables and get along with other people at work.

But at school there was a boy who would follow me and tease me about having a girlfriend. He was kicked off the bus and teachers at school told him to stop and leave me alone but he wouldn't.

The teachers taught me coping skills and to tell him to stop

Internal Tremors

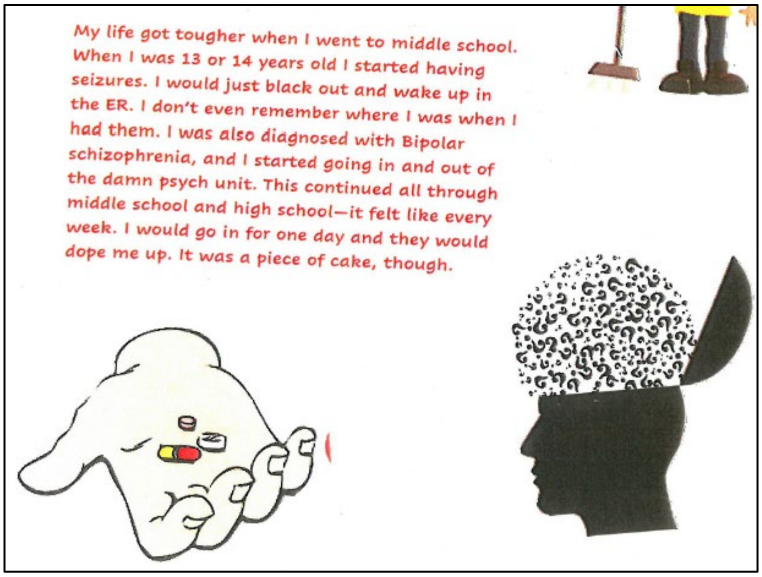
While Sports Guy began experiencing bullying in grade school, his adolescent earthquake was caused by both internal and external forces, rippling out to consume his entire life and future:

> My life got tougher when I went to middle school. When I was 13 or 14 years old I started having seizures. I would just black out and wake up in the ER. I don't even remember where I was when I had them. I was also diagnosed with Bipolar schizophrenia, and I started going in and out of the damn psych unit. This continued all through middle school and high school—it felt like every week. I would go in for one day and they would dope me up.

Sports Guy has spent his young adulthood in and out of group homes, with institutional supports unable to consistently meet his needs (see Figure 7). However, despite internal factors contributing to adolescent turmoil, Sports Guy began experiencing bullying well before his psychiatric diagnosis. And although the brunt of turmoil was external forces for Pudding and Daredevil, their emerging sexuality—particularly Pudding he identifies as gay—contributed to the harassment and increased social complexity. Further, the severity of bullying was influenced by the effectiveness of institutional supports.

Figure 7

Sports Guy's Adolescent Earthquake



My life got tougher when I went to middle school. When I was 13 or 14 years old I started having seizures. I would just black out and wake up in the ER. I don't even remember where I was when I had them. I was also diagnosed with Bipolar schizophrenia, and I started going in and out of the damn psych unit. This continued all through middle school and high school—it felt like every week. I would go in for one day and they would dope me up. It was a piece of cake, though.

Effective Institutional Supports

Like Diana, Batgirl also held a strong sense of self-determination with a consistent best friend and ability to get along with all of her peers. This, paired with strong institutional and policy support through a quality public school led to a positive and successful secondary school transition: "I liked my high school a lot. It's a good school." And while Batgirl was spared bullying at her supportive school—as was Bus Rider—effective family and institutional intervention mitigated the effects on Diana. A larger sample size would be needed to draw strong gender correlations, but for all five male collaborators, social integration became more complicated and distressful upon exiting primary school—or residential school in Bus Rider's case. All the males but Bus Rider seemed to receive less effective institutional supports.

Bullying & Institutional Failures

Pudding attended both public secondary schools and two different private schools catering to general disabilities, but both environments failed to shield him from bullying:

> In high school, the bullying got so bad that people threw things at me and my mom because of our beliefs so she when I was 14 or 15 she sent me to a boarding school in Kentucky for people with all disabilities…. I still got bullied here and one time a house staff pinned me up against the wall.

Such bullying continued into adulthood: “Then I got a job doing dishes in the cafeteria at a local college but quit because I was being bullied.” After losing a subsequent job due to COVID-19, “I went back to the college but quit again because of the bullying.” Daredevil and The Dark Knight both stated that teachers tried to address bullying, but interventions were unsuccessful. Sports Guy reported no intervention. Thus, bullying dominated their secondary school recollection, resulting in two of them dropping out and The Dark Knight persevering out of necessity until receiving reprieve through graduation. But bullying was not the only new social challenge to arise in adolescence.

Sexuality & Relationships

Sports Guy spent his adolescence and young adulthood bouncing between living situations marked by sudden expulsions. Although his psychiatric diagnoses were the major culprits, struggles with emerging sexuality and relationships compounded his struggles. While he had no friends in secondary school, Sports Guy did report romantic relationships that never became overtly sexual. And in describing the social turmoil in his group homes, he related how romantic relationships with two female residents fed into a culture of conflict: “There’s a lot of talking and bickering, plus I have two-ex girlfriends from other homes. I dumped one and went with the other who promised me sex, but neither relationship ever really got physical.” Yet he admits that he has had no guidance on this topic: “Nobody ever really talked to me about sex or relationships.”

Pudding experienced the most pervasive bullying, but this was compounded by the intersection of his LGBTQ and disability identities, setting off lifetime of instability. This began at the special school he attended in Kentucky where: “When I was 19 I got kicked out for touching one of my friends inappropriately.” After dropping out of public school to attend a PSE program this issue reoccurred: “When I was about 20 or 21 or 22 my mom sent me to a boarding school in Georgia…. But when I was like 24 I got kicked out again for touching another boy and moved back to Florida.” While he experienced punitive actions, he reported no education beyond a sex education class in high school, and upon returning to Florida was subsequently kicked out of supported living for a similar incident. He currently resides in a more restrictive group home, and also expressed a desire for guidance and education: “I would also like to learn how to not touch inappropriately and how to start a relationship.” Even Daredevil, whose narrative was half the length of others due to limited memory and articulation, noted that the bullying he experienced centered upon not having a girlfriend.

By contrast, Bus Rider was able to maintain a successful relationship prior to transition: “I also had a girlfriend at school. We went to my two proms then her two proms together four years in a row.” However, he lacked the independence to maintain the relationship after postsecondary transition: “We broke up because she wanted me to drive two hours to visit." He has not had a relationship since and is not allowed to meet friends in public because his mother worries about sexual contact, indicating he too lacks the skills he needs to manage sexual expression. This disruption caused by emergence of sexuality and increasing complexity of social relationships provides powerful insight into policy shortfalls.

Relationship to Research Questions

This theme most directly addresses RQ3: What do these stories reveal about policies currently guiding postsecondary transition and potential policy changes? Specifically, while adolescence is universally accepted as a life stressor and cause of disruption of life roles, current policy is failing to accurately address the increased challenges created by the intersection of disability with increased social complexity, bullying, and sexuality in adolescence. IDEA mandates that transition services begin at 16, but for most collaborators true transition began the minute they entered middle school. Five of seven collaborators reported some level of bullying in adolescence, and for Pudding and Sports Guy it was so bad they dropped out. The Dark Knight was forced to endure but conceptualized graduation as escape: "When I finally graduated, I felt relieved, like all the stress and nervousness was all lifted up off my shoulders. I felt like a free man." Even Daredevil, who summed up secondary education only through the lens of bullying, simple stated: "I was happy when I graduated high school." And while Bus Rider was shielded from bullying, the complexities of social interactions in young adulthood caught up with him upon aging out of his shielded environment. Sexuality is perhaps the primary contributor to the increased social complexity of adolescence and materialized in some form with all collaborators but one.

As part of the relational nature of narrative inquiry, I was aware of a sex education class being conducted at The Arc in a program specifically targeting adult skills and living including all four collaborators at that site. The positive response from attendees—as well as families wanting their adult children included—was overwhelming. When ending their narrative by looking to the future, Sports Guy and The Dark Knight were confident in marrying one day while Pudding wanted to have a serious boyfriend. Through relational interactions, I learned that one of Daredevil's agency goals was to have a girlfriend and Bus Rider mentioned a desire to have another relationship though he did not include it in his narrative. When I would retrieve Batgirl for our sessions, she was usually sitting with a male classmate who draped his arm across her shoulder in what was perceived to be an intimate manner although she did not mention relationships in her narrative. Only Diana revealed no indications of interest in a romantic relationship but recalled that high school bullies attacked her based on attractiveness. Therefore, while Theme 1 demonstrates the importance of sustained and meaningful social connections, Theme 2 exposes a large gap in current public policy addressing these complex social issues around adolescent sexuality and bullying as will be explored in greater detail in Chapter 5.

~~Dis~~Ability Identity: I Am a Complex Person not a Disability

Ability Identity

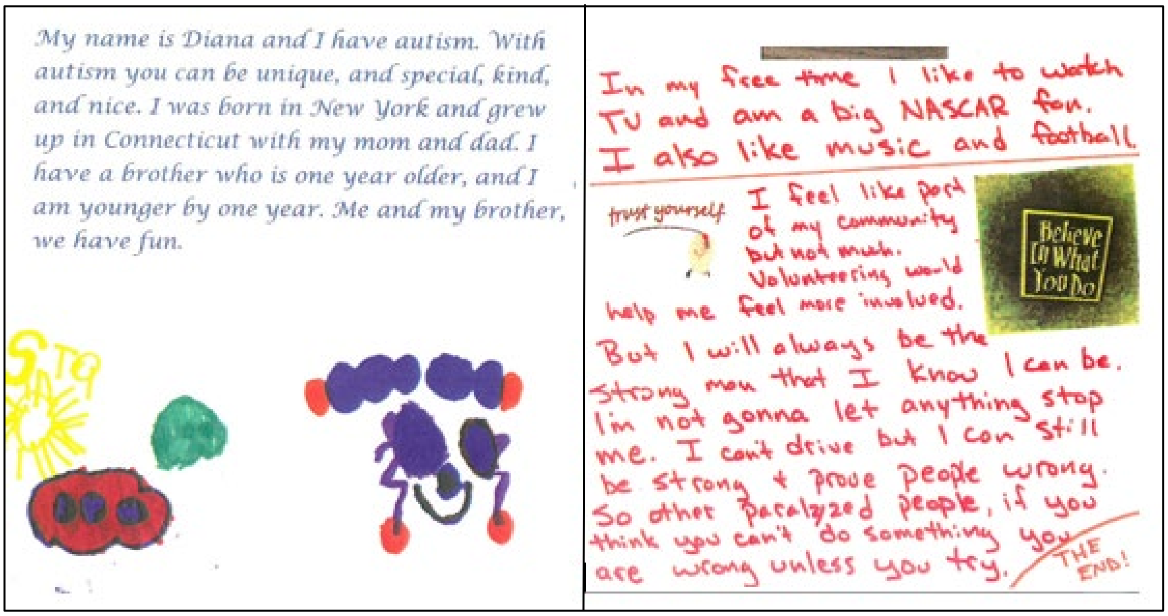
While CDT is grounded firmly in the paradox of disability identity, these collaborators generally conceptualized their lives outside this construct through abilities and preferences. When asked what makes them special, Daredevil, Batgirl, and Diana all referred to connections to their family while Pudding mentioned being a good and honest friend (see Figure 7). Sports Guy mentioned that he was once an alcoholic but does not “touch the stuff” anymore, expressing empowerment and not disability. Bus Rider was more explicit in identifying with disability: “I was 24 weeks old and only weighed one pound and a half. I spent six to nine months in an incubator before I went home.” He later continued:

> I also began having petite mal seizures, so I was on five medicines…. That’s also when I learned I had CP. I have trouble using my left arm but with this splint, I can use it a little bit. I also found that I was blind in one eye and had poor vision in the other.

Nevertheless, he summed up his self-image through inner strength: “I will always be the strong man that I know I can be. I'm not going to let anything stop me” (see Figure 7).

Figure 7

Diana's Empowered Beginning & Bus Rider's Empowered Ending



My name is Diana and I have autism. With autism you can be unique, and special, kind, and nice. I was born in New York and grew up in Connecticut with my mom and dad. I have a brother who is one year older, and I am younger by one year. Me and my brother, we have fun.

[redacted]

In my free time I like to watch TV and am a big NASCAR fan. I also like music and football

I feel like part of my community but not much. Volunteering would help me feel more involved. But I will always be the strong man that I know I can be. I'm not gonna let anything stop me. I can't drive but I can still be strong + prove people wrong. So other paralyzed people, if you think you can't do something you are wrong unless you try.

Both collaborators with ASD were also aware of their diagnosis and viewed it as part of their self-image. For The Dark Knight, autism was a source of stress and guilt:

> The first time [the doctor] addressed this to me, saying that I am diagnosed with autism, it made me angry and scared at the same time. I was sad because I can't believe this. Why is this happening to me? I was saying to myself that it's all your fault Dark Knight. Why did you cry at school? Why did you let people bully you? You should have fought back!

But still he opened his narrative by defining himself through empowerment: "I like to care for and protect people…. to help and persevere and be an inspiration. I am also creative." Conversely, Diana was proud of her autism and embraced her uniqueness, although she did not discuss it with others: "I was 11…when my Mom and my dad said to me: ‘You got autism.’ But I was happy and excited because it helped me understand who I am. But…I kept it a secret to myself.” Similarly, while Pudding related his ADHD diagnosis in childhood, his adult identity is formed through positive attributes such as his sexuality and political identity and not by deficits.

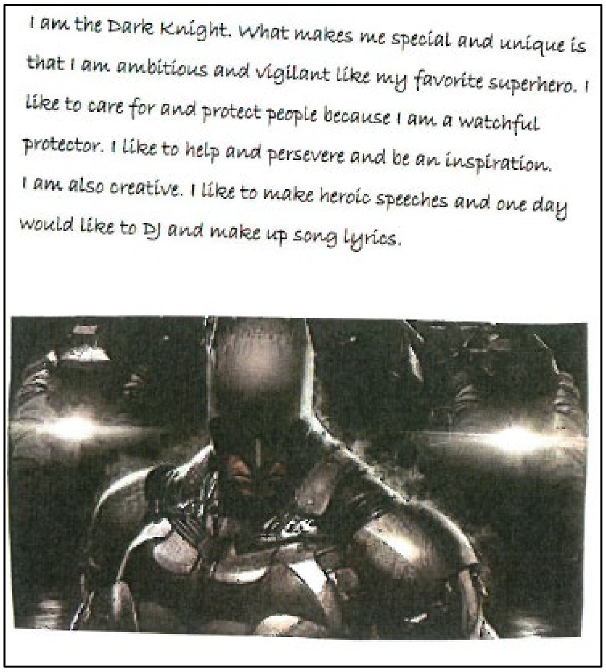
Upon prompting, Daredevil spoke of attending a special classroom but does not mention Down syndrome or impairment, instead consistently describing himself through goals and abilities. He was particularly proud of achieving supported living and when I—out of habit—referred to living in a group home several times during the interviews he became animated and made sure that I noted he lived in supported living—a mistake I quickly corrected. Batgirl described being in a special education classroom and receiving IEP services when prompted but does not mention disability at all. Instead, she defined herself as an athletic person who always had a best friend, could get along with everyone, and liked to help people so wanted to be a teacher. She was particularly proud of how many chores she did at home and how much responsibility she was given at school such as helping younger children to the bus and cleaning in the cafeteria. Sports Guy discussed his mental health diagnosis but never alluded to intellectual impairment and remained confident and determined to get a GED despite multiple failures. In fact, he was the one to read his own narrative aloud during final member check. So, while *Disability Identity* was a frequently used code, it was more often a secondary indicator. Instead, every collaborator expressed a complex identity not easily summed up by cultural reductionisms.

Empowered (Secret) Identities

Bus Rider was disappointed to discover he would never drive professionally but recalled the model of construction equipment he drove with his grandfather as well as of the bus that picked him up and dropped him off at his residential school. His chosen pseudonym demonstrated how deeply his identity is wrapped up in his of heavy equipment. Sports Guy's alias also reflects an ability-based self-identity. He sees himself as athletic and still shoots basketball to cope. Furthering a sense of empowerment, he plans to quit smoking so he can play sports again. He is also an avid fisherman who goes on trips with his group home. Diana—whose chosen pseudonym mirrors Wonder Woman's alter ego—still dreams of being a Disney Princess at a theme park one day and feels emboldened by family support: "My mom said, 'When you grow up, you will be just like Jasmine. You will sing, you will dance, and you will speak up for yourself.'" And The Dark Knight still desired to help and protect others despite being rejected by the world around him (see Figure 8). Unsurprisingly, he began imitating his namesake superhero in early childhood, attracted to the idea of an awkward, reclusive, and emotionally wounded millionaire who chooses to help from the shadows without expectation of acceptance. Similar desires to give back were consistent throughout narratives.

Figure 8

A Watchful Protector



I am the Dark Knight. What makes me special and unique is that I am ambitious and vigilant like my favorite superhero. I like to care for and protect people because I am a watchful protector. I like to help and persevere and be an inspiration. I am also creative. I like to make heroic speeches and one day would like to DJ and make up song lyrics.

Identity Through Altruism

Whereas The Dark Knight's altruism is hypothetical, Pudding framed his identity around being a good friend who helps others: "What makes me unique is that I'm very cool and nice and honest with my friends. I don't lie. I am a very social person and have a lot of friends. I like being part of a group." Helping others when she grew up was also a big part of Batgirl's developing vocational identity, and Sports Guy liked to cook the fish he catches for his roommates, was proud of doing chores, and repeatedly stated his desire to "be something with my life," dreaming of sharing his treasured fishing spot in Wisconsin with a spouse someday. Bus Rider only works one day a week but spends part of his money buying candy to share with his housemates despite their ongoing conflict. And even Daredevil, whose verbal and abstract conceptualization abilities were more restricted, was also proud of doing a broad variety of chores and framed his restaurant work around a desire to assist: “I worked in a restaurant and wanted to help customers when I grew up.” Diana was the only respondent who did few chores a child or as an adult, but misses the purpose provided by her job: “I am looking for getting a job at Publix because I need to work.” This demonstrates how the desire to give back is often connected with a desire for meaningful employment.

Identity Through Employment

Despite calls to distance from a strictly vocation-based outcomes emphasis in postsecondary transition, these collaborators also demonstrated the importance of vocation and usefulness to self-image. While they desired to help others, they also craved greater economic independence as well as the self-esteem provided through employment. As typical, exploration of vocational roles began in childhood and adolescence. Bus Rider learned to use large equipment with his grandfather but was sixteen before he realized his visual impairment would exclude him from driving equipment professionally. Sports Guy laid tile with his grandfather, though as an adult has only briefly held one job in fast food. Batgirl wanted to be a teacher when she grew up and was proud of the extra responsibilities given her to support this dream, but now she is content to sort clothes at a thrift shop part-time while contemplating working in the food industry one day, never indicating when she let go of her dream. Diana briefly spoke of wanting to be a nurse in addition to her dream of playing a princess at a theme park. As an adult she expressed satisfaction with her job bagging groceries and states a strong need to return to work: “I am looking for getting a job at Publix because I need to work.” Pudding has held multiple service jobs but still dreams of being a professional singer though he has not sung publicly since primary school. And Sports Guy repeatedly emphasized his desire to get a GED to facilitate employment. But although all collaborators desired employment, they lacked a framework through which to develop a consistent vocational identity.

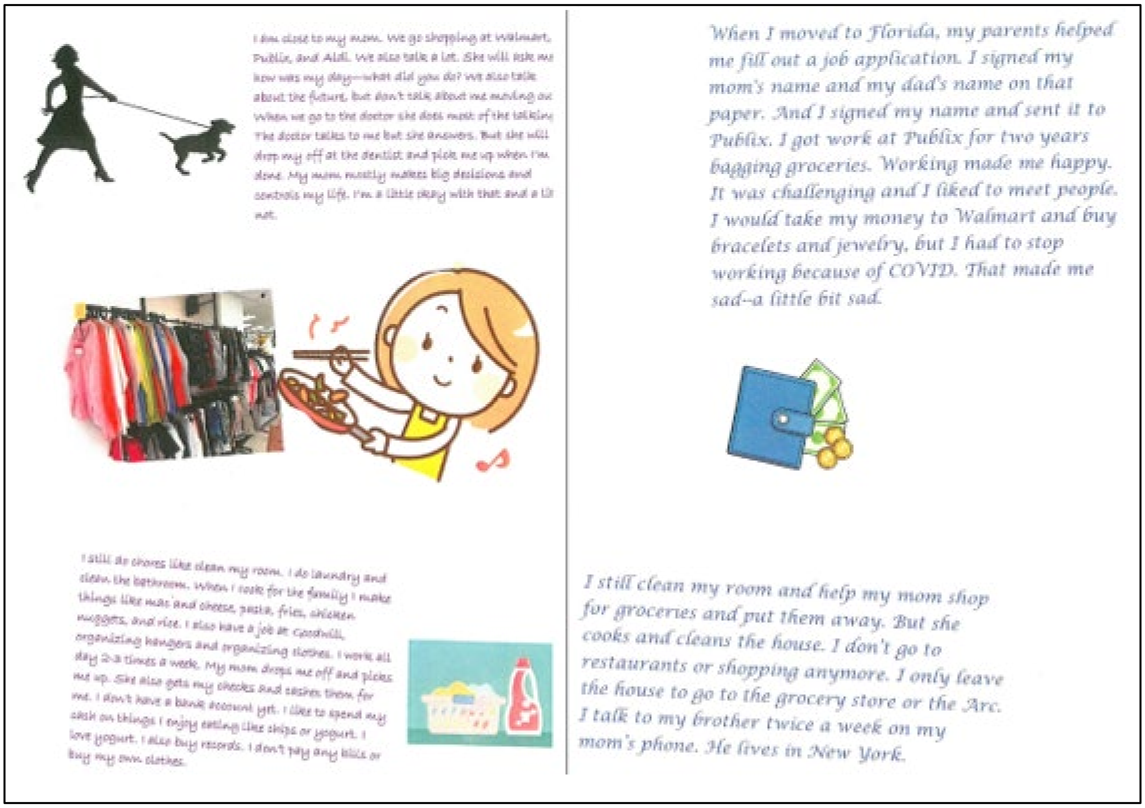
Fractured Vocational Identities

Collaborators consistently struggled to think of specific transition activities they performed to prepare them for work or community integration, with some general reference to job or social skills. A few like Diana and Daredevil did report going into the community to volunteer in vocational setting. Bus Rider participated in both volunteer experiences and paid employment, but he did not qualify for PSE vocational training and works part-time only once a week. Pudding attended a PSE vocational program but is also currently unemployed and does not have a clear goal beyond being a professional singing despite not having sang regularly in public since primary school. Policy is in place to address transition—and imperfect memory is not proof of a lack of such services—but the reported siloed nature of services appears have created at best fragmented identities for both career and broader community participation.

Daredevil came the closest to creating such a clear vocational vision. He received vocational training in community food service settings and worked in this capacity consistently if not competitively until the COVID-19 pandemic disrupted his employment as it did for Diana and Pudding. Sports Guy continues to pursue a GED but generally aspires to work in the food service industry although also mentions laying tile again without a specific plan. And Batgirl does not mention when she gave up her dream of being a teacher—it simply disappeared from the narrative, much like Diana's desire to become a nurse (see Figure 9). Now she simply desires to resume bagging groceries. When asked for plan, Pudding is hoping for a janitorial job in a local industrial plant with no real plans to resume singing. Except for Daredevil who has always aspired to work in the food industry, collaborators were unable connect their present lives with aspirations of youth.

Figure 9

Batgirl and Diana: Employment and Paternalism



I am close to my mom. We go shopping at Walmart, Publix, and Aldi. We also talk a lot. She will ask me how was my day—what did you do? We also talk about the future, but don't talk about me moving out. When we go to the doctor she does most of the talking. The doctor talks to me but she answers. But she will drop my off at the dentist and pick me up when I'm done. My mom mostly makes big decisions and controls my life. I'm a little okay with that and a lit not.

I still do chores like clean my room. I do laundry and clean the bathroom. When I cook for the family I make things like mac and cheese, pasta, fries, chicken nuggets, and rice. I also have a job at Goodwill, organizing hangers and organizing clothes. I work all day 2-3 times a week. My mom drops me off and picks me up. She also gets my checks and cashes them for me. I don't have a bank account yet. I like to spend my cash on things I enjoy eating like chips or yogurt. I love yogurt. I also buy records. I don't pay any bills or buy my own clothes.

When I moved to Florida, my parents helped me fill out a job application. I signed my mom's name and my dad's name on that paper. And I signed my name and sent it to Publix. I got work at Publix for two years bagging groceries. Working made me happy. It was challenging and I liked to meet people. I would take my money to Walmart and buy bracelets and jewelry, but I had to stop working because of COVID. That made me sad--a little bit sad.

I still clean my room and help my mom shop for groceries and put them away. But she cooks and cleans the house. I don't go to restaurants or shopping anymore. I only leave the house to go to the grocery store or the Arc. I talk to my brother twice a week on my mom's phone. He lives in New York.

Relationship to Research Questions

This theme directly answers RQs 2 and 3. In conceptualizing quality of life relating to community integration as in RQ2, this theme demonstrates how collaborators construct their identity and place in the community through their desires, preferences, and abilities.

QOL & Well-being Through Productivity and Usefulness. It should not be surprising that collaborators did not perceive a policy cliff. Their partial dependency into adulthood places the stress of seeking policy supports on caregivers. But the absence of perceived loss upon aging out of IDEA services was also influenced by the fact they do not view themselves through deficit or disability. Instead, they described themselves as persons with hopes and dreams and complex realities who simply entered adulthood like everyone else. Thus, they conceptualized their community integration through this lens. They wanted to feel useful, and when they were allowed to contribute, they felt connected. This is reflected in a strong sense of altruism and a desire to feel productive and give back through employment. It is common for one to define their role in their community by what they have to offer and what roles they assume. It is no less true for this population, whose contributions are often overlooked and underestimated. This is a small but important difference. Collaborators defined themselves not by what they were excluded from contributing, but rather by what they felt they could contribute if allowed. They do not ignore barriers and exclusion, but their loci are healthily internal. Nevertheless, their failure to nurture clear and consistent vocational and adult role identities illustrates the siloed and fractured public policy addressing postsecondary transition as explored through RQ3.

Siloed Services Lead to Fractured Identities

Per IDEA mandates, vocational goals and adult life skills were addressed with this population but not in a consistent, aligned manner starting in early childhood in a way allowing for a positive, realistic, and functional future-visions to emerge. All collaborators were optimistic, yet their present vocational aspirations rarely aligned with those of childhood and adolescence. While some of their goals such as being a professional singer or retiring young to the Bahamas may seem fanciful, it is very human to bolster achievable goals with fantasy and dreams. However, it is not unreasonable to think Batgirl could find a role in a school rather than a thrift store and Diana in a hospital as opposed to a grocery store with proper support. But collaborators had little opportunity to explore early vocational dreams in a meaningful manner that respected their interests. Therefore, they would be better served by a more coherent policy agenda employing increased service coordination to help persons with IDD form achievable dreams.

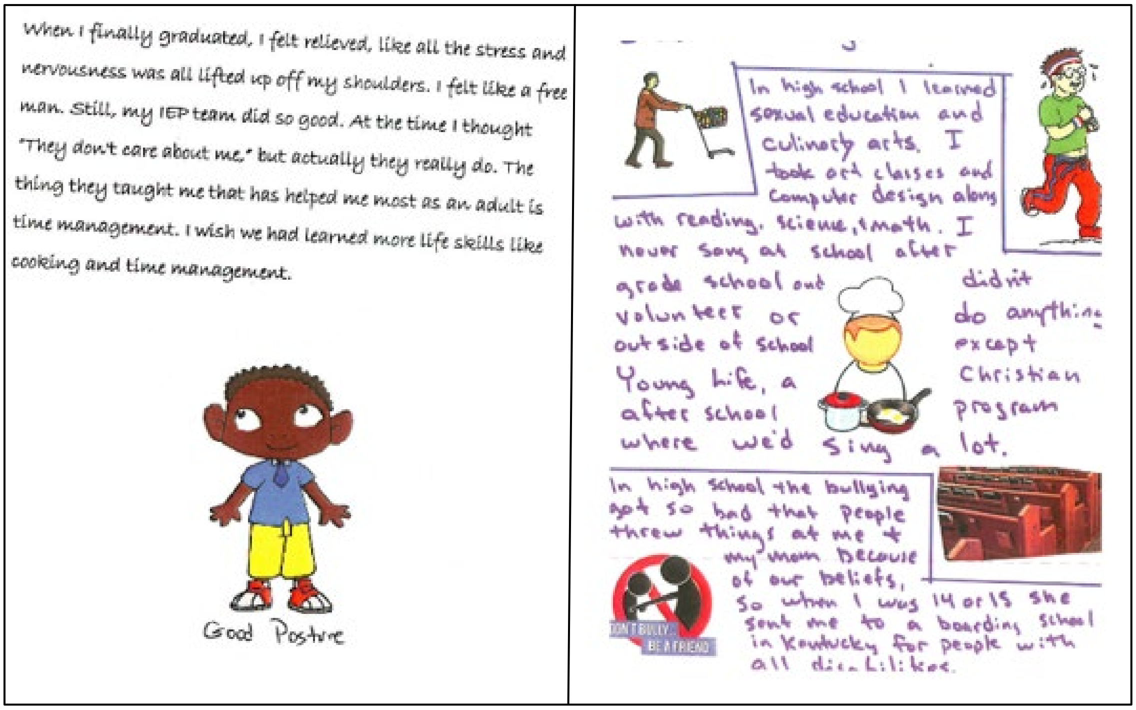
Mountains of Exclusion: The Policy Cliff as a Slow Climb, not a Quick Fall

Graduation as an Accomplishment or Relief

The code *Policy Cliff* was another code that was used in data analysis much less than anticipated. Instead, graduation or aging out of secondary schools was not perceived as an abrupt disruption, but rather as an accomplishment for those who had positive experiences and a relief for the others. Whereas The Dark Knight “felt like a free man” upon graduation (see Figure 10), Daredevil too was happy to graduate, having summed up secondary education solely through experiences of bullying. For Pudding and Sports Guy, the turmoil was so extreme that they dropped out before aging out. When asked to reflect on how IDEA and policy supports could have been more effective, Pudding responded: “I might have done better or stayed in school if there was less racism and bullying—if people accepted that I like boys” (see Figure 10). Sports Guy is not as specific, including his early exit with his unstable living situation. But even for those who had positive experience, this transition was seen as an accomplishment tinged with loss and not a tragedy.

Figure 10

The Dark Knight & Pudding Describing Mountains of Exclusion



When I finally graduated, I felt relieved, like all the stress and nervousness was all lifted up off my shoulders. I felt like a free man. Still, my IEP team did so good. At the time I thought "They don't care about me." but actually they really do. The thing they taught me that has helped me most as an adult is time management. I wish we had learned more life skills like cooking and time management.

In high school I learned sexual education and culinary arts. I took art clases and computer design along with reading, science, & math. I never sang at school after grade school and didn't volunteer or do anything outside of school except Young Life, a Christian after school program where we'd sing a lot.

In high school the bullying got so bad that people threw things at me & my mom because of our beliefs, So when I was 14 or 15 she sent me to a boarding school in Kentucky for people with all disabilities.

Diana reported: “When I graduated, I was happy because I was leaving all of my closest friends in high school. I was also scared and nervous. I felt ready to be a grown up.” And while Bus Rider and Batgirl were both sad to leave their friends, both expressed pride in the accomplishment of graduating and felt at least somewhat prepared to assume adult roles. So while collaborators did not experience a noticeable disruption upon losing IDEA support, all were aware of their ongoing struggles for independence and recognition. Sometimes the origins of this struggle were with the very ones who cared for and protected them.

Paternalism & Social Exclusion

All seven young adults still resided in dependent living situations, demonstrating how steep the mountains of exclusion they faced. NLTS2 data indicates that persons with ASD tend to achieve the lowest level of independent living and both Diana and The Dark Knight still live with parents although Diana was content with her situation and saw herself as living at home well into the future. Batgirl too lived at home and did not desire to move out but did express a desire for more independence. She noted that her mom did most of the talking at the doctor's office but was proud that she was dropped off and picked up at the dentist without supervision. Her mother also received and cashed her work check, and she had no bank account. Thus, her feelings about continued dependency were mixed: "My mom mostly makes big decisions and controls my life. I'm a little okay with that and a little not."

Bus Rider was one of few collaborators to gain early paid work experience prior to transition, but the money went to his parents, and he does not recall whether or not he was allowed to spend it on his own. He proudly noted that he is now legally an adult and can make his own decisions. He manages the money he receives from SSI and his job via a bank account but noted that his parents still held financial guardianship. Because of behaviors, he experienced a mix of family and institutional constraints that limited his independence, such as his mother blocking him form leaving the group home. And although he spent his money on candy and soda, he placed an order with staff and was not taken shopping. Sports Guy only held down one brief job as a young adult but received money from his family and only the left the group home on organized trips. He desired to get married and take control of his life, but expressed frustration that The Arc did not have programming to help him achieve his GED:

> We work on some job skills at the Arc, but…. The classes are too simple—like ABCs. What they need to do is test me, a math test or whatever. And whatever level I'm at we'd go from there and learn. Because I'm trying to get a GED and get a job.

Thus, he has a strong sense of aspiration and future vision but remained under strict institutional control. Raising children with IDD and empowering them in adulthood is a complex challenge. I would never suggest there is an easy answer. However, these collaborators clearly struggled against well-intentioned protectionism to reach their full potential.

One Step Forward, Two Steps Back

Even when collaborators achieved a degree of independence, it was easily lost. Pudding went from independent apartment living as part of a PSE program to supported living and then to a group home because of struggles with appropriate sexual expression. Diana, Daredevil, and Pudding all lost jobs due to the COVID-19 pandemic and have yet to regain them. And Sports Guy struggled to maintain a stable group home living environment: “I’ve lived in a lot of group homes ever since I was 17 or 18 and don’t like any of them. I would move to one and then they would call 911 and someone would come and I would move again." And after Bus Rider met a friend once at a fast food restaurant, even this simple act of freedom was taken away due to behaviors and safety concerns. Moreover, while all collaborators reported being active in their communities with their families while growing up, as adults the preponderance of leisure participation remained dependent—either through supported, supervised group home activities or through continued family activities. Only Diana and Batgirl saw friends socially, although The Dark Knight does have a friend that he shoots basketball with at the gym. So, the climb towards autonomy is a continuous struggle beginning in childhood and climbers can quickly backslide due to the slightest misstep.

Relationship to Research Questions

These revelations directly address RQ1: How do persons with IDD conceptualize their postsecondary transition journey and its impact on community integration through narratives? as well as RQ3 inquiry into policy insights.

A Steady Climb Instead of Steep Fall. Collaborators did not experience a policy cliff per se, but instead they spent their lives summitting a steep crest far more daunting than that required of typically developing peers. As noted under the third theme, while vocational and life skills were provided in school, collaborators failed to perceive a clear path towards transition provided by IDEA services along their journey; therefore, the loss of IDEA supports was not as traumatic or worrying as consistently reported by parents of persons with IDD. Perhaps this was because they were not connecting to their curriculum in a meaningful way applicable to their post-transition lives, for all collaborators were clearly expressed how their IDEA services were lacking and expressed a desire for greater practical training except Batgirl. By contrast Pudding, The Dark Knight, Batgirl, and Diana recalled more focus on academics over needed job and life skills during transition. And collaborators were able to clearly connect this educational failing with transition outcomes.

Policy Shortfalls. Pudding felt that greater inclusion and bullying prevention could have improved his transition services and wished he could have learned more applicable social skills. Batgirl reported "I wish I would have stayed a little longer and learned more, but I can't think of what," yet clearly her increased responsibilities at home and school failed to connect her to her job in education. And Diana stated: "I felt ready to be a grown up, but I wish I could have stayed longer and learned to be a good person, to be a good leader, and to be a good friend." Again, here desire was not for more academics but to learn how to be a better adult and citizen. The Dark Knight also reported: "I wish we had learned more life skills like cooking and time management," later expressing a complex and full-realized desire to be taught a path forward:

> The thing that would help me meet these goals is more confidence. Also motivation and more life skills—how to motivate myself instead of being inside a circled wagon. Instead, I'd be out of my comfort zone and learn how to get a job.

Perceiving similar gaps, Sports Guy admitted: "To get a job I know I need to act right, you know—don't mess up, and keep going right." Even Bus Rider, who received the most comprehensive and coordinated services still struggled to achieve independence and is thirsty to learn social skills and control his behaviors. But it was also difficult for collaborators to achieve independence when caregivers will not let go.

All seven collaborators reported control by their families, with Batgirl, Pudding, Bus Rider, and Sports Guy framing this in at least partially negative terms. Only Diana expressed contentment to live dependently, while The Dark Knight desired more but lacks the courage and knowledge to move forward:

> I don’t have a job, but I talk to my dad a lot, having deep conversations about what I want to do with my life…. He told me, “You know, whenever you feel like you want to own the business, I can teach you.” And I said “Okay, dad, I'll let you know.” So far I haven't let him know yet.

Sports Guy, Bus Rider, and Pudding all continue to struggle with institutional dependency, with groups homes also driving healthcare in addition to leisure and daily living. All reported the mundane routine of group home living, though it was particularly pronounced for Sports Guy who continually returned to his desire to get a GED and get on with his life. Bus Rider reported working with his group home manager to be allowed to meet friends socially and hopes to move on to supported living, but this still seemed a distant goal. And Pudding dreams of leaving his group home and The Arc to move in with a boyfriend, but his life journey has taken him in the opposite direction from independent campus living to supported living to a group home due to his struggles with social skills and sexual expression. Daredevil is content to live in supported living, but desires to return to work. In fact, the failures for three of seven collaborators to return to work long after society has opened up from COVID-19 lockdowns illustrates how this population is the last invited, first dismissed, and last to be asked back. So, while all collaborators viewed themselves through abilities and were optimistic about their futures and created empowered narrative, their stories also highlight ongoing struggles with both explicit and implicit social biases and barriers.

Summary

This study examined community integration outcomes of young adults with IDD upon postsecondary transition through a narrative inquiry design. Ultimately, seven people completed the interviews, and collaborated on creating mixed-media comic books telling their life stories into young adulthood in their own words. Analysis of these emic perspectives yielded four major themes relating to the three research questions. *Mountains of Exclusion: The Policy Cliff as a Slow Climb, not a Quick Fall* most directly answered RQ1, demonstrating that transition is not an abrupt disruption but a lifelong struggle that starts earlier than expected. This ongoing struggle is also represented by the theme *The Adolescent Earthquake: Transition Begins Earlier Than Expected* which demonstrates how the greater disruption from the perspective of persons with IDD began with adolescence and entering secondary education. This theme mostly closely aligned with RQ3 by showing that currently policy is falling to recognize how these issues that arise much early than age 16 where IDEA mandates transition planning begins. The findings suggest that going from grade school to middle school is the true transition due to emerging sexuality, increased social complexity, and a rise in bullying. Thus, adolescence emerged as the base of these mountains of exclusion.

Happiness is a Friend: Social Support, Not Community Integration, Drives QOL most directly answered RQ2 by demonstrating how collaborators conceptualized their well-being and sense of their place in the community more through social supports than community integration. Leisure and self-determination were also important factors, but rather than driving QOL, feeling of community integration reflected perceived QOL, with stronger social supports and self-efficacy leading to greater feelings of community connection despite quantitative measures. And *~~Dis~~Ability Identity: I Am a Complex Person not a Disability* addressed RQs 2 and 3, by demonstrating that these collaborators hold complex strength-based self-conceptualization as opposed to disability-centric identities, yet fractured policy supports and inconsistent life and vocational skills training led to fractured vocational and citizenship identities. Thus, there was a strong desire to participate in communities and give back amongst collaborators, but continued policy failures and exclusionary factors resulted in struggles to self-actualize such dreams and ambitions.

Such struggles to successfully integrate are not surprising. The quantitative and qualitative data from caregivers and other stakeholders demonstrates that persons with IDD continue to struggle to fully integrate into independent life roles at home and in the community. Despite this, these collaborators maintained positive and empowered self-images while shedding new light on how they struggled with family and institutional paternalism, social hostility, fractured future-visions, low expectations, and a lifelong climb of a steep summit of exclusion. They also maintained a strong desire and give back, as well as a thirst for continued training—particularly with social skills—to enable successful adult role participation.

In Chapter 5 I will explore the implications of these conflicting factors and interpret these findings in the context of contemporary literature on the topic. Additionally, I will present the study limitations, make recommendations in three realms based on these findings, and conclude by revisiting this study's implications for creating positive social change.

Chapter 5: Discussion, Conclusions, and Recommendations

This study employed narrative inquiry to seek perspectives on postsecondary transition outcomes from young adults with IDD relating to community integration and QOL in their own words. Research questions centered on what their conceptualizations revealed about community integration and general wellbeing in young adulthood, as well as what successes and failures during this process revealed about the public policies that guide postsecondary transition. Per recommendations for adapting research to accommodate this population, both verbal and visual data were combined into comic books for seven collaborators telling their life journeys through postsecondary transition and into young adulthood.

Collected data was analyzed through preliminary informal analysis and four cycles of coding. This information was then triangulated through an iterative process for theme development as detailed in Chapter 4, with four major themes emerging: (a) Happiness is a Friend: Social Support Not Community Integration Drives QOL, (b) The Adolescent Earthquake: Transition Begins Earlier Than Expected, (c) ~~Dis~~Ability Identity: I Am a Complex Person not a Disability, and (d) Mountains of Exclusion: The Policy Cliff as a Slow Climb, not a Quick Fall. In Chapter 5, I conclude by interpreting these findings within the context of current literature, explore the limitations of findings, make recommendations in three realms, and discuss the implications for positive social change.

Interpretation of Findings

Chapter 4 examined the four major themes from the data while relating the research questions back to the themes to emphasize the empowerment of the narrator.

Conversely, because Polkinghorne’s analysis of narratives as augmented by Kim (2016) posits that narrative data is ultimately interpreted through the lens of the research questions as derived from the theoretical framework I decided to here interpret the results through the lens of the research questions to explore how the findings support, expand upon, and/or refute existing literature in order to carry the conversation forward.

Research Question 1

How do persons with IDD conceptualize their postsecondary transition journey and its impact on community integration through narratives?

Confirming Deficits in Community Participation

Overall, the results of this study affirm the extensive findings from quantitative studies indicating significant delays in all categories of community integration, with the most prominent source being the NLTS2 (National Center for Special Education Research, n.d.; Newman et al., 2011). For example, none of the collaborators lived independently, nor were any competitively employed, as reflected in NLTS2 data demonstrating that persons with IDD consistently report significantly decreased levels of participation in these areas (Newman et al., 2011). Only two collaborators were currently employed part-time, and one had never held a paying position. As adults, Batgirl was the only respondent to report regularly meeting friends in the community. Other participants either relied on family or organized group home activities to engage in the community. And only Pudding voted. However, while this quantitatively points to low rates of community integration, the theme *Happiness is a Friend: Social Support Not Community*

Integration Drives QOL demonstrates that this was not the most important factor for collaborators in conceptualizing well-being, as will be discussed further under RQ2.

It Takes ~~a Village~~ an Extended Family

Postsecondary transition literature focused on caregiver perspectives repeatedly arrived at the theme *It Takes a Village* (Joly, 2015). But while caregivers in these previous studies relied on a broad network of friends and professionals for support when raising a child with IDD, these collaborators primarily relied on extended family for support. Although they described friendships as necessary for happiness, extended family and family-like relationships were vital for life skills development, adult role exploration, and establishing emotional well-being, with teachers and other professionals serving a minor role. Bus Rider referred to an old landlord like surrogate family. For others, grandparents were critical for support beyond the immediate household.

Sports Guy's happiest memories and only paid work experience involved his grandfather. Bus Rider learned to use heavy equipment with his grandfather. And Pudding, Batgirl, and Daredevil all reported spending extensive time with grandparents. The Dark Knight, Sports Guy, and Batgirl all traveled widely to see aunts, uncles, and cousins and cited these trips as amongst their most cherished memories. This focus on family over larger social networks illustrated the different experiences of children versus their caregivers.

The Unseen Policy Cliff

Another key difference from the literature is the absence of a perceived policy cliff. This concept is so deeply imbedded in the literature that it served as a cornerstone for this study’s development, with multiple literature reviews illustrating that caregivers consistently conceptualize postsecondary transition as falling off a cliff or into a black hole (Asp et al., 2015; Franklin et al., 2019; Hirano et al., 2018; Joly, 2015). Yet amongst these collaborators, the theme *Mountains of Exclusion: The Policy Cliff as a Slow Climb, not a Quick Fall* demonstrated that collaborators experienced exclusion and challenges as a slow climb throughout their entire lives rather than as a sudden disruption upon losing IDEA services. While respondents frequently referred to special education supports and services, rarely did these services dominate their recollections. Thus, graduation was perceived as a relief for those experiencing extreme bullying and an accomplishment by those who had mostly positive experiences.

Nevertheless, collaborators did perceive a partial failure in service provision, consistently reporting a desire for greater life and social skills training in secondary education and beyond, echoing a theme in the currently literature demonstrating a need for more of such training (Berg et al., 2017; Dymond, et al., 2017; Lee et al., 2019; White et al., 2017). The importance of these skills will be explored further under RQ2, but for these collaborators, the true freefall was felt upon leaving primary school, as noted by the theme *The Adolescent Earthquake: Transition Begins Earlier Than Expected*. This theme also uncovered specific topics absent from the literature such as bullying, increasingly complexity of social networks in middle school, and relationships and sexuality.

Gaps in Contemporary Transition Literature

In an approach similar to this one, Francis et al.'s (2020) phenomenological study of the perspectives of young adults with IDD in a PSE setting demonstrated the importance of including emic perspectives. While many of their subjects reported positive interactions with family and PSE personnel, others complained of conflict and protectiveness with their families as well as PSE professionals overstepping their boundaries and exerting paternalism that undermined their independence and sense of identity. But although caregivers may not fully grasp the effects of their own protectionism, hints of this theme crop up throughout the literature. Jacobs et al. (2018) identified this struggle to form fully realized adult identities in a literature review of qualitative studies in four major English-speaking countries, although families largely placed the blame solely on social exclusion. But this data indicated the cause goes beyond a single source.

Batgirl, Pudding, and Bus Rider al felt at least somewhat constrained by family they cared deeply about and depended upon. As illustrated by the theme *~~Dis~~Ability Identity: I Am a Complex Person not a Disability*, the subjects of this study expressed complex identities and a desire to be empowered, respected, and understood while simultaneously struggling to achieve independence and form actionable future visions. This could come in the form of families, such as Bus Rider's mom blocking him socializing outside his group home, or the institutions themselves, with all group home residents relying near completely on organized recreation for community involvement. Thus, while these subjects echo concerns raised by other stakeholders throughout the literature, there are key differences in their perceptions, making it clear that we cannot continue to address postsecondary transition through research and policy without first fully considering the goals, preferences, needs, and perspectives of those addressed.

Research Question 2

What do these narratives of the postsecondary transition journey reveal about current quality of life and sense of well-being of persons with IDD in relation to community integration?

Rethinking the Rethinking of Postsecondary Transition Outcomes

The collaborators for this study consistently identified QOL factors in conceptualizing their sense of well-being, yet community integration was at best a secondary concern. I undertook my literature review focusing on vocational transition although calls for a broader embrace of educational outcomes through community integration by authors such as Black and Lawson (2017), Lee and Morningstar (2019), and Liasidou and Symeou (2018) prompted me to broaden my perspective. While these and other authors did not explicitly connect QOL and community integration, the literature did treat community integration as a primary indicator of QOL. In this research, however, the complex conceptualizations of collaborators' place in the community as exposed by the theme *Happiness is a Friend: Social Support Not Community Integration Drives QOL* forced me to rethink this concept. Self-determination was an important marker of QOL, but that included the power to choose not to integrate.

Support Over Integration as a Primary Indicator of QOL

Authors such as White et al. (2018) and Jones et al. (2018) found strong correlations between self-determination and positive perceptions of QOL. The importance of self-determination for postsecondary success is imprinted throughout the literature (Daviso et al., 2016; Hoover, 2016; Kester et al., 2019; Oertle & O'Leary, 2017; Qian et al., 2018; Ruble et al., 2019; Sansosti et al., 2017; Wehman et al., 2014). Other authors have shown how social and institutional supports can foster great self-determination (Schillaci et al., 2021; Shogren et al., 2018). This held true in this study where those who expressed higher levels of self-determination and efficacy—Daredevil, Batgirl, and Diana—framed their lives in mostly positive narratives. By contrast, Pudding and Sports Guy struggled to navigate both their home and social environments and thus control their fates, and their narratives were dominated by these struggles. Yet this pattern seemed to have little to do with quantitative measures of community integration cited in the literature. Instead, those with stable living situations and strong social connections reported feeling connected to their community regardless of how much time they spend outside the home; thus, during data analysis I began to move away from the commonly held false dichotomy between public and private life denoted by community integration towards a focus on role participation per Rosenbaum and Gorter's (2012) the six f-words: family, fun, friends, fitness, function, and future, for these participation factors do not distinguish between public and private role performance.

For example, Diana—who has an ASD diagnosis—rarely leaves the home but was one whose story most consistently expressed happiness and contentment at home with family and friends:

> We stay home, but one time a week my friends from The Arc will come over to my house and we play games. I like being at home. For exercise I go on walks with my dad twice a week. We walk around a pond on a street. I also do yoga with my mom.

When Diana interacted with family and friends at home was she not an integrated member of her community? The Dark Knight also has an ASD diagnosis and found great meaning in going to the gym: "In my free time, mostly on weekends, I go to the gym and walk on the treadmill or shoot basketball, sometimes with my dad and sometimes with my friend." By interacting with friends and family in a public place, The Dark Knights maintained health and wellness, thus affecting his community by reducing burden on the healthcare system. But by walking near her home and doing yoga with family, was Diana less integrated and having less positive impact than The Dark Knight exercising at a gym? Such contradictions during provisional coding forced me to reconsider my own values and conceptualizations because they demonstrated how role participation was more important for collaborators than community integration, which is an externally imposed concept. For collaborators, self-determination was more important—including the right to stay at home and not integrate or participate. Therefore, by shifting analysis to role participation as defined by collaborators as opposed to community integration measures determined by researchers, a clearer picture of these participants' needs and priorities emerged. And one such need identified by collaborators that did align with current literature was a need for greater social skills training.

Social Skills as the Key to Connection and Independence

The literature suggests that social skills are being inadequately addressed during transition (Chiang et al., 2017; Lee et al., 2019), and there is emerging evidence on the effectiveness of social skills training for promoting more successful postsecondary transition outcomes (Grob et al., 2019; Landsiedel et al., 2021; Nasamran et al., 2017;

Smith et al., 2021). The results of this study confirm this evidence, showing a strong correlation between social skills and both self-determination and QOL. The Dark Knight displayed significantly higher cognitive, memory, and verbal skills than the other collaborators but lived at home, never had a job, and reported near-total social exclusion. He thus framed his narrative with low levels of self-efficacy. Also of note, The Dark Knight was the only collaborator without a sibling. By contrast, Daredevil had Down syndrome that manifested in lesser recall and conceptualizations as well as labored speech; however, he was good at following rules and getting along with others. He was also the most independent, having achieved supported living status as well as being the most consistently employed until the COVID-19 pandemic eliminated his job.

By contrast, Sports Guy and Pudding were both thoughtful and able to recall rich detail which led to heightened levels of conceptualization of their experiences, but both struggled with social interactions and thus report low levels of self-efficacy. Similarly, both feel disconnected from their communities and are unable to consistently maintain employment or graduate from group homes. Like The Dark Knight, Diana also had a diagnosis of ASD and still lived at home with no plans or desire to leave. This reflects NLTS2 data where most categories of community integration were consistently low but independent living was notably lower for person with autism—a diagnosis defined by social skills deficits. However, Diana’s contentment with her circumstance illustrates why the preferences and goals of those with IDD must be brought into discussions when analyzing community integration. For Diana independent living would be a disruptive loss of support rather than positive QOL step towards independence. Per the theme

~~Dis~~Ability Identity: I Am a Complex Person not a Disability, these collaborators did not define themselves through their deficits or exclusions, and instead expressed complex and varying self-conceptualizations that were neither simple nor monolithic. Thus, as will be discussed under Recommendations, the focus of research and policy should continue to pivot towards empowering this population to form a more fully realized vision of the future based on internal self-determination of desired role participation as opposed to external measure of integration.

Research Question 3

What do these stories reveal about policies currently guiding postsecondary transition and potential policy changes?

Siloed Supports

Collaborators in this study generally did not possess the experience or perspective to intricately comment on the policy that guided their postsecondary journeys, yet their conceptualizations shed light nonetheless. The largest policy shortfall cited ubiquitously throughout the literature—and that continues to emerge in contemporary studies—is the complaint of siloed service providers that inadequately communicate regarding transition services (e.g., Benson et al., 2021; Franklin et al., 2019; Joly, 2015; Oertle et al., 2021; Plotner et al., 2020). While collaborators did not directly identify this trend, the fractured visions and unsteady supports addressed by the theme *~~Dis~~Ability Identity: I Am a Complex Person not a Disability* reflect this failure to fully integrate services and communicate in a manner that enables person with IDD to develop full-formed future visions. Collaborators such as Pudding and Sports Guys struggled to recall IDEA supports. For example, Sports Guy stated “I don’t have memories of working with an IEP team in high school but did practice interviewing for a job, worked on getting along with other people, and learned money and time management.” Diana, Batgirl, and The Dark Knight reported scattered, isolated services, with the latter stating:

> The IEP team didn’t ask what I wanted to be when I grew up, but I told them I wanted to be a businessman like my dad. They suggested I take a class in business administration but at the time I was in a mental state, and I couldn't handle it.

This does not mean that no one asked The Dark Knight what he wanted to be when he grew up—the IEP mandate for transition services makes it likely that he was asked along the way—and his teachers offered a clear and logical step forward. However, his recollection does illustrate a failure to make his vocational identity enough of a priority to consistently craft an internalized vision over time, especially considering the strength of The Dark Knight’s memory.

Cookie-Cutter Training & Fragmented Vocational Visions

During transition, Diana stated: “We also talked about how I might want to be a nurse when I grew up and wrote goals for me to make friends,” but she is unable to provide an example where she was supported in developing or refining this vision and never mentions nursing again. Instead, she recalled: “I also worked with a job coach and teachers took me and my friends from class out in the community to volunteer, like to sweep the floors in a mall and work in a grocery store,” and her one job as an adult has been bagging groceries. She provided no evidence that her preferences were considered in designing her vocational training. While the literature clearly supports the importance of community partners (Domin et al., 2021; Honeycutt et al., 2017; Hoover, 2016; Oertle & O'Leary, 2017; Qian et al., 2018; Poppen et al., 2016; Rast et al., 2020; Stein et al., 2016), there is a parallel call to tailor services towards strengths and preferences instead of perpetuating cookie-cutter approaches that limit career horizons (Hirano et al., 2018; Joseph et al., 2017; Lee et al., 2019; Oertle & O'Leary, 2017; Ruble et al., 2019). Instead, most of the secondary school curriculum recollections by these participants centered on academic skills along with occasional low-level service job training at local businesses.

Batgirl recalled learning how to take a test and getting a 100% although academic skills are not a strong employment predictor for this population. Diana, Pudding, The Dark Knight, and Sports Guy also reported a focus on academics over life skills. Therefore, while the inconsistency of collaborator recollections does not confirm an absence of vocational and life skills training during transition, the lack of a clear and consistent future vision at least hints at a policy failure to form a fully realized, comprehensive, and ongoing transition vision that is transmitted to the collaborators and reinforced across time and setting, echoing the problem of siloed services.

Transition Policy as Late to the Fire

Conversations about adult roles are certainly happening in some fashion because IDEA dictates that transition services begin at 16—with some states mandating earlier; however, the theme *The Adolescent Earthquake: Transition Begins Earlier Than Expected* strongly suggests that waiting this late is a major policy failure, like sending firemen to stop a blaze only after it has engulfed the entire structure. As previously noted, while all seven narratives centered around mostly happy childhoods, all but Batgirl and

Bus Rider reported a steep increase in turmoil and a sharp decrease in QOL and well-being upon leaving primary school—and for Bus Rider, this turmoil was simply punted into young adulthood. This sudden disruption was most succinctly captured by Pudding: "I had a good childhood. But I started to have more troubles in middle and high school when other kids started picking on me." By contrast, Daredevil's predominately positive narrative briefly mentioned bullying before skipping over the rest of secondary school. Bullying and conflict in high school was so bad that Sports Guy and Pudding dropped out and The Dark Knight simply endured out of necessity. Clearly, these collaborators would have benefited from heightened transition supports well before age 16, but these narratives also exposed gaps in our understanding of transition concerns.

A Missing F-word and Other Conspicuous Absences

The absence of provisional codes addressing positive supports revealed a negativity bias (researchers are often looking for problems, not affirmations). It also revealed the persistence of ableism despite researchers' best intention. For example, while disability literature spends much time and effort conceptualizing adult roles through various lenses such as Rosenbaum and Gorter's (2012) the six f-words (family, fun, friends, fitness, function, and future), themes such as sex and relationships are not considered. While Rosebaum and Gorter developed their language to conceptualize childhood roles, at least a third of childhood is spend in adolescence which is defined by the emergence of sexual traits; therefore, the lack of an f-word or similar thematic indicator in postsecondary transition literature is a conspicuous—and ironic—absence that became readily apparent during open coding. Literature addressing sexuality and

IDD does exist, although it has never been clearly connected to literature on postsecondary transition. Further, while all collaborators expressed a desire to feel useful and help others, altruism was only mentioned in the literature as justification for including persons with IDD in research (McDonald et al., 2016; Sigstad & Garrels, 2017; Sunderland et al., 2015), and not as a guiding consideration of life roles and future vision despite helping others and feeling useful residing at the core of collaborator self-image. In turn, codes that weighed heavily in the literature review such as *Policy Cliff* were very infrequently used, indicating that while caregivers experience an abrupt and traumatic transition, collaborators simply experienced it as part of growing up.

Limitations of Study

As discussed in Chapter 3, qualitative studies tend to employ smaller sample sizes (Patton, 2015). This is especially true for narrative inquiry which addresses complex subjects through rich description (Kim, 2016). Ultimately this study relied on the creation of seven narratives. While data analysis indicated saturation of themes during data analysis, this study can only be considered exploratory in nature. Efforts were made to achieve a representative sample but while the results indicate a need to research concepts such as the disruption of adolescence and prevalence of bullying, the results cannot be extrapolated to confirm the presence across all persons with IDD. Sampling was also conducted through The Arc. While this agency looms large in advocating for and supporting persons with IDD in adulthood, the very fact that the sampled population regularly attended The Arc programming excluded those who may have achieved higher levels of employment and independent living conditions. The data also reflects transition specific to the North Florida regions. Nearly half of collaborators (n=3) spent a large portion of their childhood in other regions, but all currently reside in North Florida. While many policies such as IDEA are federal in origin, regional variations are part of United States policy composition. In fact, narrative inquiry embraces and focuses on the effect of place on experiences. Therefore, while many universal struggles, triumphs, themes, and considerations arose in these narratives as supported by literature on the topic, the transferability of results should not be overstated.

The memoires, communication abilities, and cognitive processing of collaborators also limited the scope of results. For example, Daredevil’s narrative was roughly half the length of other narratives due to lesser abilities to expand and conceptualize whereas The Dark Knight was highly verbal with strong recall and thus able to provide rich detail. Although human memory is broadly understood as malleable and unreliable, narrative inquiry asserts that our stories reveal how we conceptualize our experiences. Thus, the choice was made to not verify or augment narratives by interviewing caregivers or others who may have possessed corroborating information, though I did confirm age and diagnosis since these were crucial to validity in sampling. So, while this method empowered participants and respected their self-conceptualizations through a narrative inquiry lens, there were limitations to collaborator report such as in-depth critiques of public policy.

Finally, the study was limited by my own biases and perspectives. I began my literature review by focusing primarily on vocational outcomes, but the literature review spurred me to broaden my perspective. I conducted reflexive journaling where I tried to limit my influence on the narrative, but narrative inquiry in a relational method and by the nature of this interview and question selection an interviewer will inevitably influence the collaborator (Clandinin, 2016; Jovchelovitch & Bauer, 2000; Patton, 2015; Rubin & Rubin, 2012). An example of uncovering such bias can be seen in my decision to distance myself from the concept of community integration due to its external locus; however, other biases may have remained unobserved. And while I took steps throughout to maintain the highest possible level of neutrality, the impact of the researcher through the intersection of narratives must be acknowledged. In the end I chose to value and respect the recollections of these participants which is in itself a bias, though one I would argue is preferable to the alternative bias.

Recommendations

This study resulted from the intersection of my unique background and influences as a researcher. I have a Master's in literature with a long history or writing both fiction and non; therefore, I found narrative inquiry highly appealing. I am currently an occupational therapy practitioner and instructor who is seeking a doctoral degree in Public Policy and Administration. Together, these intersections have provided a unique perspective. For example, CDT, postsecondary transition, and therapy practices using superhero tropes and occupation-based methods such as creating a comic book appealed to my OT self while the policy implications called to the Public Policy and Administration scholar. Further, mental health is a major focus of the OT profession and a personal interest of mine, which led to me explore narrative psychology. Thus, drawing from these many roles and perspectives, I am making recommendations not only for further research and future policy initiatives, but am proposing this methodology as a way to the voices of person with IDD in studies of a range of topics as well as a potential treatment intervention.

Research Recommendations

This study was built upon calls by other researchers for greater inclusion of the perspectives of persons with IDD describing their postsecondary outcomes (Amado et al., 2013; Lee & Morningstar, 2019). This aligns with CDT's central premise of empowering voices of persons with disabilities as expressed in Charlton's (2000) motto: *Nothing about us without us*. While this study is a step forward, greater inclusion of the voices of IDD is needed throughout the literature. Specifically, this study highlights the need to further explore the effects of adolescence on disability to confirm or refute this as a significant and daunting transition for this population. Within these studies, specific attention should be paid to bullying and sexual relationships since this study suggests an alarming ubiquity of the former and a lack of information and education on the latter. Gender should also be examined more closely to determine if the heightened bullying experienced by male collaborators versus female is a fluke of small sample size or a broad trend worth further investigation. The fact that The Dark Knight was the only collaborator without a sibling and subsequently experienced the greatest feelings of isolation and lest efficacy regarding social skills warrants investigation into how siblings affect social skills and personal identity development for persons with IDD, because those with the strongest sibling relationships such as Batgirl and Diana also possessed the most stable self-images. Finally, further study is warranted on the public/private dichotomy regarding community integration. These results suggest that personal connections and not connection to community institutions or activities are more important for QOL and feelings of life satisfaction and that in some cases forcing community integration could actually have negative effects. With a continued research and policy focus on community integration as a measure, the validity of this concept should be explored further. Perhaps role participation should be the standard, although this exploratory evidence is not sufficient to affirm this paradigm shift.

Policy Recommendations

Although further research is needed, the most pressing policy implication of this research is that IDEA's mandate that transition services begin at age 16 (United States Office of Special Education Programs, n.d.) is grossly insufficient and needs to commence much earlier. These collaborators experienced a greater freefall upon exiting primary school as opposed to high school. Thus, it warrants examination if transition services should begin earlier and occur at each stage of educational transition with emphasis on changing social complexities. Further, while bullying programs are being embraced with greater urgency, emphasis should be placed on protecting persons from vulnerable populations. And although sex education is a hotbed issue, these results suggest that persons with IDD would benefit from mandates to address sexuality and relationships as part of life skills training.

These results also connect the literature exposing the problems with siloed services (Benson et al., 2021; Francis et al., 2020; Joly, 2015; Oertle et al., 2021; Plotner et al., 2020) with those illustrating fractured identity formation (Franklin et al., 2019;

Jacobs et al., 2018). So, although these results are limited in scope, supporting evidence throughout the literature suggests that adult role and vocational identity should be more explicitly addressed. The above-cited studies indicate that persons with disabilities are less likely to be asked what they want to be or do when they grow up, inadvertently limiting their options through soft discrimination. Thus, all stakeholders should be educated and encouraged to repeat and reinforce these concepts to help persons with IDD develop a fully realized future vision as they grow. Persons with IDD are cognitively able and self-reflective, but they tend to rely more on concrete thinking; thus, these concepts should be reinforced more concretely. This could be codified in the form of an actual document attached to the IEP that is shared and continually reviewed and revised throughout the transition process. Again, future goals and vocational identity are being addressed in public schools; however, these collaborators demonstrated the disconnect identified in the literature of internalizing coherent future visions. Thus, a concrete plan that is shared between parents and service providers could help break down these siloes and help persons with IDD construct concrete visions of their future selves beyond transition.

Practice and Methodological Recommendations

There is also a need for greater inclusion of the voices of persons with IDD throughout all disciplines and areas of research. My greatest hope for this study is that it can serve as an IRB-tested path forward for future researchers with a firm theoretical and evidence-based foundation drawing from multiple disciplines and perspectives. This concept of creating a comic book proved not only concrete and readily accessible for collaborators, but also enjoyable and motivating. While further research into efficacy is needed, non-verbal and verbal responses were indicative of pride and empowerment in being enabled to share their stories and being told that their stories matter. And the theoretical foundation and methodological evidence provided in Chapters 2 and 3 support the validity of this unique approach to narrative inquiry.

Further, the evidence provided regarding the therapeutic use of these story tropes as well as positive identify formation through narrative psychology suggest that this method is also applicable for therapeutic applications as well, particularly in occupational therapy, although counselors and other mental health practitioners could also explore this method. Additionally, tying back to the purpose of this study and suggestions for policy, perhaps such concrete serial storytelling employed by comic books could be harnessed throughout transition processes and programs to aid students in their identity and vision formation. Ultimately, I defer to the passion and creativity of future researchers and practitioners to build on this foundation with the ultimate goal of lifting this underrepresented population.

Implications for Positive Social Change

This study was conceptualized from the beginning to promote positive social change. The research questions emerged from a general literature review concerning postsecondary transition for persons with disabilities where it became apparent that, while there was much quantitative data showing that persons with IDD in particular are lagging behind their peers in all categories, there was a need to broaden the general understanding of transition aims (Black & Lawson, 2017; Lee & Morningstar, 2019;

Liasidou & Symeou, 2018). However, while there is a growing body of qualitative data seeking the perspectives of family caregivers and others on the periphery of this process, there is a gap in the literature empowering this population to conceptualize their journeys and outcomes in their own words (Amado, 2013; Lee & Morningstar, 2019). This aligns with a call from CDT literature for greater inclusion of excluded voices in the research process (Bjornsdottir et al., 2014; Clandinin & Raymond, 2006; Flynn, 2019; McDonald et al., 2016; Nind, 2008; Sigstad & Garrels, 2017; Smith-Chandler & Swart, 2014; Sunderland et al., 2015; Woodfield et al., 2020). Therefore, this study was designed to not only empower the voices of the seven collaborators, but to provide a path forward for future researchers seeking to collaborate with this population that has suffered inadvertent discrimination from well-meaning gatekeepers through paternalism and protectionism (Lessard et al., 2018; McDonald et al., 2016; Sigstad & Garrels, 2017; Sunderland et al., 2015).

The immediate implications for researchers and policy makers include findings such as *The Adolescent Earthquake* which indicate transition needs to be addressed much earlier than anticipated, as well as collaborator conceptualizations of their lives as a slow climb against exclusion as opposed to a sudden policy cliff at graduation that shows that this process is much more complicated than previously understood. This does not negate the concerns of caregivers who perhaps bear more of the brunt of the policy cliff, relying on policy supports to support their children with special needs, but it does show the importance of understanding the perspectives of those involved when designing outcomes.

This study also illustrated the prevalence of bullying and its devastating consequences for vulnerable populations which cause postsecondary transition to as often be a relief as a loss for those undergoing the journey. While bullying is increasingly a national point of concern addressed through policy, this study indicates a possible hidden epidemic where—like for so many other risk factors—persons with IDD suffer well beyond what is experienced by the general population. Equally important were the pride, determination, hopes, and dreams uncovered by this method. While victim narratives are common with this population, this study illuminated the complexity of the internal lives of persons with IDD as fully formed beings who seek to rise above the constraints that society casts upon them. Therefore, both the successes and failures exposed by these narratives have the potential to better inform future research and policy agendas by considering the perspectives of those being targeted.

Conclusion

While indisputable evidence has accumulated proving that persons with IDD are struggling to succeed in young adulthood for a variety of community integration and life role participation measures compared to their peers, this study provided one of the first conceptualizations of postsecondary transition outcomes in the actual words of those involved. By seeking these previously overlooked perspectives, this study found that transition truly begins upon entering adolescence and leaving primary school, as opposed to being an acute event upon aging out of IDEA services. While these results affirmed decreased levels of community participation and the need for greater social and life skills training per current literature, they also exposed the potential role of ableism in the very concept of community integration. These collaborators framed their well-being and QOL around connections over involvement, and this rather than quantity of community participation suggested that perhaps future studies examining outcomes and policy initiatives should focus on role participation in order to allow persons with IDD to determine their own desired levels of engagement as opposed to being judged by integration benchmarks as defined by the dominant culture.

Overall, convergences, expansions, gaps, and departures from the prevailing literature illustrate the importance of empowering person with IDD to speak for themselves, for the perceptions and lived realities of those with IDD clearly diverged in places from those of parents and professionals. A prevalence of victimization narratives and paternalistic practices have heretofore informed policy decisions based on insufficient data by excluding these perspectives like a presumptuous waiter bringing one’s order without affording the respect to view the menu or even state one’s appetites and preferences. Therefore, if there is but one takeaway from this study it is that persons with IDD are not a monolith and certainly not simple, but rather inhabit rich inner lives founded upon deep introspection. Not only did these collaborators desire to be listened to, but they deserve and need to be heard.

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Appendix A: Semi-structured Interview Session Scripts

Interview Guide for ____________________

Session 1

Introduction & Consent

Thank you for working with me today. As you may recall, my name is Eric Sarrett, and I am conducting a research study into what life looks like for young adults like you who went through the IEP transition process in high school [clarify as needed: An IEP team is the teachers, therapists, and other school officials that met with you and your parents to discuss the goals you work working on in school]. I want to help you share your story of leaving school and becoming an adult so people can learn from your experiences. I hope this will help show other people what kinds of things worked during your transition from high school and what different things we could do to help other people in the future. So, before we go on, do you understand why we're talking today?

Check: _______

That's okay. Let's go over what I'm doing again, then you can tell me if you have any more questions.

Good. Before we start, I want to review the form you signed and make sure that you are okay with me asking you questions and having you choose or draw pictures so we can create a comic book together telling your story. You can keep the book when we're finished and share it with your friends and family if you want to, but I want to make sure you understand that I will keep a copy and share parts of it with my professors [or teachers] at school as well as other people through things like journal articles—which are magazines for college professors—and conferences where teachers and therapists and other people interested in topics like this get together. But, I will keep your identity secret, so no one will know who I am really talking about. We'll talk more about that in a minute. [Answer questions about why their identity needs to be hidden if comes up, as some might like the idea of getting attention.]

Over the next few weeks we will talk about many things in your life. We will start by looking at what it was like growing up with a disability or maybe attending a different classroom than some of your peers. We will look at what it was like going to school when you have an IEP [a plan written just for you to help you learn the best you can]. We are going to then focus on what you did in middle school and high school to prepare you to transition to being an adult when you left school. Then we will end the story by looking at how you are doing now—what you feel good about and what you would still like to improve. I am particularly curious about what kinds of things you are currently doing outside your home and how teachers, therapists, vocational workers, and other people in the community prepared you to be as independent as you can as an adult. We also want to know how your family helped you. Are you comfortable talking about these things with me?

Check: _______

I completely understand. This isn't part of your training program here at the Arc so you don't have to do this if you don't want to. But thank you for coming back and talking to me about my project. It's okay to go back to what you were doing.

Good. For my research I will ask you questions and choose what parts to include in the book we write together, checking with you to make sure you like my choices and that they are accurate or correct. We will also choose pictures to help tell your story. It's really up to you. If you feel better using more pictures than words, we can do that. But if you like telling stories we can use more of your words in the story. And we can use any kinds of pictures you want. If you want to bring in photographs, we can use those, but we will make copies so we don't damage them and may have to draw a mask on your face to protect your identity. If you want to clip pictures from magazines that help you say what you want, that's fine too. I will have some magazines here you can look through, or you can bring favorite magazines if you don't mind cutting them up. And if you want to draw pictures to tell me what you are thinking, you can draw pictures and bring them in or I'll bring paper and markers and we you can draw while we work together. And remember, you don't have to answer any questions you don't want to or share anything that makes you uncomfortable. Just tell me you don't want to answer that question, and I promise never to be mad or pressure you to answer. We can stop talking at any time. Do you understand?

Check: _______

Is there anything in particular you are worried about? We can discuss it some more if you want. But if this isn't something you want to do, I promise I won't be mad, and neither will anyone else at the ARC. We can stop right here.

Great! For our book, I will not use your real name, where you live, or any other information that could help someone guess who I am talking about. I want to share your story, but I will keep your identify confidential—or secret—so no one bothers you and so you won't feel embarrassed or uncomfortable about anything you share. I hope you'll find this is fun, though, because you are going to choose your own secret identity, just like heroes in comic books do to keep them safe. Just make sure you choose a name no one will recognize. For example, if you already have a nickname don't use that because it's not a secret.

Do you understand?

Check: _______

It's okay. Ask me any questions or tell me what you don't understand. I don't want to continue until I'm sure you know exactly what we're doing.

Good. Each week we are going to work on a different part of the story, and I'll have to do some work in between our sessions to shape our words and pictures into a story, though I will ask you to help. When it's done we will read it together to make sure we told your story correctly. This is *your* story, so I don't want to get it wrong. Okay?

Today we're going to talk about your childhood. From time to time I will go over the things we talked about so that if you changed your mind, I can take out anything that you don't want anyone else to know. But for us to choose which of your answers to include in our book, I need to record what you say. I am the only one who will listen to the recording unless one of my teachers has questions. Is it okay if I record these sessions?

Check: _______

Thank. You.

I understand if you don't want to be recorded. A lot of people don't like their own voices. But remember, I will be the only one to listen to the recordings. If you still don't want me to record, that is fine. But I don't have a perfect memory, so we will have to talk slow because I will take lots of notes. I also might have to make you repeat some things if I can't write fast enough. Do you still not want me to record our conversation? Okay. I'll just take notes.

Check: _______

So before we begin, do you have any questions you want to ask me? I am going to ask you a lot of questions so it's only fair if you want to ask me some. I want you to feel comfortable and understand what we're doing and why we're doing it.

Check: _______

Great! Let's get started.

Background & Early Childhood (Origin Story)

[Note: Narrative inquiry is a relational method performed over multiple sessions in a semi-structured format. Extensive questions and prompts are included to demonstrate interviewer language, prompt researcher to cover topics thoroughly, and provide extensive explanation and redirection based on varying ability levels with IDD, but all interviews will be conducted in a semi-structured manner and omit questions or depart from script as needed]

First, as we talked about earlier, I want you to choose a fake name or secret identity. Unfortunately, there are always villains out there that could do bad things if they have your personal information. And remember, don't use a nickname or something someone would recognize. Can you think of a name you'd like to use? I can help you come up with ideas if you like.

My Secret Identity Is: ______________________________

Okay, ________________, we are going to start working on your story. I'm sure you've watched a lot of movies and TV shows. Maybe you've read some books or comics. Think about how every story has a hero. A hero doesn't have to have magic powers or be someone famous. A hero is just a person that we root for while they try to solve a problem or challenge. Sometimes they go on an adventure and face a series of challenges. We like following their adventures because it's fun to see how they solve those problems. And sometimes we learn from it. This can be something big like figuring out how to defeat a supervillain or something small like figuring out how to make up with someone you love after you've had a fight. We tell stories about heroes dealing with any kind of problem you can think of. So we're going to tell your story like you're the hero who dealt with a problem or had an adventure.

Comic books are often about superheroes, so we can use that as an example of how to tell a story. First we learn who the hero is and how they became that hero. Then, while the hero is just living their life suddenly, they are faced with some kind of challenge or adventure. After that, most of the story deals with how they make it through the problem they are facing. And once they solve the problem, we usually learn a lesson from what they did. But that doesn't mean all their problems have gone away. Sometimes they only solve one part of a bigger problem and sometimes brand-new problems show up. Either way, there's usually a next issue of the comic or a sequel to the movie. So, just like in a comic book we want to describe who you are and how you became *you*. Then we'll talk about the challenge you planned on leaving school and becoming an adult who does as much for yourself as you can. And then the lesson at the end is going to be describing how you are doing now. How have you succeeded as a young adult and what are you still struggling with. We want to look at all the great ways you have grown up, but we also want to look at the problems you still face, because the end of the story doesn't mean all your problems have gone away. If you were going to write a sequel to our book, what problems would you deal with next?

It is important that you tell the truth, though. Even though we are making you the hero of this story, I don't want you to make things up. People don't really have superpowers, but we all have special abilities that help us work through our problems. So, as we work together I want you to think about the powers you have that helped you become the young adult you are now. If other people are going to learn from you, it's important that you tell the truth. Do you understand?

Check: _______

Excellent! Today, to begin our story, let's talk about what it was like growing up and learning you have a disability. First, tell me what makes _______ unique or special—different from other people. How would you describe yourself to someone who's never met you? What kinds of things do you like or are important to you? What kinds of things do you not like or avoid?

Great. We should start with a picture of a hero. Do you want to draw a picture or choose one that shows people who you are?

Now let's tell your origin story. What are some things you remember most about growing up? Describe your family to me.

[Prompts]

- What were some of your favorite games or things to play?
- How did you play with brothers and sisters or friends?
- What were some of your favorite games or things to play?
- How did you help out around the house?
- I'm sure we can find or draw some pictures to help show this.

Do you remember being told that you were diagnosed [told by a doctor] with a disability, or did you always just know something was different? How did this make you feel? How do you think your disability affected how other people treated you? We can use pictures for this too.

When you were little, what did you want to be when you grow up?

[Prompts]

- Do you still want to be this/do you feel like you succeeded?
- Did you want to be something different when you got older—like as a teenager?
- What were some things that made you change what you wanted to be?
- Let's find some pictures to show who you wanted to be as an adult.

Besides school, what kinds of things did do you do away from home?

[Prompts]

- This could be visiting friend, going to a church/mosque/synagogue, going shopping or to restaurants, or traveling.

- Do you have any favorite memories of doing things or any bad memories that stand out?

Wow, we've talked a lot already, haven't we? Let's end the first part of your story by talking about what kinds of things you did in grade school and maybe even middle school. If you were telling your story as a child going to school, what would you want people to know?

[Prompts]

- Do you have fun or happy memories that you want to share?
  - [Use examples as needed: Doing things with parents, taking a trip, playing with friends?]
- Do you remember things that happened because they were bad?
  - [Use examples as needed: Getting in trouble at school or home, getting in fights, feeling left out?]
- Tell me why these were good or bad memories.

Well, I think we have plenty to tell the first part of our story, so let's stop there for today.

Member Check

I want to quickly summarize what we talked about today. It will take me some time to work this into the first part of our book, but it sounds like our story basically begins like:

____

_

Does that sound right?

Closing

Thank you so much for your time. I know this has been a long conversation and we talked about a lot of big issues. Now that we are done, are you still comfortable with the things we talked about?

Okay. Let's go over our conversation so I will know you want me to leave out. If you don't want to continue with the book, that is fine too. We can stop here and I won't share anything we talked about.

Great! So thank you so much for your time today. I will be back _____________. Next time we are going to focus on middle and high school. We will talk about your IEP and how your family, teachers, therapists, counselors, and people in the community helped you prepare to be as independent as possible when you became an adult and couldn't go to school anymore.

Do you have any more questions for me before we wrap up?

Okay. Here's a note reminding you to bring in photographs about middle or high school next week if you want to use them. We will copy any pictures you want to use so that we don't damage them. If you need to contact me before our next session, XXX at the Arc can help you reach me, or your guardian has my contact information.

Thank you so much and I'll talk to you again soon.

Session 2

Introduction & Consent

Thank you for working with me again. In case you don’t remember, my name is Eric Sarrett and I am conducting a research study into what life looks like for young adults who went through the IEP transition process in high school. I want to help you share your story to help show other people what kinds of things worked during your transition from high school and what different things we could do to help other people in the future. So before we go on, do you understand why we’re talking today?

Check: _______

That’s okay. Let’s go over what I’m doing again, then you can tell me if you have any more questions.

Good. Today we are going to work on the part of your book dealing with your IEP and transition planning in high school—maybe even middle school [Discuss and explain IEP and transition based on level of understanding]. I want to learn about the things you did that helped you prepare to be an adult and maybe some of the things that didn’t happen that you think might have helped, including how teachers, therapists, vocational workers, and other people in the community helped you prepare to graduate. We also want to know how your family helped. We might also go over some stuff we talked about last time. Sometimes after I listen to our conversations, I think up new questions and want to make sure I’m telling your story accurately. Are you still comfortable answering questions like these?

Check: _______

I completely understand. This isn't part of your training program here at the Arc so you don't have to do this if you don't want to. But thank you for coming back and talking to me about my project. It's okay to go back to what you were doing when I got you.

Good. As you remember, we are going to make your story into a comic book with pictures and words. We can tell your story with as many words and pictures as you want, and we can use photographs, clip pictures from magazines, or you can draw pictures. I want you to communicate however you feel most comfortable. Once the comic book is finished, we will review it together to make sure we told your story correctly. This is *your* story, so I don't want to get it wrong. Does that sound good?

Check: _______

Is there anything in particular you are worried about? We can discuss it some more if you want. But if this isn't something you want to do, I promise I won't be mad. We can stop right here.

I want you to feel comfortable sharing with me, so remember that I will not use your real name, where you live, or any other information that could help someone guess who I am talking about. And you don't have to answer any questions you don't want to or share anything that makes you uncomfortable. Just tell me you don't want to answer that question, and I promise never to be mad or pressure you to answer. We can stop talking at any time. Do you understand?

Check: _______

It's okay. What do you not understand? I don't want to continue until I'm sure you know exactly what we're doing.

Good. Remember that for me to make sure I'm telling your story exactly right, I need to record our conversation. I am the only one who will listen to the recording unless one of my teachers has questions but try to use you secret identity when you're talking if you can remember. Is it okay if I record our conversation?

Check: _______

Thank you.

I understand if you don't want to be recorded. A lot of people don't like their own voices. But remember, I will be the only one to listen to the recordings. If you still don't want me to record, that is fine. But I don't have a perfect memory, so we will have to talk slow because I will take lots of notes. I also might have to make you repeat some things if I can't write fast enough. Is that okay?

Check: _______

Before we begin, do you have any questions you want to ask me? I am going to ask you even more questions today so it's only fair if you want to ask me some. I want to be sure you feel comfortable and understand why we're doing this.

Check: _______

Great! Let's get started.

Middle & High School Transition (Confronting the Problem)

Last session we talked about your childhood. I went back and listened to our conversation so before we move on, I had some more questions to clear things up:

[Redirects and clarifications]

Now that we've cleared that up, let's talk about when you were an adolescent or teenager. As you grew up, how did your family talk to you about what you would do after you left school? Do you remember the first time your teachers or IEP team started talking about transition or leaving school? About how old were you? Can you describe that meeting or conversation?

What kinds of things did your IEP team—teachers and therapists and counselors—talk about to help you plan for being as independent as possible after you graduated?

[Prompts]

- Did they describe the challenges you would face?
- Can you remember examples of kinds of goals they wrote?
- How did school involve your family in these activities?
- Let's find or draw some pictures to represent some of these discussions.

What kids of things did you do in school to prepare you to meet these goals or be as independent as an adult?

[Prompts]

- Did you talk about different jobs or careers?
- Did you try different activities that might help with jobs some day?
- Did you practice interviewing or filling out a job application?
- Did you work on getting along with bosses and other people in the community?
- Did you work on taking care of yourself or doing chores/paying bills?

- Did you talk about managing money or paying for things and keeping track of how much you've spent?
- Did you do activities about getting around in the community to different places?
- How did they involve your parents in these activities?

What kinds of things did your parents and IEP team help you do outside of school in the community to help you prepare for being as independent as possible after you graduated?

[Prompts]

- Did you visit job sites or a charity organization?
- Did you have a job outside school or volunteer?
- Did you take trips into the community?
- Where and what did you do? [Museums, movies, shopping]
- Let's find or draw some pictures to represent your work/volunteering/training (if any) in the community.

Now let's get a little more specific. How did your family or IEP team help you be ready to do specific things in the community like:

[Interviewer note: Only address issues not previously discussed; Based on *six F words*]

- Get around our use transportation?
- Find a job?
- Manage money or pay for your own stuff?

- Cook, clean, and take care of a home?
- Visit doctors and stay healthy as an adult?
- Hang out with friends or do other fun things?
- Go to things outside of home like a religious service, movie, shopping, or restaurant?
- Volunteer or vote or do other things to help others and be a good citizen?
- Plan for your future?

How did you feel when talking about leaving school and being more independent such as finding a job or moving out or taking on more responsibility? Again, we can use pictures to help show how you felt.

[Prompts]

- Examples are scared or excited or nervous or happy or sad. You might have felt many different things.
- It's okay if you felt different about different things, like leaving school versus living somewhere different getting a job.
- It's okay if the feelings were different, like somedays you were excited and some days you were scared. We all experience different emotions like that.]

Well, that's a lot to talk about—just like last time—so how about we end here?

Member Check

I want to quickly summarize what we talked about today. It will take me some time to work this into the middle of our book, but it sounds like some of the big problems you faced and ways you prepared for them were:

____

_

Does that sound right?

Closing

Great. I'm going to listen to our conversation before we meet again and then we will work on the end of our story. It sounds like you did a lot of things to prepare to be an adult. Now that you are out of school, we want to look at what you're actually doing and which of the things you did in school helped. Then we'll discuss things that you wished you'd done that maybe would have helped that no one thought of back then. Remember, we are going to go over the comic book once it is finished, but first we need to gather words and pictures for all three parts.

So, thank you so much for your time. I know this has been a long conversation and we talked about a lot of big issues. Now that we are done, are you still comfortable with the things we talked about?

Okay. Let's go over our conversation and I will make a note to not mention anything you don't want me to. If you don't want to continue with this book, that is fine too. We can stop here and I won't share what we talked about with anyone.

Great! Do you have any more questions for me before we wrap up?

Okay. Here's a note reminding you to bring in photographs or drawings about all the things you've done since leaving school. This can be things at home or out in the community. We will copy any pictures you want to use so that we don't damage them. If you need to contact me before our next session, XXX at the Arc can help you reach me, or your guardian has my contact information.

Thank you so much and I'll talk to you again soon.

Session 3

Introduction & Consent

Thank you for working with me again. As you know, I'm Eric Sarrett and I am conducting a research study into what life looks like for young adults like you who went through the IEP transition process in high school [Explain as needed]. I want to help you share your story of leaving school and becoming an adult so people can learn from your experiences. I hope this will help show other people what kinds of things worked during your transition from high school and what different things could do to help other people in the future. So, before we go on, do you understand what we're doing and why?

Check: _______

That's okay. Let's go over what I'm doing again, then you can tell me if you have any more questions.

Good. Today we are working on the ending of your story where we talk about where you are now. Of course, your story will go on after we're done, but this will be the end of the story we're writing together. This week I want to understand what you do with your time and how you feel about your life now that you're out of school. Where do you live? What kind of things do you do in your community from work to volunteering to religious services to having fun and meeting friends? We might also go over some stuff we talked about last time. Sometimes after I listen to our conversations, I think up new questions and want to make sure I'm telling your story accurately. Are you still comfortable answering questions like these?

Check: _______

I completely understand. This isn't part of your training program here at the Arc so you don't have to do this if you don't want to. But thank you for coming back and talking to me about my project. It's okay to go back to what you were doing when I got you.

Good. As you remember, we are making your story into a comic book using pictures and words. We can do this however you are most comfortable. You can answer the questions however you are most comfortable, using photographs, clipped pictures from magazines, or drawings to help. Once the comic book is finished, we will review it together to make sure we told your story correctly. This is *your* story, so I don't want to get it wrong. Does that sound good?

Check: _______

Is there anything particular you are worried about? We can discuss it some more if you want. But if this isn't something you don't want to do, I promise I won't be mad. We can stop right here.

I want you to feel comfortable sharing with me, so remember that I will not use your real name, where you live, or any other information that could help someone guess who I am talking about. And you don’t have to answer any questions you don’t want to or share anything that makes you uncomfortable. Just tell me you don’t want to answer that question, and I promise never to be mad or pressure you to answer. We can stop talking at any time. Do you understand?

Check: _______

It’s okay. What do you not understand? I don’t want to continue until I’m sure you know exactly what we’re doing.

Good. Remember that for me to make sure I’m telling your story exactly right, I need to record our conversation. I am the only one who will listen to the recording unless one of my teachers has a question but try to use you secret identity if you can remember. Is it okay if I record our conversation?

Check: _______

Thank. You.

I understand if you don’t want to be recorded. A lot of people don’t like their own voices. But remember, I will be the only one to listen to the recordings. If you still don’t want me to record, that is fine. But I don’t have a perfect memory, so we will have to talk slow because I will take lots of notes. I also might have to make you repeat some things if I can’t write fast enough. Is that okay?

Check: _______

Before we begin, do you have any questions you want to ask me? I am going to ask you more even questions today so it’s only fair if you want to ask me some. I want to be sure you feel comfortable and understand why we’re doing this.

Check: _______

Great! Let's get started.

The Ending: Life and Community Integration As An Adult

Last session we talked about how you prepared in middle and high school to be an adult. I went back and listened to our conversation and before we move on, I had some more questions to clear things up:

[Redirects and clarifications]

Now that we've cleared that up, let's talk about how our story ends.

Let's start by talking about where you live now. We can also use pictures to go with each of these answers. Describe your home and who you live with. Describe the types of things you do in the home for yourself.

[Prompts]

- Getting dressed and grooming or staying clean
- Cooking, cleaning, or fixing things in the house
- Paying bills and planning how to use your money

Can you describe a typical weekday from the time you wake up until you go to bed? We can use pictures to help describe both types of day.

How about a typical Saturday or Sunday?

Now that you're an adult, tell me about the things you do outside the home in your community. To make it easier we'll break the questions down into categories.

First, let's talk about your *family*. [Adjust based on whether they live at home.] How much do you still talk to your family and what kind of things do you do with them? What kinds of things does your family still do for you as an adult? We can pick out some pictures, too, of things you do. How is that different than when you were in school?

Next let's talk about work or volunteering. [*Function*] Tell me the type of things you have done since you graduated up until now. We'll go one thing at a time. [Prompt to tell as chronologically as they are able to recall. If no work, skip to volunteering]

Since this is a story, let's talk about things like how you got this job/volunteer position and how it has changed. Remember, we can also choose pictures to go with all of these answers.

Last time you talked about things you worked on with your IEP team like __________. Tell me how these helped you with your job or if they didn't help, let's talk about why not.

What kinds of things do you wish you could have worked on in school to help you with work/volunteering?

Tell me how you feel about your work/volunteer position.

[Prompts]

- Do you like your job/position or do you not look forward to work?
- Does it make you feel challenged or bored?
- Do you work as much as you'd like? If not, how much more would you like to work?

- Do you have any idea how you could accomplish this?
- Do you make enough money? If not, how much more would you like to work?
- Do you have any idea how you could accomplish this?
- What would you change about work/volunteering if you could?

[Repeat sequence as needed]

Let’s also talk about other important things you do in the community. Besides work or volunteer, describe other things you do to help people?

- Do you vote or do other things to feel involved in politics or your religion?
- Let’s use some pictures to show the types of things you do.

Besides working and volunteering, what kinds of things do you do for *fun* outside your home, in the community? We should choose some pictures for this, too.

[Prompts]

- Hang out with friends
- Go to movies
- Shopping
- Travel
- Go to museums or interesting places

Describe how you feel as part of the XXX community with words and pictures. It might be more than one emotion, and that’s okay.

[Prompts]

- Proud?
- Excited?
- Scared?
- Awkward or embarrassed?

Why do you feel that way? How much do you feel like you are a part of your community? Are there any things that make you proud of or grateful about living here? Can you give me examples? If you could change anything about living here, what would you change? Are there things that would make you feel better about living in XXX?

Last time you talked about things you worked on with your IEP team like __________. Tell me how these helped you do things in your community or if they didn't help, let's talk about why not.

Now let's talk about *fitness*. Let's talk about how often you go to the doctor and how much you talk with him yourself. Do you get exercise, get outdoors a lot, or go to a gym? What kinds of foods do you like to eat and do you think about whether or not those foods are health? Let's use some pictures to describe how you look after your health.

Last time, we talked about ___________ on your IEP. Has that helped you make healthy choices or do you feel like you didn't learn enough about these things in school? [What would you have liked to learn more about?]

Tell me about your *friends*?

[Prompts]

- How often do you see them

- What kinds of things do you do?
- How would you describe your friendships? [Giving, happy, cooperative, selfish, one-sided]
- Do you feel like you have a lot of friends or do you want more friends
- How often do you feel lonely?
- Do you talk to friends and family about feeling lonely?
- How do the things we talked about last time like __________ help you make and keep friends?
- Are there things you wish you'd learned in high school to help you make more friends or be a better friend? Let's choose some pictures to describe you and your friends.

So, we talked about how there's always a sequel or another issue to a comic book, so let's finish by talking about the *future*. What does 'the future' mean to you? What words would you use to describe your future? Use as many as you like?

- Ten years from now, where do you want to be and what do you want to be doing?
- Do you think you will be doing more or less things in your community? Why?
- What are some problems you think you would face if we were doing the next issue of your story?
- What people and things do you think will help you reach these goals?
- What people or things do you think might try to stop your or make this more difficult?

When we started our book I asked how you would describe yourself to other people. Now that we’ve talked about all the different parts of your story, would you change this description? How? After reflecting on this journey do you feel better or worse about your life? Why?

Well, I think we’ve covered everything, so let’s stop for the day.

Member Check

I want to quickly summarize what we talked about today. It will take me some time to work this into the first part of our book, but it sounds like our story ends like:

____

Does that sound right?

Closing

I’m going to listen to our conversation before we meet again. I will bring in a rough draft—or a start—to our story and we will talk it over and decide if we need to add anything or take anything out. Then, after I finish making our changes I’ll bring the final comic book in so we can read it together. Thank you so much for your time. I know this has been a long conversation and we talked about a lot of big issues. Now that we are done, are you still comfortable with everything we talked about?

Okay. Let’s go over our conversation so I will know you want me to leave out. If you don’t want to continue with this book, that is fine too. We can stop here and I won’t share anything we talked about.

Great! So thank you so much for your time today. I will be back ________ to work on putting our book together. Do you have any more questions for me before we wrap up?

Okay. Here's a note reminding you to bring in photographs if you remember something we missed. We will copy any pictures you want to use so that we don't damage them. If you need to contact me before our next session, XXX at the Arc can help you reach me, or your guardian has my contact information.

Thank you so much and I'll talk to you again soon.

Session 4 [Expanded to 4a and 4b sessions if needed]

Introduction & Consent

Thank you for working with me again. As you know, I'm Eric Sarrett and I am conducting a research study into what life looks like for young adults who went through the IEP transition process in high school. I want to help you share your story of leaving school and becoming an adult so people can learn from your experiences. I hope this will help show other people what kinds of things worked during your transition from high school and what different things we could do to help other people in the future. So, before we go on, do you understand what we're doing and why?

Check: _______

That's okay. Let's go over what I'm doing again, then you can tell me if you have any more questions.

Good. Today we are going to work on putting together our comic book. This might involve asking some new questions as we review what we've already done. It will also involve making sure that I told your story right and that you are comfortable with the things I shared. Remember, you don't have to answer any questions you don't want to or share anything that makes you uncomfortable. Just tell me you don't want to answer that question, and I promise never to be mad or pressure you to answer. We can stop talking at any time. Do you understand?

Check: _______

I completely understand. This isn't part of your training program here at the Arc, so you don't have to do this if you don't want to. But thank you for coming back and talking to me about my project. It's okay to go back to what you were doing when I got you.

Good. Remember that I will not share your name or anything that could help someone guess who you really are. I need to record our conversation, though, so I can make sure I am telling your story correctly. I am the only one who will listen to the recording unless one of my teachers has questions but try to use you secret identity when you're talking if you can remember. Is it okay if I record our conversation?

Check: _______

Thank. You.

I understand if you don't want to be recorded. A lot of people don't like their own voices. But remember, I will be the only one to listen to the recordings. If you still don't want me to record, that is fine. But I don't have a perfect memory, so we will have to talk slow *because I will take lots of notes. I also might have to make you repeat some things if I can't write fast enough. Is that okay?*

Check: _______

Before we begin, do you have any questions you want to ask me? I am going to ask you more even questions today so it's only fair if you want to ask me some. I want to be sure you feel comfortable and understand why we're doing this.

Check: _______

Great! Let's get started.

Pulling It All Together (Expanded Member Check)

Last session we talked about all the different things you are doing as an adult. I went back and listened to our conversation so before we move on, I had some more questions to clear things up:

[Redirects and clarifications]

Great! I went ahead and started putting together a version of our book. I made some notes about things I still didn't completely understand and marked places where I think the story is missing part of the plot. We will go through it together so you can answer these questions. While we are looking through it, I want you to let me know if:

- I got any of your words or memories wrong.
- Anything is missing from the story.
- You are uncomfortable or embarrassed and don't want something in the story shared.
- You have a question about how I told your story.

- There are words or pictures you would like to change.

Here is a copy of the things I want you to look out for so you can follow along.

Closing

Well, I think we've covered everything. I have a little more work to do but I think we have everything we need to finish your book. Thank you so much for your time and for trusting me enough to share your story. Now that we are done, are you still comfortable with everything we talked about?

Okay. Let's go over our conversation so I will know you want me to leave out. If you don't want to continue with this book, that is fine too. We can stop here, and I won't share anything we talked about.

Great! So, thank you so much for your time today. I will be back ________. We will go over your completed book and if we both think it is finished, I will make a copy and bring the original back so you can keep it once I am done with my study. If you need to contact me before then, XXX at the Arc can help you reach me, or your guardian has my contact information.

Thank you so much and I'll talk to you again soon.

Session 5

Introduction & Consent

Thank you for working with me. This will be our last session together and I couldn't have done this without your help. As we've discussed, this research study is to collect stories of what life looks like for young adults like you who went through the IEP transition process in high school. I hope this will help show other people what kinds of things worked during your transition from high school and what different things we could do to help other people in the future.

Today we are going to review the completed comic book we put together. We may discuss some ideas it brings up, or themes, but if we are both comfortable with it, I will bind it together and return it to you as it is right now. But we are reviewing it because this is your story, and I want to make sure it is accurate. Does that sound okay?

Check: _______

That's alright. Ask me any questions you have. And if you're not comfortable with the book now that we have finished it, I don't have to share it with anyone but you.

I don't want to or share anything that makes you uncomfortable, so as we go through the book tell me if there's something you want to take out. But as we discuss this, I still need to record our conversation in case anyone has questions or I need to go back and check something. I am the only one who will listen to the recording unless one of my teachers has a question but try to use you secret identity when you're talking if you can remember. Is it okay if I record our conversation?

Check: _______

Thank. You.

I understand if you don't want to be recorded. A lot of people don't like their own voices. But remember, I will be the only one to listen to the recordings. If you still don't want me to record, that is fine. But I don't have a perfect memory, so we will have to talk slow because I will take lots of notes. I also might have to make you repeat some things if I can't write fast enough. Is that okay?

Check: _______

Before we begin, do you have any questions you want to ask me? This is our last session together, so I want to be sure you feel comfortable and understand why we're doing this.

Check: _______

Great! Let's get started.

Book Review (Final Member Check)

This is meant to be the final version of our book based on all of our work together. But you always have the right to correct the story or taking something out that you are not comfortable sharing. So here is the list of questions we used last week. Keep these in mind as you read through our book in case we need to make any more changes. Please tell me if:

- I got any of your words or memories wrong.
- Anything is missing from the story.
- You are uncomfortable or embarrassed and don't want something in the story shared.

- You have a question about how I told your story.
- There are words or pictures you would like to change.

Here is a copy of the things I want you to look out for so you can follow along.

Closing

Well, I think we’ve covered everything. Your story is complete. I just need to make a copy for myself and bind it together and then I will return it to you in a few months when I am finished with my study. I am also doing this with other people to see how all of your experiences are alike and different, so when I return, I will also tell you what I found out by comparing all these different stories. I will also send a summary to your parents/guardian. Thank you so much for your time and for trusting me enough to write this book with me. I will let you need when I’ve finished my research and am planning to return. If you need to contact me before then, XXX at the Arc can help you reach me, or your guardian has my contact information.

Thank you so much and I hope the next chapter in your book is a success.

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Appendix B: Provisional Categories & Codes

Barriers to Role Participation	Intrinsic Traits Affecting Community Participation	Postsecondary Transition	Quality of Life	Role Participation
Ableism & Discrimination	Cognitive Skills/ Academics	IEP/Special Education	Despair or Turmoil	Community Mobility
Disclosing Disability	Disability Identity	Siloed Services	Happiness	Dependent Living
Physical Barriers	Life Skills & Homemaking	Support/Policy Cliff	Hope	Employment & Volunteering
Policy Barriers	Pre-Employment & Job Skills	Transition Planning	Loneliness	Family
Social Barriers	Self-Care Skills	Transition Process		Fitness
	Self-Determination			Friends
	Social/Emotional Skills			Fun/Leisure
				Future Vision
				Healthcare
				Politics or Community Involvement
				PSE
				Religious Participation

Appendix C: Open Concept Coding by Category

Intrinsic Characteristics	Quality of Life	Supports & Barriers
Abilities & Skill Development	Community Engagement	Family
-Coping & Emotional Control	-Adequate Participation	-Extended Family
-Independent Living Skills	-Inadequate Participation	---Grandparent
-Money Management	-Religious Participation	---Stepparents
-Self-care & ADLs	-Voting & Civic Involvement	---Surrogate Family
-Social Skills	-Work & Volunteering	-Family Stressors
Disability-Related Impairments	Conflict & Turmoil	IEP & Special Education
-Cognitive Impairments	-Adolescence & Turmoil	-Community Mobility Exposure/Training
-Medical Conditions	-Bullying	-Coping Skills Training
-Physical Impairments	-Denial or Self-Protection	-Early Paid Employment
-Psychiatric Impairments		-Educational Supports & Successes
-Social or Emotional Impairments	Failure & Role Exclusion	-Failures & Shortcoming
	-COVID	---Dropping Out
	-Disability-Related Exclusion	-Policy Cliff
Identity & Disability	-Unemployed	-Pre-Transition Vocational Training & Exploration
-Adult Role Exploration		
-Emerging Disability Identity	Fitness	-Social Skills Training
-Healthy Identity Attributes	-Unhealthy Habits	-Transition Celebration or Relief
-Insecurity & Self-Doubt		-Transition Readiness
-Role Limitations	Happiness	
	Hope & Future Vision	Institutional Insufficiencies
	Leisure	Institutional Support
	-At Home	
	-Outside the Home	Medications
	-Supported Leisure	
	-Travel	PSE
		-Coping Skills
	Loneliness & Exclusion	-Social Skills
		-Vocational Training
	Self-Determination	
	-Altruism	Social Support
	-Confidence & Resiliency	-Family Support
	-Empowerment	-Friends & Socialization
	-Family Paternalism	-Institutional Staff
	-Institutional Paternalism	-Teachers & School Staff
	Sadness or Despair	Supported Living
		-Family
	Sex & Relationships	-Institutional
	-Inappropriate Sexual Expression	
	-Romantic Conflict	