# **Research Articles and Essays**

My Life, My Words: Postsecondary Transition Outcomes for Young Adults with

Intellectual & Developmental Disabilities

Eric Sarrett

Walden University

#### Abstract

Young adults with intellectual and developmental disabilities (IDD) struggle to integrate into their communities after postsecondary transition despite decades of policy and research initiatives, and few studies explore adult role participation outside the home from their perspectives. This study employed narrative inquiry grounded in critical disability theory to enable young adults with IDD to conceptualize community integration in their own words.

*Keywords:* intellectual and development disabilities, postsecondary transition, community integration

# My Life, My Words: Postsecondary Transition Outcomes for Young Adults with Intellectual & Developmental Disabilities

Assuming adult roles upon leaving school is perhaps the most challenging transition in a lifetime, yet this journey is especially perilous for students who lose the support of the Individuals with Disabilities Education Act (IDEA) (Acharya et al., 2017; Newman et al., 2011). The Office of Special Education and Rehabilitative Services (OSERS, 2015) defines transition for students with disabilities 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). However, with no comprehensive public policy to pick up where IDEA leaves off, families are left feeling anxious and abandoned, comparing transition to "falling off a cliff' (Franklin et al., 2019; Joly, 2015). As a result, young adults with disabilities are struggling to successfully integrate into adult roles in the community defined by OSERS such as in employment, civic engagement, socialization, participation in religions, and volunteering (Newman et al., 2011). Those with intellectual and developmental disabilities (IDD) are experiencing the greatest delays (Benson et al., 2021; Lee & Morningstar, 2019). Yet, the perspectives of such young adults are consistently omitted from community integration research about them (Jacobs et al., 2018; Lee & Morningstar; 2019). Therefore, this study empowered persons with IDD to describe community integration in the decade following postsecondary transition through multimedia narratives.

# **Background & Literature Review**

Chang et al. (2013) define community integration as "active involvement in activities that are intrinsically social and either occur outside the home or are part of a nondomestic role" (p. 772). When the 1975 Education for All Handicapped Children Act granting free and appropriate public education for all was reauthorized in 1990 as IDEA, it included a mandate that transition services be addressed on individual education plans (IEP) starting at age 16 in recognition of persistent struggles with community integration (United States Department of Education, 2023). However, when the decade-long National Longitudinal Study-2 (NLTS2) sponsored by the Department of Education, taking a broad view of transition that included community integration, concluded in 2009, it highlighted persistent transition deficits for young adults with disabilities despite the postsecondary transition planning mandate. For example, within a decade of transition, only 60% of young adults with disabilities enrolled in postsecondary education (PSE) as opposed to 67% of the general U.S. population; only 60% were employed as opposed to 66% of the population; and only 45% were living independently as opposed to 59% overall (Newman et al., 2011). And those labeled with significant disabilities such as autism spectrum disorder (ASD) or intellectual disability (ID) fared even worse with employment rates of only 37% for ASD and 39% for ID, while only 17% with ASD and 36% with ID were living outside the family home. There were also indicators of social isolation from the community, with only 48% of respondents with ASD and 58% with ID having recently seen friends outside the home (Newman et al., 2011). Yet obstacles to successful transition are well-documented.

Decades of transition literature has identified bureaucratic failings in the postsecondary transition process such as limited availability of information and resources to families, underdeveloped self-advocacy and self-determination skills in adolescents with

disabilities, limited stakeholder collaboration, limited family involvement in the process, siloed services that fail to coordinate, and generic training that ignores individual strengths and preferences (Franklin et al., 2019; Hirano et al., 2018; Joly, 2015; Stein et al., 2016). There is also a need for more clearly identified stakeholder roles, more effective communication channels, increased training for professionals, and incentives for crossagency collaboration (Benson et al., 2021; Oertle et al., 2021; Plotner et al., 2020.) In turn, evidence for strategies that promote successful vocational transition is growing, emphasizing early career exploration, improved stakeholder communication, community involvement in planning, early paid work experience, and providing individualized services tailored to a student's interest (Kester et al., 2019; Oertle & O'Leary, 2017; Qian et al., 2018; Rast et al., 2020). Yet the persistent barriers have resulted in slow implementation and continued struggles to achieve competitive employment for those with complex disabilities (Lee & Morningstar, 2019; Qian et al., 2018). Postsecondary education also correlates with higher rates of competitive employment (Sannicandro et al., 2018) and there have been some successes on this front, such as the Higher Education Opportunity Act of 2008, which has helped increase PSE programs for students with ID tenfold (Baker et al., 2018; Wilczenski et al., 2017). However, successful PSE participation for those with IDD requires supports that are often absent or difficult to access such as inclusive classes, strong campus engagement, concurrent part-time employment, and collaborative engagement with community partners (Domin et al., 2020; Horn et al., 2020; Qian et al., 2018). Further, the social barriers to disclosing disability and requesting accommodations as well as the complex social and bureaucratic systems remain significant obstacles (Bell & Zamani-Gallaher, 2017; Berg et al., 2017; Shogren et al., 2018). Yet struggles with community integration extend well beyond PSE and employment.

Critical disability studies (CDS) in particularly is grounded in calls for greater participation and inclusion for marginalized populations (Hall, 2019), and many disability studies scholars argue for measures of postsecondary transition success that includes broad views of community integration. Liasidou and Symeou (2018) argued that marketplace conceptualizations of educational outcomes reduce education to an investment and thus the educated to units of corporate profitability, often rendering persons with disabilities as nonessential. Black and Lawson (2017) similarly rejected a narrow dehumanizing focus on productivity that ignores personal priorities, while Charlton's (2000) "Nothing About Us Without Us" slogan remains a cornerstone of disabilities studies, scholars argue that selfactualization and not economic utility represents true freedom from oppression and thus should be our goal. But while a community integration approach is slowly seeping into transition literature, Dean et al. (2016) found that participation—as defined by widely accepted International Classification of Disability (IFC) language—was only mentioned in 88 articles within ID literature and clearly defined in six, with only three of those citing IFC language. Chang et al.'s (2013) systematic review similarly found that instruments used to measure community integration were inconsistent and failed to fully embrace participation per IFC guidance, while a systematic review by Taylor-Roberts et al. (2019) uncovered widespread psychometric scores with standardized measures of community integration. Yet not only is transition research struggling to fully define and measure community integration, but we are ignoring the most critical piece to this puzzle. A literature review by Jacobs et al, (2018) found that not only were the voices of those with IDD excluded from transition literature in favor of other stakeholders, but few authors even bothered to justify this exclusion, clearly failing to comply with the inclusive and emancipatory mandate of CDS (Hall, 2019).

Yet calls from movements such as CDS to include these voices are slowly making inroads. Hall's (2017) qualitative study of community involvement of persons with IDD in the Midwestern United States examined community transition through employment, recreation, and leisure. The study described the internalized sting of exclusion from both vocational and social participation, paired with a desire to become more involved. Yet a preponderance of community integration literature remains quantitative, relying heavily on microanalysis of the NLTS2. Even original quantitative studies of community integration, such as that of Tint et al. (2017), rely on caregiver perspectives. Amado et al.'s 2013 literature review identified an urgent need to include the perspectives of young adults with IDD. Six years later, Lee and Morningstar (2019) found such inclusion still lacking, calling for "extending current research to provide a deeper and more descriptive understanding of community participation among young adults with severe disabilities" (p. 196). Therefore, this study employed narrative inquiry to allow this population to broadly conceptualize their community integration following postsecondary transition in their own words.

#### **Research Methods**

Narrative inquiry asserts that humans organize and explain the randomness of their lives through narratives built upon shared stock stories (Clandinin, 2016; Kim, 2016).

Narrative inquirers seek *collaborators* rather than subjects to cooperatively collect and create narratives, thereby flattening traditional power dynamics where data collection and interpretation was predominately controlled by the privileged researcher (Clandinin, 2016; Kim, 2016). Because of this collaborative empowerment, narrative inquiry has been embraced by critical disability theory (CDT)—the theoretical expression of CDS which defines disability as the confluence of contextual and personal factors rather than an individual fault (Bjornsdottir et al., 2014; Hall, 2019; Sigstad & Garrels, 2017; Smith-

Chandler & Swart, 2014). However, citing the need to protect vulnerable populations, researchers and institutional review boards (IRBs) have perpetuated exclusion of persons with IDD from such research by exaggerating the challenges of collaboration and underestimating their ability to comprehend the social benefits of research participation (McDonald et al., 2016; Sigstad & Garrels, 2017). Fortunately, disability studies provides a clear path forward.

# **Adapted Methodology**

For this study, narrative inquiry was modified per adapted collaboration recommendations from disability studies and CDT. For example, St. Pierre (2015) challenged researchers to enable non-traditional speakers by embracing noise, dissonance, silences, and alternative methods of communication, while Sandahl (2018) offered visual media as a path towards inclusive research. Nind (2008) also recommended a multimedia approach for overcoming challenges for collaborating with those with IDD in a National Center for Research Methods report. Other recommendations included using simple language, restating concepts, frequently checking for understanding, allowing increased processing time, and attending to non-verbal cues (Jovchelovitch & Bauer, 2000; Nind, 2008; Sigstad & Garrels, 2017; St. Pierre, 2015).

Drawing from a different tradition, psychology literature demonstrated how superhero iconography empowers therapeutic expression (Lawrence, 2006), while narrative psychology proved that people who develop positive story arcs exhibit greater resiliency and self-esteem (McAdams & McLean, 2013; Murray, 2003). Therefore, combining narrative inquiry and CDT-recommended multimedia approaches with culturally available stock stories and narrative psychology led to a unique method of creating narratives via comic books to

provide an accessible story structure that empowers collaborators as heroes of their own journey in opposition to victimization stereotypes.

### **Instrument Development**

Semi-structured interview scripts were developed with a clear beginning, middle, and end of the transition journey. These were based upon the adaptations noted above and holistic inquiry survey of community integration using Rosenbaum and Gorter's (2012) six participation categories derived from IFC language: *family, fun, friends, fitness, function, and future*. Next, methodological and population experts reviewed the script and made recommendations while the language was confirmed at a 5th grade level through Microsoft Word analysis.

# Sampling

# Setting

Participants were selected from three programs through an organization serving persons with IDD in North Florida. Confidentiality documents were signed by the researcher and agency supervisors that assisted in sampling per IRB recommendation.

# Participant Selection and Sample Size

Purposeful sampling was conducted to identify attendees who:

- 1. Had an IDD-related diagnosis
- 2. Received IEP transition services
- 3. Exited secondary education within 10 years (ages 18-32)
- 4. Possessed basic speech or augmented communication ability
- 5. Received vocational rehabilitation services (VR)

By studying young adults within a decade of graduation, I was able to extend the study's scope beyond the oft-studied immediate aftermath of transition. Additionally, I extended the age range to 32 as persons with IDD often stay in school until the year they turn 22, as allowed under IDEA.

#### Recruitment and Consent

Seven participants were recruited, and all were able to provide legal consent. IRB oversight confirmed consent forms were transparent and free of coercion. Restatement of informed consent was also built into each interaction. Collaborators were monitored for hesitancy, confusion, or other signs of involuntary consent as well as signs of intentional dishonesty; however, such concerns did not arise.

#### **Data Collection**

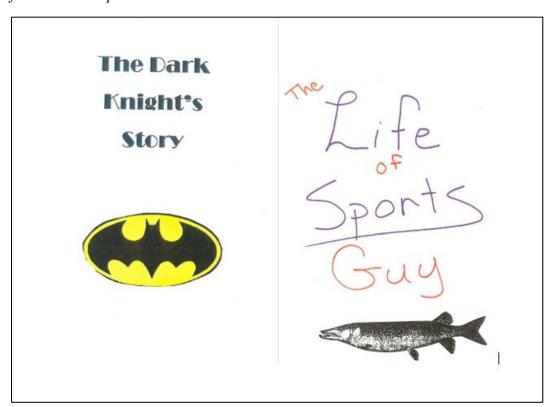
Collaborations required five to six sessions each of around 45 minutes, with no more than two interactions scheduled in a week. Allowing participants to choose secret identities from the outset created buy-in, while reinforcing the narrative structure and concretely demonstrating the importance of confidentiality (Figure 1). Raw data was collected in the first two sessions using interview scripts, then transcribed and printed. In two to three additional sessions, the researcher and collaborators sifted through and organized raw data into narratives while selecting or creating associated images. Initially, final text was handwritten by the researcher as agreement was reached, but this proved cumbersome and collaborator attention wandered. So the researcher began typing the text and printing it.

Typing also allowed for greater on-site editing, as text was continually shared and modified with collaborators to assure their perspectives and not the language of the researcher were being captured. Collaborators contributed photographs, drawings, and magazine clippings as well as chose from stock images via internet search. Images and texts were then arranged in

narrative order and pasted into comic books formed from card stock. A final member check was then performed during an additional interaction to assure narrative accuracy. All seven collaborators completed the process and expressed satisfaction with the results.

Figure 1

Covers from Two Completed Narratives



# **Data Analysis**

Two rounds each of first cycle coding and second cycle coding were conducted per Polkinghorne's narrative analysis and analysis of narratives as modified by Kim (2016). To respect the intended communication of collaborators, only member-checked completed narratives were coded and analyzed. First cycle provisional codes derived from the literature review applied deductive reasoning to narrative text and images while open concept coding allowed for inductive analysis. In this way, data was both related to existing concepts and

examined for novel expression. For second cycle narrative coding, the books were read aloud and compared, then their overarching themes were summarized into three sentences (beginning, middle, and end). Finally, pattern coding was used for triangulation of first cycle and narrative coding into categories and emergent themes. After multiple iterations of pattern analysis, four themes emerged.

#### **Results**

# **Demographics**

Two females and five males collaborators participated, reflecting an IDD category that skews male. One male participant was a first-generation immigrant with parents hailing from Asia and Africa. All other participants were White, not Hispanic. Two collaborators fell within what was labeled the early transition period (19-24), three mid-transition (25-28), and two late transition (29-32). Two were diagnosed with ASD, one with Down syndrome, one with ADHD, and one with cerebral palsy. Other diagnoses included bipolar schizophrenia, visual impairment, and auditory impairment. Three collaborators had a history of seizure. Three lived at home with parents, three in a group home, and one lived in supported living. Two collaborators were employed part-time while four reported previous employment. One never held paid employment. One collaborator identified as gay; five referenced heterosexual relationships (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 Schizophrenia	1	Race/Ethnicity	
Down Syndrome	1	White	6
Hearing Impaired	1	Multinationality	1
Visually Impaired	1	(non-White)	

#### **Narrative Themes**

Happiness is a Friend: Social Support, Not Community Integration, Drives Quality of Life (QOL)

Transition and CDS literature cite community integration indicators such as work, civic engagement, and leisure engagement as primary contributors to QOL, but community integration was not a dominant driver of QOL in these narratives. Instead, QOL was primarily expressed through human connection within and outside the home and in turn influenced how community integration was perceived. Those who felt more confident in their personal connection felt more connected to their community despite quantifiable engagement levels. For example, most narratives established initial context through recollections of

childhood friendships. Daredevil began: "When I was little, I played with Disney toys with my brother and sister [and] went to daycare and passed ball with my friends.... I was a happy child." Pudding reminisced, "When I was young .... I had friends at school and a close best friend who was like Pudding #2." Batgirl stated, "I had a best friend, and we would play outside after class," while Diana was friends with all her classmates. Despite severe early impact of his disability, Bus Rider was also a social child with many friends, and while Sports Guy was bullied in early childhood, he enjoyed playing sports with other children. By contrast, The Dark Knight was the only collaborator to lack friends, lamenting: "Nobody liked me. I wanted to make friends, but I was just a loner." Yet, like the others, he achieved childhood stability through family connections.

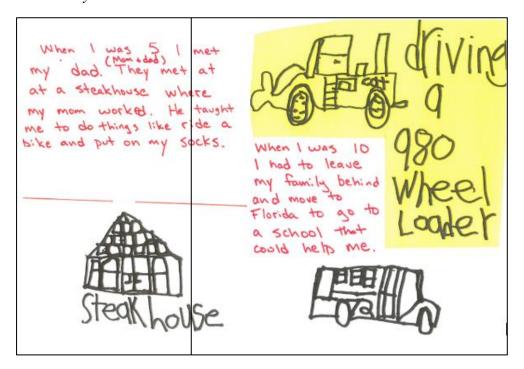
Batgirl stated, "What makes me unique is that I am a very happy person and that I spend big time with my family," while Daredevil declared: "What makes me special is how much I love my family." The Dark Knight focused on family memories over peer isolation, while close sibling relationships were a key to Diana's, Batgirl's, and Daredevil's identities. Both Diana and Batgirl included more pictures of their siblings than anything else, and though Pudding was bullied by his older brother, they now talk regularly. Reflecting upon a different sibling dynamic, Sports Guy accepted banishment from his house when his stepfather explained he was setting a bad example for his younger brother and sister. The friendless Dark Knight was also the only collaborator without a sibling, although extended family was critical for him as well as others.

Despite being forced into group homes, Sports Guy concluded: "I am happy knowing that so many people actually care about me—my mom, my stepdad, family, but also everybody here." A stepparent was also critical to Bus Rider: "When I was five, I met my dad [who] taught me to do things like ride a bike and put on my socks." Grandparents were also

prominent. Bus Rider's grandfather inspired his love of heavy machines by teaching him to operate farm equipment (Figure 2), while Sports Guy's grandfather brought him into his tile business during his turbulent teens. Batgirl, Diana, and Pudding also had close relationships with grandparents, while aunts, uncles, and cousins were sources of leisure and travel for Batgirl, The Dark Knight, and Sports Guy. So, while the research script was designed to focus on community integration, collaborators consistently steered their narratives toward personal connection.

Figure 2

Bus Rider's Family Connections



# The Adolescent Earthquake: Transition Begins Earlier Than Expected

Despite stable childhoods, most collaborators encountered turbulence in early adolescence upon the transition to middle school due to increasingly complex social relationships, emerging sexuality, and the ubiquity of bullying. Daredevil's only recollections of secondary school revolved around bullying: "There was a boy who would follow me and

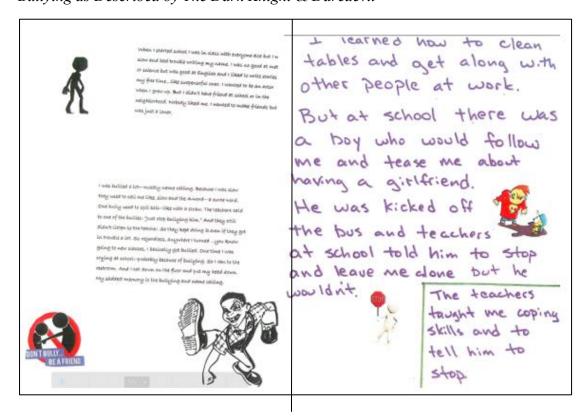
tease me about having a girlfriend, and teachers at school told him to stop and leave me alone, but he wouldn't" (Figure 3). Pudding similarly recalled: "I started to have more troubles in middle and high school when other kids started picking on me." And for The Dark Knight, isolation morphed into aggression:

I was bullied a lot—mostly name calling. Because I was slow they used to call me slow and the A-word—a curse word .... The teachers said to one of the bullies: "Just stop bullying him." And they still didn't listen ... so they kept doing it ... anywhere I turned ... I basically got bullied (Figure 3).

Diana also recalled: "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." However, teacher intervention ended her harassment, and she made new friends. But in adolescence, such external shockwaves are inseparable from internal tremors which hit collaborators particularly hard.

Figure 3

Bullying as Described by The Dark Knight & Daredevil



For Sports Guy, adolescence resulted in seizures and mental health issues, and things quickly spiraled out of control: "I started going in and out of the damn psych unit. This continued all through middle school and high school ... . I would go in for one day and they would dope me up." He was soon kicked out of his home and has bounced around ever since. And while both Diana's and Daredevil's bullying involved emerging sexuality, Pudding identifying as gay led to such severe harassment his mother transferred him to a special school out of state which, like Sports Guy, began a life of institution hopping. Despite the disruptive role of emerging sexuality, such issues went largely unaddressed.

Sports Guy lamented: "Nobody ever really talked to me about sex or relationships," while Pudding admitted his inability to appropriately express his sexuality led to expulsion

from secondary school, an adult vocational program, and supported living. He now lives in a group home after being penalized but never educated: "I would ... like to learn how to not touch inappropriately and how to start a relationship." Bus Rider maintained a successful relationship throughout his years in a specialized school, but it ended upon graduation due to a lack of transportation, and his mother restricts his ability to leave his group home out of worries over sexual contact. In some cases, however, effective institutional supports mitigated the turmoil.

Batgirl and Bus Rider escaped secondary school bullying while attending supportive institutions. Batgirl felt valued and connected through responsibilities such as helping younger children to the bus. Bus Rider attended a diagnosis-specific institution where he too felt engaged and supported, and effective intervention mitigated bullying for Diana. In contrast, teachers were unsuccessful intervening on behalf of Daredevil and The Dark Knight, leading to overwhelmingly negative secondary school experiences. Pudding's harassment was so severe he moved out of state and eventually dropped out. Sports Guy also dropped out, while The Dark Knight persevered but likened graduation to escaping to freedom.

Overall, then, difficulties integrating into controlled secondary school communities foreshadowed community integration delays in young adulthood.

# DisAbility Identity: I Am a Complex Person not a Disability

Although study design sought insight into how participation and community integration informed self-conceptualization, collaborator identities emerged not from how their communities embraced and integrated them. Rather, they emerged from how they perceived their own strengths and interests as well as what they could contribute, if allowed. When asked what makes them special, Daredevil, Batgirl, and Diana all referred to loving their family while for Pudding it was being a good and honest friend. Sports Guy proudly

described being a recovered alcoholic, and Bus Rider declared: "I will always be the strong man that I know I can be. I'm not going to let anything stop me." Despite his turbulent adolescence, Pudding formed his identity through pride in his sexuality, political identity, and loyalty to friends. And although diagnosis and special services were mentioned, they never dominated the narratives.

Although The Dark Knight was troubled by his ASD diagnosis, he still defined himself through a desire to help: "I like to care for and protect people ... to help and persevere and be an inspiration." For Diana, her ASD diagnosis was a source of pride: "I was happy and excited because it helped me understand who I am." Daredevil attended a special classroom but never mentioned Down syndrome. He touted his work ethic and proudly reiterated multiple times attaining supported living, which allows greater independence than the group homes of most of his peers. Batgirl passingly referenced special education but identified as an athletic person who always maintained a best friend. She liked helping others and wanted to be a teacher, proud of her jobs at school. Sports Guy discussed his mental health diagnosis but never identified as ID and remained determined to earn a general equivalency degree. Even collaborators' secret identities reflected empowerment. Riding a regular bus to his new school instead of being driven to a special bus was a seminal event for Bus Rider. Sports Guy identified as athletic. Daredevil, The Dark Knight, Batgirl, and Diana (Wonder Woman's alter ego) all identified through a favorite hero (perhaps taking the comic book format literally). And Pudding's alias reflected a playful and optimistic personality. However, it was the desire to give back that most defined collaborators.

Despite stereotypes of social dependence, collaborators consistently expressed a desire to help others. Pudding worked at being a good friend while Batgirl and Diana aspired to serve through teaching and nursing, respectively. Sports Guy—an avid fisherman—always

cooked his catches for roommates and remained determined to "be something with my life."

Despite working only one day a week, Bus Rider spent part of his earnings on candy to share with roommates. Daredevil was proud of his childhood chores that he maintained in supported living, and always aspired "to help customers" in the food industry. However, motivation extended beyond altruism. Every narrative demonstrated the importance of employment to identity, and all collaborators craved the economic independence and the self-esteem gained through employment.

Daredevil was the most consistently employed, a frequent source of pride. Exploring vocational interests with their grandfathers ranked amongst Bus Rider's and Sports Guy's most cherished memories. Batgirl and Diana were proud of jobs sorting clothes at a thrift shop and bagging groceries. Pudding was out of work but eager to return, and while The Dark Knight had never been employed, he helped with the family hotel business and spoke to his father about taking over one day. However, reality fell far short of their aspirations and collaborators consistently struggled to form realistic and actionable career plans.

Diana and Batgirl had no plan or path at attaining dream jobs in nursing and teaching. In fact, most collaborator training during transition focused on janitorial tasks such as sweeping at a mall or cleaning booths in a restaurant. Bus Rider volunteered and held early paid employment in such settings but did not qualify for PSE training. Pudding recalled little early vocational training, and PSE vocational training failed to result in consistent employment. Sports Guy professed higher ambitions, but admitted his future likely lies in food service, too. Perhaps more focused career training was provided, but nothing that was effective in creating enduring and actionable vocational identities. So, while collaborators did not directly define their identities through community integration, a lack of integrated opportunity clearly affected their self-image.

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

This study was built upon the expectation that postsecondary transition would be traumatic and disorienting. However, this turned out to be the case upon entering—not exiting—secondary school. In fact, transition was experienced as overwhelmingly positive. Diana recalled: "When I graduated, I was happy .... I felt ready to be a grown up." Bus Rider and Batgirl also were proud despite missing their friends. For others, leaving school was a relief. The Dark Knight stated he "felt like a free man," while for Daredevil it meant escaping bullying. Both Pudding and Sports Guy dropped out to flee harassment rather than cling to IDEA, although Pudding reflected: "I might have done better or stayed in school if there was less racism and bullying—if people accepted that I like boys." Nevertheless, although transition was not a sudden tumble, all collaborators have struggled to attain independence in adulthood.

None of the collaborators lived independently, and all either depended on or struggled with their families for control. Batgirl admitted: "My mom mostly makes big decisions and controls my life. I'm a little okay with that and a little not." Bus Rider's mom prevented socialization outside his group home, and all four institutional residents relied on staff for leisure, shopping, and other excursions. Batgirl and Diana, both living at home, were the only collaborators to spend significant time with friends, and Diana preferred friends visit her home. None were employed full-time, and all struggled to maintain work when obtained. And even those who earned money seldom controlled it. Bus Rider's parents maintained financial guardianship while Batgirl's mother cashed and controlled her paychecks. Sports Guy depended on money from family. And whatever independence was achieved was easily lost.

Pudding went from apartment living during PSE 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 COVID-19 and had yet to regain them. And Sports Guy has struggled to achieve residential stability: "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." Bus Rider met a friend at a fast-food restaurant once before his mother intervened out of fear of inappropriate contact. Therefore, gaining autonomy and community integration was a continuous climb beginning in adolescence with any ground taken easily forfeit by the slightest misstep.

#### Discussion

While CDT and disability studies continued the march towards greater autonomy and integration, these narratives confirm continued obstacles to community integration upon postsecondary transition for young adults with IDD and noted through studies such as the NLTS2. No collaborators lived independently or were competitively employed, and all were largely dependent for leisure and social pursuits. Such social barriers are particularly concerning because the "Happiness is a Friend: Social Support Not Community Integration" Drives QOL theme demonstrates the importance of personal connections to self-fulfillment. This theme also reflects the importance of family and positive institutional support as expressed in Joly's (2015) It Takes a Village theme. Similarly, the "DisAbility Identity: I Am a Complex Person not a Disability" theme reflects the fractured vocational identities resulting from siloed services, cited throughout transition literature (e.g., Benson et al., 2021; Franklin et al., 2019; Oertle et al., 2021; Plotner et al., 2020). The Dark Knight complained: "The IEP team didn't ask what I wanted to be when I grew up." Collaborator dreams eventually gave way to inconsistent service work promoted by heavily criticized cookie cutter job training centered on food services and janitorial tasks (Hirano et al., 2018; Joseph et al., 2017; Oertle & O'Leary, 2017). This does not prove that underfunded and understaffed

professionals are not trying but it does provide insight into how fractured services result in fractured outcomes. Rather than feeling entitled to additional services, collaborators consistently expressed a desire to give back, although their altruism appeared conspicuously absent from transition literature. However, the most striking divergence from prevailing literature was the absence of a perceived policy cliff.

The transition to secondary school caused the primary trauma throughout these narratives, thus "The Adolescent Earthquake:Transition Begins Earlier Than Expected" theme. For example, Pudding stated: "I had a good childhood. But I started to have more troubles in middle and high school when other kids started picking on me." The implications for CDS and disability studies in general are profound, suggesting the focus should shift to much earlier in life. While further study is needed, waiting until 16 to address transition per IDEA may be much too late. Instead, the "Mountains of Exclusion: The Policy Cliff as a Slow Climb, not a Quick Fall" theme demonstrates that exclusion and disorientation begin at the onset of adolescence, and collaborators entered adulthood desiring access to greater life skills and social skills training. Sexuality and relationships were among the topics that collaborators most desired knowledge, yet these were conspicuously missing in the literature, even by Rosenbaum and Gorter's (2012) six f-words conceptualizing emerging adolescent participation.

Sports Guy described several girlfriends, although the relationships never lasted long; he expressed disappointment in receiving little guidance on relationships. Bus Rider's long-term relationship ended due to lack of transportation. For Daredevil, Diana and Pudding, sexuality was a source of bullying, with Pudding stating he wished he would have been taught how to touch appropriately. This further reflects the paternalism identified in the theme "DisAbility Identity: I Am a Complex Person not a Disability," which also appears in

Francis et al.'s (2020) study of the perspectives of PSE students with IDD, which found overprotectiveness was a major impediment to independence and identity. Batgirl, Pudding, and Bus Rider all felt at least somewhat constrained by family while institutional control loomed large for all. This should not diminish the concerns of families and other stakeholders. Guiding children with IDD into adulthood is a complex and demanding process; however, there is clearly room for improvement.

These results also suggest a need to rethink the concept of community integration as defined by engagement of tasks in the community. Collaborators were more interested in giving back than demanding services, and they conceptualized QOL through connections rather than community engagement. Chang et al. (2013) and Rosenbaum and Gorter (2012) provided broad and inclusive definitions of participation and community integration, which authors such as Black and Lawson (2017), Lee and Morningstar (2019), and Liasidou and Symeou (2018) used to expand the scope of educational outcomes measures, but perhaps we need to go a step further. Integration implies an impetus on individual assimilation per external measures rather than emphasizing individual preferences. For example, Diana rarely left home and would score low on community integration measures but was largely content:

We stay home, but one time a week my friends ... 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.

By contrast, The Dark Knight helped with the family business and attended the gym regularly but felt the most alienated. Pudding was still bullied at work and Bus Rider experienced constant turmoil at his group home. They also would score higher on quantitative measures but expressed greater detachment from their community. By contrast, Daredevil, Batgirl, and Diana expressed stronger feelings of self-determination in maintaining social

connection and thus expressed higher QOL and community connection. Therefore, as disability studies cultivates more inclusive research, perhaps role participation as determined by respondents should be emphasize over externally imposed ideal of community integration to truly empower this population.

#### Limitations

While data saturation was achieved, this study was exploratory. Sample size was limited due to complexity of interactions, and sampling through a support agency excluded those who may have achieved full independence. Further, this study was conducted in North Florida, and both policy and culture can vary significantly by region; therefore, while many universal concerns arose, transferability should not be overstated. Also, while care was taken to capture honest and accurate narratives, memory is imperfect and narrative inquiry concedes that stories are interpretations rather than confirmable facts. The comic book conceit may have also influenced storytelling as demonstrated in the choice of aliases. Finally, this study was limited by my own biases and perspectives, despite reflexive journaling and grounding in CDT. We are all beholden to our experiences, and I chose to value and respect the views of participants, which I find preferable to the alternative bias.

# Recommendations

#### Research

This study highlighted the need to further explore the effects of early adolescence on disability, with specific attention paid to bullying and sexuality specific to IDD, neither of which emerged as deductive codes from existing literature. While efforts have moved transition planning to age 14 in some states, this study supports further investigation into how early transition planning should begin. Further, as one collaborator without siblings failed to make friendships, the effects of siblings on social skills development for persons with IDD

may warrant exploration. Finally, community integration as a transition outcomes measure should be examined for cultural bias.

# **Policy**

Although further research is needed, this study indicates IDEA's transition mandate at age 16—and perhaps the age 14 mandate of some states—is insufficient and should begin upon entering secondary school. Also, greater emphasis on bullying prevention for persons with disabilities should be considered, and persons with IDD may benefit from mandates to address sexuality and relationships as part of life skills training, as these themes failed to turn up in deductive coding yet were consistently cited as a concern by collaborators. Finally, these results connect studies illustrating the problem of siloed services with that illustrating fractured identity formation and indicating a need to promote concrete and enduring vocational identities.

# Methodology

This IRB-tested design drew evidence from diverse perspectives such as disability studies and CDT, narrative inquiry, narrative psychology, and occupational therapy. As a methodology, it embraces the ideals and goals of disability studies to promote social justice and equity through amplifying excluded voices. The design may present a blueprint for navigating the collaborative challenges of working with those with IDD while mitigating IRB and other oversite committee reluctance, thereby generating more inclusive research.

#### **Conclusion**

While evidence shows young adults with IDD struggle with community integration, this study provided one of the first conceptualizations of postsecondary transition outcomes in the words of those involved. The findings affirm decreased levels of community

participation and the need for increased social and life skills training. They further underscore a need for earlier emphasis on transition services while exposing the inadequacy of community integration as an outcomes measure. Collaborators formed empowered identities through abilities and preferences and were hopeful of the future, yet raised concerns about bullying, paternalism, inadequately coordinated services, and a lack of information on sex and relationships. These narratives described rich inner lives founded upon introspection and complex identify formation, demonstrating that not only does this population desire to speak but deserve to be heard.

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