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“I Should Have Big Dreams”: A Qualitative Case Study on Alternatives to Guardianship

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Abstract: This qualitative single case study explored (a) the underlying beliefs of the connected individuals involved in determining guardianship or alternatives to guardianship for a young adult with intellectual disability; (b) the attitudes, resources and skills needed for educators and families to develop transition plans that address alternatives to guardianship; (c) barriers that may exist in the school setting for the young adult’s development of self-determination skills; and (d) derive lessons and best practices needed to maximize student self-determination skills and implement alternatives to guardianships. Findings were that the implementation of alternatives to guardianship for the young adult was related to many factors including a k-12 inclusive education, the value of interdependence, connection to advocacy organizations and utilizing resources outside of the school.

The Individuals with Disabilities Education Improvement Act of 2004 (IDEIA) requires school staff and parents to work together to begin transition planning for students with disabilities as they approach the age of majority. This planning should focus on developing necessary skills for life after high school (Gutierrez, 1999; IDEIA, 2004; Pierangelo & Giuliani, 2004) including self-determination skills and independence (IDEIA, 2004; Shogren, Wehmeyer, Palmer, Rifenburg, & Little, 2015). In addition to requiring transition planning, the IDEIA mandates that all rights accorded to parents under the IDEIA “transfer” to the student once he or she reaches the age of majority, so that the student will be able to make his or her own independent decisions. However, according to the IDEIA such rights will not transfer if the young adult’s “competence” is questioned, whether by teachers, professional staff, or parents (section 300.514). In such cases, the school transition team may encourage parents to become the legal guardian of their adult child (Lindsey, Guy, Wehmeyer, & Martin, 2001; Millar 2007). Once the parent is appointed as guardian, the parent is legally authorized to make many or all decisions for their young adult

child, including decisions about work, school, housing, food, and friends (Millar, 2007), and individuals with guardians often lose their right to vote, marry, sign contracts, file lawsuits, consent to medical treatment, or possess a driver’s license (Gutierrez, 2015).

Research shows that the decision to obtain guardianship is often made with good intentions to protect the young adult (Millar, 2007; Payne-Christiansen & Sidlington, 2008). However, because the young adult must be designated “incompetent” or “incapacitated” to obtain guardianship, whereupon his or her rights are legally removed, the practice of guardianship can reify ableist beliefs regarding who is valued enough to participate in the rights of citizenship (Agran & Hughes, 2013) and may impact the development of self-determination, autonomy, and independence (Frolik, 2002; Millar, 2007). Therefore, the appointment of a guardian during the transition process appears to violate the language, if not the spirit, of the IDEIA (Kanter, 2015).

Several studies support the conclusion that guardianships interfere with the development of important independent living and self-determination skills of young adults with intellectual and developmental disabilities (IDD) (Millar, 2003, 2007, 2008; Millar & Renzaglia, 2002). Research also suggests that students who receive frequent adult assistance that does not help to foster student independence

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or honor student preference and choice often develop learned helplessness (Bos & Vaughn, 2002), which can lead to loss of personal control and identity, fewer interactions with non-disabled peers, and a failure to develop self-determination skills (Giangreco, Edelman, Luiselli, & MacFarland, 1997).

Theoretical Framework

This study is grounded in disability studies theory, which generally refers to disability as a social, cultural, and political phenomenon in which disability is the result of an individual's interactions with society (Danforth & Gabel, 2006; Davis, 2006; Siebers, 2008). Disability studies challenges the dominant medical model that views disability as a "problem" within the person, as something to be fixed or cured by "experts" in order to conform to normative values. Instead, disability studies uses the social model to frame disability, which recognizes disability as something caused by the way society is organized rather than by the person's impairment. Specifically, the social model seeks to discover ways to remove those barriers that restrict people with disabilities in order to help them become equal in society, with choice and control over their own lives.

The practice of guardianship is largely based on a medical model of disability that labels a person as unequal and incompetent, socially excluding them simply because they may need support when making decisions. While limited research exists about young adults and guardianship experiences, the existing research suggests that these young adults often had guardianships appointed even though other less intrusive systems of support could have sufficed (Jameson et al., 2015; Millar, 2007; Payne-Christiansen & Sitlington, 2008). Studies also evidence that often parents would prefer not to have to resort to guardianships, but they believe they have no choice (Millar, 2008). Parents often consult with educators and transition teams for advice, but studies illustrate that neither parents nor educators are very knowledgeable about what guardianship entails or what alternatives to guardianship may exist (Jameson et al., 2015; Millar, 2013; Millar & Renzgalia, 2002). In a recent study in which 1,223 participants completed a survey about guardianship

practices, full guardianship was evidenced as the most consistently discussed option with parents of students with disabilities (Jameson et al., 2015).

Alternatives to guardianship provide less restrictive ways to offer people with disabilities the support they may need and want when making decisions (Millar, 2013). These alternatives include informal support from family and friends, often referred to as supported decision-making, as well as more formal instruments like trust funds, specialized bank accounts, powers of attorney, representative payees, and case management services (Millar, 2013). However, the study by Jameson et al. (2015) found that when educators and families determine the transfer of rights for a student, guardianships remain the most frequently discussed option. Alternatives, like supported decision-making, are the least frequently discussed.

When considering the extant, but limited research, these collective findings are troublesome. Guardianship alternatives that use person-centered planning models have the potential to allow the student to assume the intended roles and responsibilities of adulthood with support (Agran & Krupp, 2011) and without the stigma of control and incompetence that can be attached to the appointment of a guardian. Many of these alternatives also allow the person with a disability to identify another person or group of people to assist them (Millar, 2003). By providing support to young adults during decision-making, rather than making decisions for them, these alternatives align with the social model of disability by helping to remove barriers to full inclusion of people with disabilities (Kanter, 2015). In addition to aligning with the social model of disability, guardianship alternatives, like supported decision-making and person-centered planning, are also more consistent with the framework of IDEIA.

Purpose of Study

Alternatives to guardianships occur naturally in many different forms within the family or within formalized networks. Research about alternatives to guardianship is only just emerging and therefore there is much to be investigated. Few studies have explored the pro-

cesses or outcomes of supported decision-making in order to suggest best practices for families and educators. Similarly, few studies have explored the beliefs and attitudes necessary to help educators and families, and the students themselves, to more effectively implement supported decision-making. This study intends to add to the emerging evidence base in this area by examining the perspectives of those involved in the process of creating alternatives to guardianship for one young man with an intellectual disability. The purpose of this research is focused on (a) understanding the underlying beliefs of the individuals involved in determining alternatives to guardianship; (b) understanding the attitudes, resources and skills needed for educators and families to develop transition plans that address alternatives to guardianship; (c) exploring how families and schools facilitated the young adult's development of self-determination skills; and (d) deriving lessons and best practices needed to maximize student self-determination skills and implement alternatives to guardianships.

Method

This study is grounded in the traditional qualitative approach (Taylor & Bogdan, 1984) in order to focus on the beliefs and perspectives of those involved in the process of transition to adulthood and its relation to alternatives to guardianship for one young man with an intellectual disability. I chose to explore this topic using a case study method. I drew from Biklen and Attfield's (2005) qualitative inquiry to examine the way a small group of connected people view the complex issue of guardianship and Dehyle's (2009) mutual collaborative approach in order to highlight the perspective and expertise of the young man with a disability. The emphasis on the young man's beliefs and attitudes toward guardianship and its alternatives is an essential aspect of this study and seeks to build on prior studies in which stakeholder perspectives regarding guardianship have been addressed (see Millar, 2008, Payne-Christiansen & Sitlington, 2008). In order to emphasize the importance of his voice, I adopted an epistemological stance that sees the participant as the expert, or collaborative researcher, and the re-

searcher as someone who learns from the expert, rather than someone who develops theories about the subject (Knox, Mok, & Parmenter, 2000).

Therefore, I asked the young man to participate as an expert and collaborative researcher, explaining that if he so chose, he could be involved in the collection of data and analysis of data. He agreed to participate as an expert and collaborative researcher and was subsequently involved in many of the decisions about whom to interview (i.e., his parents, teacher, and friend) and the questions we might ask them. He assisted me during the interview of his friend and high school teacher. I consulted with him on the interpretation and analysis of all interview data, including his own interview and relevant document data. Together we explored meanings participants gave to certain concepts and life events (i.e., inclusion, independence, interdependence, competence, adulthood and transition).

To create a study where the participant is also a collaborative researcher, I strived to develop what Ellis, Kietlinger, and Tillmann-Healy (1997) call an empathetic, safe space, in which the participant feels comfortable and trusts the researcher enough to open up and explore opinions and perspectives about sensitive topics, such as competence and independence. I strived to avoid any clinical relationship of researcher to subject, so that I did not reify the notion that participants with disabilities are seen as an object of research, but instead viewed him as an expert.

Participants

The main participant, Brian, engaged in this study as an expert and collaborative researcher. He was purposefully selected following what Bogdan and Biklen (1998) call the "optimistic approach," (p. 220) in which the researcher looks at situations that others might consider successful in order to learn from them. I purposefully chose Brian because throughout his life he and his family have utilized supported decision-making and because he has transitioned to adult life without a guardian. Brian has an intellectual disability and is able to communicate independently.

The process of transitioning from high school and determining the use of either guardianship or its alternatives is likely to include the person with a disability, his or her family, teachers, friends, and other supporters. Therefore, the young man and I decided it to interview the following participants: his parents, a high school teacher who played a significant role in his transition into postsecondary life, and a friend whom he met during this transition period. Our choice of participants is consistent with previous studies by Millar (2007, 2008) and Payne-Christianson and Sitlington (2008).

Brian. I first met Brian at a university in the Northeast where he worked as a peer trainer for students with intellectual disability and was enrolled at the college in a non-degree program. After graduating high school at the age of 18, Brian attended college through a similarly structured non-degree program and one of many across the country that encourage and support students with intellectual disability to attend college. Due to his own experience in college he was able to provide great insight and assistance to the students.

Brian is a caring and thoughtful 29-year-old who is passionate about disability rights and politics. He requires many supports in his life. For example, Brian reads and writes using technology like screen readers, which read electronic text out loud to him, and voice-to-text software, which type his spoken words. Using these tools, Brian is able to read and send all of his emails and text messages and keep up with all of his favorite political news on the Internet.

He currently lives with a friend in a two-bedroom apartment in a bustling neighborhood near the college where he works. He takes the bus or walks to work because he does not drive. Brian maintains a circle of support (Falvey, Forest, Pearpoint, & Rosenberg, 1997), which I will address in greater detail later in this article. His support circle includes many people in his life, such as friends, family, and colleagues who support him in discussing day-to-day events, important life decisions, goals and future plans. For example, agenda items for a circle meeting from the spring of 2015 included housing updates, health updates, social life (trivia night, dance at the fair), and a social justice conference.

With his Medicaid benefits, Brian employs a case manager and two staff members through a local community living agency. He is fully included in the process of hiring and firing these staff members. They assist him with activities such as cooking, grocery shopping, banking, and apartment hunting. With the support of his parents, Brian maintains a bank account and uses direct bill-pay for rent and utilities. He uses on-line banking to access information about his account and visits a credit union to deposit and withdraw money in person. In addition to the money he earns from his job at the university, his parents maintain a trust for him. With the help of a lawyer they created the trust when Brian was 9 years old.

Brian's parents. Rita and Anthony Brown live in a suburban area of a Michigan. They both self-identify as activists and community organizers, and several years after the birth of Brian, they became involved specifically in disability rights and advocacy. Rita is a social worker, and Anthony has worked as auto-worker and community and labor activist. The Browns have two children, Brian and Stephanie, who are both young adults who have moved out of the family home and who currently live in states on the East coast.

Brian's teacher. Mary was a special education teacher at Brian's high school when she first met him. Although she did not teach him in the classroom, he was placed on her caseload during his senior year. This meant that she was the case-manager during his Individualized Education Program (IEP) meeting and was extremely involved with Brian and his family during his transition process from high school to postsecondary life. She played an integral part in helping Brian realize his college dream. She worked with Brian and his family, the high school transition coordinator and several adult service agencies to develop a program that supported Brian's enrollment as a non-degree seeking student at the local university. Mary is now a district-level transition coordinator.

Brian's friend. Dan and Brian became friends while Brian was in college, a pivotal transition period in Brian's life. Not only had Brian begun to transition from high school to college life, all of his educational rights had also been transferred from his parents to him.

Dan was initially a social support staff person for Brian but quickly became a close friend. Dan began going with Brian to see him speak about disability advocacy, and eventually Dan joined him on stage. In fact, Dan explains that his friendship with Brian has led him to a career in Disability Law. Today they remain friends and often travel around the country to present about inclusion, disability advocacy, and person-centered planning.

Data Collection

The majority of data were collected over the course of six months through in-depth interviews (via phone, Skype, and in-person). Document analysis was used primarily to elaborate and verify information. Brian worked with me to create guiding questions and assisted in asking questions during interviews with both Mary and Dan; he chose not to participate in the interview with his parents.

Interviews. Interview questions focused on general background, familiarity with guardianship and its alternatives, and experiences and events related to Brian's transition. Each interview ranged from 80 to 120 minutes in length and was audio-recorded and transcribed verbatim. After the first read through and annotation of transcripts, I sent clarification questions via email and requested documents to review (i.e. high school Individualized Education Programs and Circle of Support meeting minutes). I then conducted 10 to 30-minute follow-up interviews with each participant.

Document data. After my request for archival IEP documents, Anthony sent a copy of Brian's IEP from his senior year of high school. This IEP document included the section detailing his transition goals, action steps required to achieve these goals, and parties responsible for implementing these steps. I then requested recent Circle of Support meeting minutes from Brian. He gave me nine consecutive monthly Circle of Support meeting minutes recorded from the summer of 2014 through the spring of 2015. These meeting minutes detail topics and issues discussed during these meetings, any decisions made, and any action items needed to be completed by Brian or his supporters.

Data Analysis

After all interviews were transcribed, totaling over 200 pages of data, I began a content analysis procedure (Merriam, 1998) to organize and begin an initial inductive analysis of all data. Each data set (e.g., interviews, meeting minutes, and IEP document) was analyzed separately using this process, wherein I read and re-read the data to identify small units that expressed an idea (Minichiello et al., 1990) relating to my research questions. Each unit of meaning was assigned a code, for example "self-determination" or "resources", and I created a codebook including all codes and emerging themes (La Pelle, 2004). I completed coding 25% of the data before asking a fellow researcher interested in guardianship to review this first 25% of coded data. She utilized my codebook as a guide with the intention of confirming consistency in the application of the codes. We met to discuss differences of opinion and we addressed our coding disagreements by either creating new codes or collapsing codes (Strauss & Corbin, 1994). I then went on to analyze the remainder of the data using a constant comparative method. I developed categories that cut across the multiple sources of data and compared these categories across data sets to determine any convergence and divergence within data sets. After these categories were created, I met separately with my colleague and with Brian to discuss the grouping of categories, for example "resources" into themes, such as "resources for building community". During conversations with Brian I utilized appropriate quotes from the transcripts and documents to help convey the essence of each category in order to facilitate our analyses discussions.

Self as Researcher

I entered this study with many pre-theoretical dispositions regarding the concept and practice of guardianship, so I used best practices in qualitative analysis to address the authenticity and credibility of my findings, interpretations and conclusion (Bogdan & Biklen, 1998). I sought to integrate various sources of data (i.e., interviews and documents) not for purposes of verification, but to ensure that the account is rich, comprehensive, and well-de-

veloped. Data incorporated information from different periods of Brian's life (i.e. childhood, high school, college, and present day) and various settings (i.e. school, home, Circle of Support) but also compared people with differing points of view (i.e. Brian, teacher, friend, parents, supporters). I utilized multiple researcher collaborators in the analysis process to various degrees (i.e. Brian and myself were directly involved with data collection while my colleague was not involved in data collection). I conducted stakeholder checks from each one of my participants as well as from two outside researchers who have a specific interest in the topic of guardianship. The stakeholder comments and insights I received on preliminary drafts were incorporated into this final version. Finally, having Brian as a collaborator and sounding board throughout the entire process was invaluable, as always I could refer back to his "sense and understanding of the world" (Cherryholmes, 1998, p. 108).

Findings

The Browns's Story

I met Brian's parents, Rita and Anthony Brown, on a Tuesday night via a Skype video call. I began the open-ended interview by asking them to tell me about Brian's history. They explained that at 3 months old Brian was diagnosed with "failure to thrive" syndrome and a few months later diagnosed with development delays. When he was 13 months old he showed difficulty in motor motive planning, sensory integration, low muscle tone, delayed speech, and began receiving therapy and early intervention services. When Brian was 5 years old, his neurologist explained that he had a neurological or cognitive impairment, though no doctors could explain what had caused the impairment. The neurologist explained that Brian would always struggle in school but that supports and interventions should be continued in order to help him progress and succeed. As the Browns realized Brian had what the doctors called "delays," they connected with Bonnie, a family advocate from a local advocacy organization. Bonnie encouraged them to seek out a financial advisor familiar with disability law, so that they could create a trust for Brian that would not impact his dis-

ability benefits. She also suggested that Brian should be fully included in general education.

But when it came time for grade school, Brian was initially placed in a self-contained classroom, separated from his peers without disabilities. As Brian moved through the early years of elementary school he struggled greatly in reading, writing, and math and had many academic delays. He scored a 40 on the Stanford-Binet I Test and his Individualized Education Program (IEP) identified him with the label "trainable mentally impaired," what is today known as intellectually disabled (ID). Rita explained that Brian began to notice the difference in his self-contained class and told them he wanted to be in the "regular" classroom. So in the third grade, his parents moved Brian into the general education classroom, leaning upon the Individuals with Disabilities Education Act (IDEA, 2004) and the timely legal decision (*Oberti v. Board of Education*, 1993) that determined all children with disabilities have the right to be educated in the least restrictive environment (LRE), alongside their general education peers, with appropriate supports and services. The Browns explained that while Brian's inclusion was never perfect, often inadequate, and sometimes very difficult, they believed that his inclusion provided people involved in Brian's transitions to middle school, high school and adulthood with a positive framework for understanding Brian and his needs and strengths. They also explained his inclusion provided him with ongoing opportunities to engage in the classroom and in the community. This constantly challenged his supporters (family, teachers, friends, and advocates) to seek new ways to facilitate the development of his interests, desires, and self-determination.

The first time the concept of guardianship came up occurred when Brian was in middle school. In conversations about transition planning with the local advocacy center, Rita and Anthony learned that Brian would not need a guardian when he reached the age of majority (age 18 in their home state). IDEIA mandates that when children turn 18, the rights accorded to their parents transfer to them, unless a child is "determined to be incompetent under State law" (2004, 34 CFR §300.520). However, at that point in time, Rita and Anthony didn't fully grasp what guardianship

meant. Rita said that for much of his adolescence guardianship wasn't even discussed. They were "focused on getting him through the day, getting him through middle school and high school, making sure he received the support he needed, and that he was fully included in meaningful ways with the best supports and accommodations." In fact, Brian's parents believed that because he "was fully included, he didn't have a lot of special ed teachers and so guardianship just didn't come up." Similarly, Brian explained, "I don't really remember hearing about it at school" and recalled truly learning about the term legal guardianship for the first time "from other self-advocates and um, like in my summer internship" with the Youth Leadership Network.

When Brian approached the age of majority the issue of guardianship was still not considered by the Browns nor encouraged by any members of Brian's school transition team. His caseload teacher, Mary, remembered that guardianship was only briefly discussed during the annual review of his Individualized Education Program (IEP) during his senior year and only so that she could check a box on the IEP documenting that, as mandated by IDEIA (2004, 34 CFR §300.520), she had informed Brian and his parents of the rights that would transfer to him at age 18. Mary said that, "The focus of the IEP is about so much more than guardianship, and so it's something that we actually discuss with one breath, with one sentence." She added, "We probably asked the question, got the answer, checked the box and went onto bigger things."

The team's brief attention to the issue of guardianship was not because they believed Brian didn't need help with decision-making. In fact, the "bigger things" the team went on to discuss at his IEP meeting were the many supports for decision-making and daily living that he needed then and will likely continue to need throughout his life. For example, an "adult living" transition goal on the IEP reads that Brian, with support from both a non-profit human services agency and the college he would attend the following year, would "discuss adult living opportunities on campus" using an "ongoing" timeline. It is clear that the Browns envisioned a self-determined life for Brian and they believed guardianship would be "antithetical to raising Brian as

someone who would not be excluded from making decisions that affected his life."

Beliefs and Perspectives of the Participants

After interviewing, transcribing, reading and re-reading transcripts, reviewing documents, coding and discussing codes with Brian, I identified several important themes: the presumption of competence, the importance of interdependence, the use of advocacy, and a rethinking of traditional "transition" for students with intellectual disability. In the following sections, I elaborate on and substantiate this assessment.

Presumption of competence. An implicit statement regarding a young adult's competency is made with the advocacy for or appointment of a guardian. The guardianship law in Brian's home state determines an individual "legally incapacitated" if appointed a full guardian (MCL §700.5306). It is therefore essential to consider the social and political context regarding the determination of "competency" or "incompetency" for an individual person. Legal definitions of "incompetence" vary by state and county and are largely rooted in the historic bias that individuals with intellectual disability are often believed to be incompetent (Agran & Hughes, 2013). The assumption that a label of intellectual disability (ID) correlates to incompetence is even exemplified by the definition of ID in the American Psychiatric Association's (APA) DSM-5 (2013) which reads that "a failure to meet developmental and sociocultural standards for personal independence and social responsibility" (p. 33).

The laws of guardianship therefore seem to exclude people from legal participation in society based on an assumption that they have "failed" to meet the standards for independence and social responsibility even though likely they simply require various levels of support throughout their lives. This assumption of failure creates what Biklen and Burke (2006, p. 167) refer to as the need for "demonstrating-competence-in-order-to-be-granted-it." In Brian's case, rather than assume the DSM-V's "incompetence" or "failure" due to difference, Brian's family, educators, and supporters rightly questioned the DSM-5's very

“standards for personal independence and social responsibility” (2013, p. 33).

Literature in DS and DSE has long discussed the social construction of disability labels and how once labeled, teachers and supporters often perceive a student through a lens that focuses on their deficits (Baglieri, Bejoian, Broderick, Connor, & Valle, 2001). But Brian’s family presumed competence and shared this vision with his school team. They believed that Brian could and would grow despite any perceived deficits attached to his disability label. As Anthony explained, “in relation to other people giving him opportunities and not them controlling what he did.” Because of these supported opportunities, Brian demonstrated complexities in thought, actions and relationships that might not have necessarily been anticipated. For example, his parents always acted as if he would one day be able to travel on his own, but they were never sure if he actually would. But by providing him with supported opportunities and purposeful practice, Brian now flies by himself. Rita was very proud but remained amazed by the logistics: how did he handle the complexities of changing planes and dealing with layovers? She said she once asked him, “‘Brian, how do you do that?’ And he looked at me, baffled by my stupid question, and said, ‘mom I just ask for help!’” In her reflection on this story, Rita explained that Brian’s clear understanding of his own needs and his ability to ask for help are key components for her perception of him as a “competent” person and skills they practiced and nurtured throughout his life.

Similarly, Brian stressed that he always felt his parents believed in him. He said that they always told him, “I should have big dreams.” He believes the presumption of competence has greatly contributed to his success as a young adult. He emphasizes that because he is without a guardian he is able to make his own decisions. When I asked why he thinks it is important for him to make his own decisions, he said, “it means I am capable of doing stuff, knowing when I can and should do things, and knowing where I want to work and live.”

Building purposeful community. The Browns had concerns for Brian when he was a child, and continue to have concerns for him now that he is a young adult. But rather than focus on protecting or shielding Brian, they empha-

sized the importance of acknowledging their concerns and then reaching out to the community and professionals for support. Throughout the interviews, participants discussed helping Brian to build a community and support network in order for him to succeed. Anthony explained that,

Guardianship is this concept that only an individual can provide security for someone. Our general belief was the opposite of guardianship; that you believe the person can grow and make mistakes, but that there is a community of people around him that care about him and will intervene if necessary.

Brian echoed this sentiment, explaining that when it comes to living independently, the most important thing for him is “having a good community and having people that are able to help me and believe in me. It’s also important to have people to go talk to—to help me make decisions.” Building a community for Brian was an intentional and ongoing process for the Browns. As early as third grade, the Browns facilitated person-centered planning (PCP) tools for Brian, such as a Circle of Support, Making Action Plans (MAPS) and Planning Alternative Tomorrows with Hope (PATH) (Falvey, Forest, Pearpoint, & Rosenberg, 1997). PCP is a concept built around values of inclusion and seeks to understand the supports a person needs to be included and involved in their school and community. Particularly, PCP rejects the medical model of disability, in which Brian’s needs would have been assessed, and services and decisions allocated for him, not with him. Instead, PCP is grounded in the social model of disability and aims to empower by giving individuals the power to make their own decisions with support.

The Browns first used PCP tools when Brian was in the third grade by establishing a Circle of Support, which consisted of peers from school as well as important adults in his life. His “Circle” meetings were held both at school and at home, and Rita explained that for the meetings “the kids would come over here and sit in the basement and talk about his [Brian’s] strengths, and that was just who he was. Those were intentional ways to make sure there were people around him.” When Brian

and I talked about his Circle of Support he explained, “like if I have a problem or if I need something I can go to them and try to explain it and get like help from them.”

During one of our reviews of the notes from each of this year’s monthly Circle of Support meetings, Brian and I noted that while there are various supports discussed during his meetings (i.e., help to find a new roommate, advice about going on romantic dates, where to throw an upcoming birthday party, feed-back on a presentation he gave, etc.), they are basically the same supports that most adults seek from their friends, family and colleagues. I mentioned that it seems like the Circle of Support simply provides a reliable structure of support, Brian said, “yes, but I lead it,” referring to the very important fact that he leads each meeting, determines the agenda ahead of time with support from one of his circle members, delegates a meeting note-taker and emails out the meeting notes after reviewing them with the note-taker. He is fully in charge. This leadership was corroborated by an example Rita’s shared. She explained that several years before, Brian had flown by himself to a city on the east coast where he had presented his life story and advocated for inclusion at a conference for educators. When he returned home, Rita remembered him saying, “I’m going to move there and here’s what I have to do—the first thing that I have to do there is make a circle of friends.” Rita elaborated, “It was an absolutely stunning example of how something that we started in third grade that wasn’t perfect—and at times, I didn’t think was going to work—helped him to develop the skill of knowing that if he was going to live in this world, he would do it interdependently with others helping him. I mean, you can’t get a higher IQ than that in my opinion.” When Brian and I discussed Rita’s story, he added that, “oh ya, I knew I had to have a Circle of Support if I was going to do something big like move.”

Mary echoed the idea that students with complex needs like Brian should be a part of their community. She explained that students “should have regular social recreational opportunity and they should have a certain amount of ability to navigate their community.” Additionally, when Mary discussed Brian’s transition to postsecondary life she explained that much of it had to do with

providing opportunities in the community. She said, “all the way along we were trying to provide Brian with different experiences because that’s how we find out about what we want to do—we wanted him to have the opportunity to try things.”

Interdependence serves independence. All of the participants stressed that Brian would need supports in order to be successful and interdependent. His friend Dan explained that, “he [Brian] really demonstrates that through community you can reach independence and you can reach your goals, you can have success through the support of community, and be an individual, be independent.” When Brian and I were preparing our questions for our interview with Dan, Brian suggested I write down the following question, “Dan, do you see me as more independent now than you did when you met me?” When I read it back to Brian he paused. Then he said, “Well, I like the word independent but I need to ask for help for things. And I am able to do that.” Here, Brian’s ability both to recognize his needed supports and to ask for those supports illustrates valuable self-determination and self-advocacy skills.

When I asked Brian about the specific supports, he explained that some of the areas in which he feels he needs support are “banking, my checkbook, food shopping; though I know how to cook some food.” He also said, “I need help figuring out where to live, and help with dating.” His parents echoed his expressed areas of support. And his friend Dan elaborated on this concept of support for daily living. He said that Brian helps him understand that “achieving independence is not an individual act”. Instead, Dan now believes that independence is really a collective concept, where someone like Brian can be empowered, make choices and lead his own life with the support of community. With this understanding we can move away from the misconception or overuse of independence to the more honest and realistic goal of interdependence. Dan explains further, “I think community is the foundation for advocacy in general and the idea that we share space with others and we are consistently benefitting from those around us.”

Guardianship, then, lies in direct contrast to the idea of achieving independence

through community support. Relying on the medical model, guardianship designates a person deficient and incapable of making decisions. When Brian and I discussed this particular idea, I asked him whether or not he believed people could be “capable” and simultaneously need many supports. In response he asked me to first explain “capable.” After we looked the word up and discussed it, he decided that capable, “makes me think of what I’m trying to do in life and what I’m trying to get done.” Once he had determined his definition of capable, we decided together that we believed it was possible for a person with an intellectual disability, or in fact, any person at all, to be considered capable and simultaneously rely on community support. He said insightfully, “Maybe someone would say, ‘oh, well you should do it all on your own’, but the thing is, everyone needs help with some things in their life.”

Advocacy, agencies and experts. Brian’s teacher Mary explained that for students with more complex needs, the transition process has many parts and can become complicated and overwhelming for both the family and the teachers. “I cannot be the expert on everything,” Mary said, “I can be the expert on education and IDEA, but there is something about guardianship and social security that evades me.” In fact, Mary’s experience working with the Browns to facilitate Brian’s transition “was a whole new level” of complexity for her. Therefore, while she explained she doesn’t have all of the answers, she understands the need to be aware of local agencies and professionals that focus on areas of transition that may be beyond her scope of expertise (i.e., alternatives to guardianship, social security benefits, or financial planning for students with more complex needs). She said that staying informed means, “even when I can’t answer a question eloquently, I know what direction to point the parents in; I have a brochure or a card to hand them.” She also explained that she, “creates workshop opportunities and learning opportunities for the families in my district, and I learn alongside them.” She believed providing in-school access to outside agencies and experts is a proactive way for her to support families and students while benefitting her own ongoing professional development. She said, “the biggest help is having all the voices and all the experts in the different areas

at the table, together. It helps to fill in all those gaps and answer all those questions.”

In addition to professional experts, Brian was also connected with self-advocates who introduced him to the culture of disability in a way his able-bodied parents and educators could not. Rita explained that Brian’s experience with youth leadership programs such as Kids As Self Advocates (KASA) and the National Youth Leadership Network (NYLN) were “life changing moments.” She told a story about the time Brian created a timeline of his life in which only two dates were present, “when he was born, which was also when the Detroit Tigers won the world series, and then, the next thing was when he was in 10th or 11th grade and he went to our state’s Youth Leadership Forum for four days . . . as if there was nothing else in between!” In 11th grade, Brian also became a national board member for KASA and learned a great deal about disability culture and history. When Brian talked about his experience with KASA he said,

KASA was important to me because I met some great self-advocates with disabilities and I met great friends that I still have today. And it like helped me to know my rights, and learn about self-advocacy skills, and just, it did a lot of great things.

These advocacy organizations were grounded in the social model of disability and in the beliefs that all people with disabilities should maintain self-control, foster notions of self-worth and have the opportunity to develop self-determination. Rita explained that these organizations thought “guardianship was absolutely not an option and so at a very young age he was around folks that knew guardianship was not the road for him.” And while the Browns may not have always used the words “self-advocate” or “self-determined,” these concepts were integral to the way they raised Brian. Anthony expressed that they push and nudge Brian forward, just as any parent might with their child, they also have to be careful because they are navigating both their understanding of how Brian is defining his own world and the world they envision for him. Anthony explained, “there’s this fine line between what’s real for everybody and what’s particularly real for your child with a disability.” When I spoke to Brian about this data, I asked

him whether or not he was ever worried that people in his life, even though they cared about him, might try to sway one of his decisions.

Brian: Well I try to talk to them, and say, “ok . . . I can make my own decisions and if I need more help then I’ll come to you.”

Researcher: What happens if someone you care about gives you advice that you completely disagree with?

Brian: What my parents say is, if I agree or disagree, I should just talk to the person and say, “I’m gonna think about it and then I’ll let you know.”

Our conversation illustrates that Brian knows how to navigate difficult conversations with his supporters. Brian said he thinks this ability means he is a self-advocate. When I asked him how he thinks he developed these self-advocacy skills he said, “I learned it from having great parents that helped with stuff. I saw them advocating for me when I was younger and then they taught me how to advocate for myself.”

Discussion and Recommendations

The conclusion that Brian would not need a legal guardian was decided due to many on-going factors. Brian was provided with continual opportunities to develop supported decision-making skills, dream, and plan for his future. These opportunities proved essential in supporting Brian to become a highly self-determined individual. This is consistent with previous research on the effective links between self-determination and successful postsecondary transition (Sitlington & Clark, 2006; Wehmeyer, 1997). Based upon interview data, on-going analytic discussions with Brian, and previous research in this area, I make the following recommendations for schools and families related to the role of guardianship and its alternatives for students with intellectual and developmental disabilities.

Presume That Students Can Be Included

Inclusion in the general education classroom had a positive impact on Brian’s transition planning process and the development of skills required for postsecondary life. These

findings support previous research that inclusion in general education significantly correlates with improved post-school outcomes in the areas of education, employment, and/or independent living (Test et al., 2009) and the already substantial research that evidences greater academic and social outcomes for students with disabilities who are included in the general education classroom (Causton & Theoharis, 2008; Cosier, 2010; Fisher & Meyer, 2002).

These findings, however, are contrary to the recent study by Jameson et al. (2015), which evidenced that educational setting had minimal influence on whether guardianship was deemed necessary for students with disabilities. This discrepancy between Brian’s experience and the participants in Jameson et al’s large study could be because the driving forces behind Brian’s inclusion was the presumption that Brian was competent and could be included. These assumptions of competence and inclusion greatly helped to support him in the development of communication and academic performance skills; self-determination; interpersonal relationship skills; and integrated community participation skills, all skills identified by Sitlington and Clark (2006) as important domains related to the concept of effective transition.

Establish Person-Centered Planning (PCP)

Previous research has shown that when the need for guardianship is determined, alternatives have generally not been fully explored during the transition process (Payne-Christiansen & Sitlington, 2008). This study is therefore consistent with the recommendations of Payne-Christiansen and Sitlington (2008) that alternatives to guardianship should be explored in tandem with an ongoing assessment of the student’s strengths, needs, preferences, and interests. Brian’s story highlights effective strategies for this ongoing assessment in the form of specific PCP tools: Circles of Support, MAPs, and PATH planning (Falvey, Forest, Pearpoint, & Rosenberg, 1997). The use of PCP placed Brian at the center of his educational and transition planning and this led to increased self-determination, self-advocacy skills, and ultimately more positive postsecondary outcomes for Brian.

These findings support prior research by Shogren et al. (2007), which suggests that there is an increase in student levels of self-determination when they feel empowered to be a part of their education and transition planning. Prior research has shown that PCP is most effective when the individual with disabilities is near his or her family (Robertson et al., 2006). However, this study evidences that by establishing PCP tools early and using them consistently throughout Brian's youth, he was able to effectively establish and lead his own PCP tools (i.e., Circle of Support) even after moving half-way across the country from his family.

Create Peer and Community Connections

Consistent with findings by Test and colleagues (2009) and Landmark, Ju, and Zhang (2010) who identified family involvement, social skills and community collaboration as key indicators for positive student transition, this study found that the establishment of peer and community connections helped Brian to develop social skills, daily living skills and connections with his community. While the Browns facilitated much of these connections without teacher initiation, instructional and support staff can also implement these connections for students. IEP goals for transition planning can even specify these supports. For example, an IEP goal might state, "the school will work with the student to create peer connections throughout the school day (i.e., partner work, group work and lunch bunches)" or "the parent will work with the student to establish community connections (i.e. with a personal banker, a community center, and neighborhood stores)."

It Takes a Village: Use All Available Resources

This study affirms research by Millar (2003, 2007) and Jameson et al. (2015), which has suggested school teams require more training and information about alternatives to guardianship as well as the promotion of self-determination for young adults with disabilities. This study also supports previous studies (Jameson et al., 2015; Millar, 2003, 2007, 2008) that teachers and school teams should not be expected to be the experts on every factor related to transition, particularly for

students like Brian who have more complex needs, and should instead be knowledgeable and up-to-date about the local agencies, professionals and networks with whom to connect families and students. Like Brian's teacher, school teams should make the effort to bring these agencies and professionals to the school whenever possible (i.e. facilitating transition fairs, alternatives to guardianship workshops, connecting students with self-advocates, and inviting agency representatives to IEP meetings). Families and school teams can write this type of professional preparation directly into the IEP, for example, that "the instructional and support staff will receive training about alternatives to guardianship." (See IDEIA 2004, § 300.703(b)(1)). This is a mandated way that families and teachers can seek professional development from agencies and professionals who are experts in the areas related to guardianship alternatives.

Rethink Transition

Participants in this study expressed concern that high school to postsecondary transition can often be a prescribed process, one in which educators and families can let their fears and uncertainties for their child with a disability outweigh the need for him or her to grow and become self-determined. However, the language of the IDEIA (2004) mandates that transition should be an individualized process, based on the student's needs and goals in order to help the student improve their self-determination and postsecondary quality of life (Wehmeyer, 1997). In order to achieve the IDEIA's goals for transition, the staff must take into account that students like Brian will likely continue to need supports and services for the remainder of their lives, particularly with decision-making. While this concern may lead families to appoint a guardian for their child in order to protect them (Millar, 2014), research has found that guardianships do not automatically address these issues of concern (Millar, 2003). This study shows that when families and educators expect and plan for interdependence during transition students with disabilities have many opportunities to partake in making the decisions with support that lead to growth and maturity.

Limitations

Although this study utilized inter-coder reliability checks, stakeholder checks, integrated-data sources, and ongoing collaboration with the main participant, various limitations remain. I chose to use the optimistic approach (Bogdan & Biklen, 1998) to understand how and why an individual and his supporters decided not to appoint guardianship. This decision, however, means that the experiences of the participants may not be reflective of others in similar situations and questions of whether Brian's experience was an exception still remain. However, the research in understanding the use and outcomes of alternatives to guardianship is still relatively new and this qualitative case provides an in-depth look at the process and outcomes for one young man. I hope, therefore, that the lessons learned from this study can assist in the design of future research studies in which researchers can examine a greater number of individuals using a variety of alternatives to guardianship.

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