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A Qualitative Study of the Transition Process from and Educational Setting to Adulthood for Adolescents with Intellectual and Developmental Disabilities (IDD)

Rachel Tokarski

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for Adolescents with Intellectual and Developmental Disabilities (IDD)

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Literature Review

   The transition planning process is mandated by the Individuals with Disabilities Education Act (IDEA,2004) for all students who have an Individualized Education Program (IEP) in the public school system. This process must begin before the student turns sixteen, must be individualized, and must be focused around the interests and strengths of the individual student. The transition plan should include opportunities for the student to explore work options and community life (Learning Disabilities Association of America, 2019). Compared to typically developing peers, adolescents with disabilities experience unique challenges during the transitional process (Hetherington et al., 2010). Past research has shown what the predictors of successful transition may be (Test, Bartholomew, & Bethune, 2015; Wehman et al., 2014; Simonsen & Neubert, 2012). Predictors of successful transition out of high school include school characteristics, adolescent characteristics, and family characteristics. There has additionally been research on how the family defines successful transition and how the success of transition impacts family well-being (Henninger & Taylor, 2014; Neece, Kramer, & Blacher, 2009). Past research has shown that many parents are dissatisfied with the transition process and describes barriers to more successful transition that parents have identified (Hetherington et al., 2010; Francis, Regester, & Reed, 2018). Existing literature has highlighted the main areas of dissatisfaction and includes "inadequate communication from school staff, frustration with assumptions made about the student, funneling of the student into traditional adult service programs, and a lack of accountability from the schools" (Hetherington et al., 2010, p. 163). Dissatisfaction also lies in the lack of direct engagement of students in the transition planning process (Hetherington et al., 2010). Even when students are directly engaged in the process, they have still experienced inadequate transition planning (Hetherington et al., 2010).However, not enough is known about the parent perspective in the present and if any of these barriers have been resolved since the literature has been published. Furthermore, there is not enough evidence regarding the student perspectives on the transition process. The aim of this study is to address these gaps in the literature by answering the following questions: 1) How do parents of adolescents with a diagnosis of

intellectual and developmental disability in an educational setting perceive and describe the transition

process? 2) How do adolescents with a diagnosis of intellectual and developmental disability in an

educational setting perceive and describe the transition process?

Methods

A phenomenological approach is being used to address these two questions, as the researchers are

examining the lived experience of adolescents with intellectual and developmental disabilities and their

parents. Purposeful sampling, specifically snowball sampling, is being used to gather participants.

Inclusion criteria are that the participants have an IEP and are between the ages of 14 and 22 or are the

parents of someone who fit this criteria. Participants were contacted using an Institutional Review Board

(IRB) approved flyer that was emailed or physically handed out. All participants are asked at the end of

their interview to pass along the researchers' information to anyone who might also be interested in

participating. Informed consent has been obtained from all parent participants, and informed assent has

been obtained from all adolescent participants. This is an ongoing study; currently, there are 10 parent

participants and 2 adolescent participants. The researchers are actively seeking more participants because

saturation has not yet been reached. The parent participants are all female and both adolescent participants

are female.

Interviews were approved to be conducted in person, over the phone, or via Skype/video calling.

3 interviews have taken place in person, while the remaining 7 have taken place over the phone.

Interviews have lasted between 10 and 35 minutes. All interviews are recorded and transcribed verbatim.

Data points are selected from the transcriptions and transferred into a code sheet. Open coding is

completed by two researchers separately. Then, the researchers meet to complete axial coding. Lastly, a

final collaborative code is created. Collaborative codes are merged in order to create themes. Data

analysis is still ongoing.

Results

There are six preliminary themes which have emerged from ongoing data analysis. They are: 1.) Creating a supportive environment through open communication; 2.) "Walking the path alone": Understanding the parent & student perspectives; 3.) Finding the right fit: The match between client and context; 4.) Building a bridge between family & community via resource sharing; 5.) Going above and beyond: The relationship between family and professionals; and 6.) Phases of the transition process: From exploration to implementation. Data analysis is ongoing and the two researchers who are currently on the project are in the process of identifying new themes.

Creating a supportive environment through open communication

Many of the parents discussed the ways in which the schools used open communication in order to create a supportive environment. This was highly valued by the parents because they were better able to understand what was going on with their children in the school at a daily basis, as well as understand the trajectory of transition for their children. Communication about what happened at school was crucial to many participants, and some felt that they received this more than others. Participant 7 shared that the school was "excellent" at communicating "what goes on during the day". However, Participant 9, whose son was nonverbal, expressed that it was more difficult for her to receive information about the school day because he was not able to share much with her and the school was not providing a daily log. However, the knowledge that staff was available to discuss resources and answer questions was reassuring for parents. Participant 1 stated, "If you have to call for anything or you're not sure about something, they'll find you the place you need to go."

"Walking the path alone": Understanding the parent and student perspectives

This theme was created using the words of participant 3, who stated, "I feel like as much as the school gives you options, you kind of feel like you're walking on the path alone." This was a very powerful quote, which was echoed by many of the parents during their interviews. Parents explained how

they felt that they were the only ones who were truly responsible for the success of their child's transition process, and even described this as their job. When discussing finding jobs for her daughter, participant 7 said, "At the end of the day, it's my job to find them." She added, "I don't feel like any school that I have ever been a part of felt like it was their job to provide information." Participant 8 shared that "A lot of it I have to do on my own." Participant 9 stated, "The only person who has our best interest is us." Overwhelmingly, the parents who participated in this study felt this lack of support and lack of guidance as they were helping their child move through the transition process. The lack of guidance and support left parents experiencing self-doubt regarding the weight of each decision and a fear of missed opportunities, which overall reduced parent and family well-being during the transition process. Parents expressed that they were doing their best, but were unsure that this was enough to give their children the best opportunities possible.

Finding the right fit: The match between client and context

This theme emerged from the participants discussing the ways in which the school and its staff were striving to find ways to make the transition process match the desires and characteristics of the student. This included taking into consideration the sensory characteristics of the child and asking the adolescent and his or her family about their preferences regarding jobs after school. Parents reported schools testing out different types of jobs in order to see "what fits". Unfortunately, this can be hard to do, especially when children fall somewhere in the middle in terms of their functional ability. Participant 7 reports that her daughter is "too high-functioning for a day program", which will make it more difficult for her to transition. In addition, some parents reported that the schools were not attempting to find the right fit for the adolescent as an individual. Participant 3 described this as being "funneled"; in other words, the school was giving the family a limited range of options for the future, rather than working towards the family's desired goal. Therefore, this theme of "Finding the right fit" is a continuum from the school finding the appropriate fit for the adolescent as an individual to the school funneling the adolescent and failing to treat him or her as an individual.

Building a bridge between family & community via resource sharing

This theme was identified because families described ways in which professionals at their children's schools shared resources to help the families find programs and services for post-transition life. As noted in Stewart, Law, Rosenbaum, & Willms (2001), transitioning from school-based to adult services can feel like coming to the edge of a cliff. There are so few adult services for the IDD population, and services can be hard to access. Families will suddenly go from having a variety of services to having none. When professionals share community resources, this builds a bridge for the family that will ease their transition process. In our preliminary findings, parents reported that schools were doing "a great job of providing resources". However, later interviews have revealed that this is not the case in all schools, which indicates that this theme is also a continuum. Schools' performance at providing community resources varies, but it has been noted that parents find this to be a priority during transition planning.

Going above and beyond: The relationship between family and professionals

This theme was utilized to describe the ways in which parents described the positive aspects of their relationship with staff, as well as the relationship between staff and their children. Parents seemed to highly value when staff made transition planning client-centered. Participant 1 described how the school kept the family involved in the transition planning process, explaining that staff "ask us if we think it's appropriate and what our feelings are." Participant 6 also described how important it was that the staff have high expectations of her child, saying, "They push her to be at her best." This participant described the importance of the staff in making the transition process successful because they were the individuals who were responsible for her daughter on a daily basis and were preparing her for a job. It is essential for staff to develop a relationship with the families with whom they are working in order to establish trust. Once trust has been established, the families will have confidence in the staff to have their children's best interest at heart.

Phases of the transition process: From exploration to implementation

This theme was used to categorize statements from parents in which they discussed the phases of the transition process that they had been through. A phase that was discussed frequently was the school providing opportunities for the students to explore different community placements. Some parents discussed a lack of clarity on what was supposed to be happening during this phase. Participant 6 revealed that she had not "been told much about what happens for her next year". Her daughter was getting ready to graduate with her typical peers, but would be continuing to attend the school for an additional three years. Participant 8 described her confusion about what was supposed to happen after her son turned eighteen. Overall, participants discussed being unclear about what the transition process was supposed to look like, especially once their adolescents had reached the typical age of adulthood and graduation. This lack of clarity indicates that for some families, exploration is occurring, but well-executed implementation is not occurring in a timely manner.

Emergent Themes

Themes that are currently emerging from ongoing analysis include: 1.) Falling short: The parents' desire for more from the team. This theme will juxtapose the theme "Going above and beyond: The relationship between families and professionals". There are also subthemes emerging from the theme "The phases of the transition process: From exploration to implementation". These subthemes are: a.) Financial/legal; b.) Options or lack thereof; and c.) Supports in new setting. These subthemes have been identified due to a clear distinction between the types of actions that a family needs to complete in order to have a successful transition process.

Conclusions

Preliminary results indicate that parents identify client-centered planning, staff guidance, resource sharing through organized deliverance of information, and multi-way communication as the most sought-after practices in transition planning. Adolescents identify client centeredness and relationships as the

most important part of the process. This is consistent with past literature (Hetherington et al., 2010).

Currently, there is a continuum on which schools fall in terms of their skill in appropriately implementing

these most sought after practices. It has additionally been found that many parents develop strong

relationships with staff members who value their children as individuals. However, preliminary results

also reveal that the transition planning process is not satisfying for all parents. Many parents feel lost and

alone in regards to the process by which their children leave school-based services. There is a need for

better defined roles for professionals during the transition process and for higher standards regarding staff

involvement in the process in order to remediate this gap. The barriers that parents have identified so far

in this study are consistent with the barriers identified in Hetherington et al. (2010), indicating that there

has not been a significant change in transition planning in the past decade.

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