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Parents' Experiences in the Transition of Students with Autism Spectrum Disorders to Community College

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Due to the rising number of students with autism spectrum disorders (ASD) attending community colleges and the important role that parents play in their student's transition process, the current study aimed to explore the experiences of parents as their student with ASD transitioned to community college. Eighteen parents of students with ASD who attended community college completed an hour-long interview regarding their experience assisting their student with the transition. Parents reported playing two predominant roles: (1) coaching students to navigate campus services, and (2) encouraging students to participate in college more independently. In addition, two major challenges emerged from parent reports: (1) navigating the Federal Educational Rights and Privacy Act (FERPA), and (2) finding supportive faculty. Implications for future research as well as recommendations based on the data regarding ways to support students with ASD and their families as they prepare for this transition are discussed.

The dramatic rise in Autism Spectrum diagnoses has **■** been well documented, with the latest report from the Center for Disease Control finding that one in 88 individuals now has an Autism Spectrum Disorder (ASD) (CDC, 2012). The CDC also suggested that the prevalence of ASD may be as high as one in 50 children, based on parental reports (2013). According to the National Institute of Neurological Disorders and Stroke (2011), "Autism spectrum disorder (ASD) is a range of complex neurodevelopment disorders, characterized by social impairments, communication difficulties, and restricted, repetitive, and stereotyped patterns of behavior" (para 1). This range includes individuals with extremely diverse ability levels and combinations of symptoms. While professionals agree there are likely many genetic and environmental factors contributing to this increase in prevalence, one of these factors is likely "an improvement in our ability to recognize and diagnose higher-functioning individuals who may have been overlooked in the past" (Adreon & Durocher, 2007, p. 272). The term high-functioning autism spectrum disorder (HFASD) has been used to characterize individuals on the spectrum who do not have a co-occurring intellectual disability (ID) and includes the diagnoses of high functioning autism (HFA), Asperger's Syndrome (AS), and Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS). Interestingly, research has shown that the majority of individuals with an autism spectrum disorder have milder forms of the disorder, such as Asperger Syndrome (VanBergeijk and Shtayermman, 2005).

As students with ASD continue to gain access to

early interventions and academic and behavioral supports in K-12 schools, cognitive and behavioral outcomes will continue to improve (Adreon & Duracher, 2007). In turn, colleges will continue to see an increase in the number of students they serve with ASD (Wei, Yu, Shattuck, Mc-Cracken, Blackorby, 2012). For individuals with ASD, college is not only an attainable goal due to their cognitive ability, but may also be important to their growth in other ways as well, both practical and psychological. Given that adults with ASD experience low employment rates (Barnard, Harvey, Prior, & Potter, 2001; Hurlbutt & Chalmers, 2004; Newman, Wagner, Cameto, & Knokey, 2009), achieving their goals at a community college can lead to increased job opportunities, financial independence, and ability to contribute to the economy. In addition, as explained by Camarena and Sarigiani (2009), "For many talented youth with ASD, their intellectual capabilities may become a critically important domain essential to their feelings of self-worth...[and] self-esteem" (p. 115). Therefore, as more and more students who are diagnosed with ASD graduate from high school, there is a growing urgency to better understand how to prepare these students for the transition to post-secondary education, and what services are needed at the postsecondary level to best support these students.

Transition to Community College

Research thus far indicates that community college is often a preferred post-secondary option for students with disabilities, including ASD. According to the United States Government Accountability Office (GAO) analysis of the 2008 National Postsecondary Student Aid Study, students with disabilities are much more likely to attend community colleges than students without disabilities (GAO, 2009). A study from the Department of Education found that nearly 60% of individuals with disabilities who pursue post-secondary education, chose a two-year, or less than two-year, setting (Horn, Peter, Rooney, 2002). Ankeny and Lehmann (2010) list the following "factors that contribute to individuals with disabilities attending community college: open door admission policies, geographic accessibility, emphasis on faculty teaching over research, strong counseling components, special services for special populations, affordability, and supportive legislation" (p. 478).

Currently the literature on the experience of individuals with ASD at community colleges is scarce and focuses specifically on the types of programs available to students, such as programs which include a partnership between secondary and post-secondary services (Neubert & Redd, 2008; Anken & Lehman, 2010). However, as explained by Neubert & Redd (2008), "While descriptive information on models now exists, there is little documentation on how these services have evolved, student outcomes from services, or consumer satisfaction with services" (p. 221). The few studies that do exist in this area have focused on specific transition programs and have examined individuals with varying disabilities. For example, Neubert & Redd (2008) conducted a case study to examine the experiences of students with ID (including ASD) in a transition program at a community college and parental satisfaction with the program. A more recent qualitative study explored the experience of four students receiving special education services who successfully completed a vocational program at a community college (Anken & Lehman, 2010). However, more research is needed regarding the general experiences of students with ASD in the community college setting.

As highlighted by VanBergeijk, Klin, & Volkmar (2008), "although many individuals with ASD are intellectually capable of university level education, they will require a range of academic and supportive accommodations in order for them to succeed both educationally and in terms of transitioning to greater independence" (p. 1359). This awareness has led to a recent increase in the literature on topics such as the specific difficulties that individuals on the spectrum may face due to the academic and social demands of post-secondary education (Hewitt, 2011), practical considerations for these students (Weymann, Smith, & Schall, 2010), post-secondary options for individuals on the spectrum (Hart, Grigal, & Weir, 2010), as well as advice for post-secondary institutions regarding how best to meet these needs (Gobbo & Schmulsky, 2012; Obi & Obi, 2008; Safran, 2001). This body of research discusses how difficulties related to socio-emotional skills, executive functioning, social pragmatics, and social communication may affect these post-secondary learners, and how support offices and faculty can help to increase the success of these students.

Parental Involvement

It is becoming clear that one important variable for increasing the likelihood of a successful post-secondary experience for students with ASD is transition planning. As explained by Roberts (2010), "Transition planning is a process or coordinated set of activities designed to successfully move students identified under the Individuals with Disabilities Education Improvement Act (IDEIA, 2004) from school to post-high school settings" (p. 158). Parents and caregivers of students with ASD play a pivotal role in supporting and advocating for their child in the K-12 context, a trend that tends to continue into adulthood because of the student's special needs.

While articles have been written regarding advice for successful transition planning for students with ASD (e.g., Roberts, 2010), far fewer studies have examined the first-hand experiences of families with students transitioning to community college. Thus far, studies indicate that parents have a wide range of experiences with transition services, both positive and negative (Defur, Todd-Allen, & Getzel, 2001). While some parents have experienced success, many others report that students experience inadequate transition planning and that often transition meetings are implemented too late in the student's secondary experience (Hetherington, et al., 2010). Studies that have directly explored the factors which predict successful postsecondary transitions for students with disabilities have found family involvement to be critical (Defur, Todd-Allen , & Getzel, 2001). Given its importance, some researchers have examined barriers to parental involvement. Defur, Todd-Allen, & Getzel (2001) examined family involvement in the transition planning process and found the following to be barriers to enhancing parent participation: teacher and administrator attitudes, diversity concerns, and the stigma associated with special education students that tends to focus on the student's weaknesses rather than his or her strengths.

While parental involvement and support are critical to the transition planning process (Grigal & Neubert, 2004), less is known about the experience of parents supporting their student once they have transitioned to post-secondary education. In a study examining parent perceptions of the support their student with ASD would need to be successful in college, Morrison, Sansosti, & Hadley (2009) found that all of the parents in their study reported that their students would continue to need high levels of parental support and involvement in college compared to

their neuro-typical peers. Although this research indicates that parents will continue to play an important role in their student's post-secondary life, thus far, little is known about parents' experience supporting their student once they have transitioned to post-secondary education.

Purpose of the Current Study

Due to the rising number of individuals with ASD attending community college and the important role that parents play in their student's transition process, the current study aimed to explore the experiences of parents as their student with ASD transitioned to a community college. This exploration was part of a larger qualitative study examining parents' perceptions of the transition process and their students' experiences in any post-secondary educational setting. The goal of the current study was to add to the emerging body of literature to inform community colleges regarding the services families believe will be most helpful for supporting these students.

Method

The researchers employed a qualitative research design to understand the experiences of parents in assisting students with ASD to transition into community college. Since very little is known about the experiences of parents who are in the midst of this transition, the qualitative study included methods that encouraged "one to understand the world as seen by the respondents" (Patton, 2002, p. 21). The researchers appropriated three qualitative design strategies advanced by Patton. First, in a naturalistic inquiry approach, the researchers study real-world situations and contexts as they unfold. Second, by following an emergent design, the researchers adapt inquiry, including data collection and analysis, as new findings or changes emerge. Third, the researchers employ purposeful sampling by selecting participants who can provide rich information on the phenomenon under study. Toward this end, interviews documented parents' stories, revealing the perceptions and the meanings that they make of their experiences in the transition of students with ASD to community college.

Participants

Participants included 18 parents whose students had an ASD and attended a community college. Sixteen parents were mothers and two were fathers. This sample was part of a larger study, including 41 parents whose students with an ASD were either in the process of transition planning (while their student was in high school) or whose students were attending a post-secondary educational setting. The diagnoses of 18 students on the spectrum included Asperger's Syndrome, Autism, and Pervasive Develop-

mental Disorder-Not Otherwise Specified. The majority of families reported having at least one parent with a college education and an income greater than \$90,000.

Data Collection

In order to gather participants for the study, a recruitment email was sent to various university support services offices, clinicians who work with clients with ASD, in addition to autism support groups and social networking sites in California. Parents who volunteered participated in interviews which lasted approximately one hour and were audio recorded. The researchers used a semi-structured interview approach so that the interview protocol guided the conversation, but allowed the researchers flexibility in following the parents' lead when information was rich and relevant. Participants were given \$30 upon completion of the study.

Data Analysis

Audio files were transcribed and uploaded to Saturate App, a qualitative software program. Consistent with an emergent design, the researchers used a constant comparative analysis method in which data were collected and analyzed simultaneously (Patton, 2002). Parents' stories were analyzed by first coding significant statements relevant to answering the research question. The codes assigned to text were then grouped and organized into themes that explained the experiences of parents during students' transition into community college. As themes emerged, the researchers modified the interview protocol to clarify and follow up on thematic findings with subsequent participants. The themes that were most prevalent and relevant to answering the research question are included in the narrative that follows.

Results

The research results highlighted in this section underscore the critical role parents play in enabling their children with ASDs to gain access and transition into community college. The great lengths that parents went to support their children through the transition into community college suggests that most of the students in our study could not have gained access or transitioned successfully without their parents' involvemen common thread across all participants' experiences was the tremendous amount of time and resources parents invested on a daily basis to support their children. One parent noted her tireless efforts: "Pushing him every step of the way is mainly what my burden is. Trying to support him through it and motivate him every step of the way." The results of this study are organized into two sections – one detailing the major roles and responsibilities that parents assume as their children transition into community college, and the other exploring the barriers they encounter with their children during the transition experience.

Parental Roles in the Transition to Community Colleges

Even though parents believed in their children's ability to meet academic requirements in community college, parents anticipated challenges during the transition because of the communication, executive functioning, and social challenges associated with ASD. Parents found themselves coaching students through processes involving course registration, services for students with disabilities, and financial aid. They described themselves as "advocates," "coaches," and "orchestrating from behind the scenes." Parents sat alongside their children during phone conversations with campus staff, completing website forms, and in campus meetings helping them to enroll in classes and navigate campus services. One parent explained why this level of involvement was necessary: "The phone is very difficult for him; he is a very visual person. So I had to call to make an appointment to schedule an assessment or a counselor meeting... It is really hard for him." When the same parent found out that her child had a problem with his financial aid, she accompanied her son to the financial aid office to help him problem-solve the issue. "This [financial aid issue] is a really complicated thing... He can't explain all that."

While any parent with a typical child can experience anxiety as the child transitions to college, parents of students with ASDs faced an even more difficult transition due to the additional burden of managing unique challenges associated with the disability. Most parents had become accustomed to handling all communication with teachers, counselors, and administrators in their student's academic lives thus far. For example, many parents reported making all of the educational decisions for students during Individualized Educational Plan (IEP) meetings. One parent acknowledged, "I kind of control his life pretty much, which is not such a good thing. But I've been doing it for so many years I really have to start stepping back, and I have."

Parents must strike a delicate balance between acting as a coach to students with ASD to navigate campus life and encouraging their independence. They recognized that students were not yet able to ask the right questions and self-advocate when it came to solving academic or social dilemmas. "He is barely at the 'help me' stage," described a parent about her son. "To get somebody to really go out of their way to help them is really hard. And that is what he needs to do." Because of these difficulties, some parents admitted that at times they had the tendency to step in and problem-solve for the student rather than

with the student. For instance, a parent reported that she made all of the decisions for her son in terms of what courses he would take. "I already applied online for him. I told him a couple times, 'Here's what you're going to do.' 'OK' 'So I'll drop you off and pick you up.'"

The majority of parents in the study acknowledged the need to "let go" or "back off a little bit" to allow their children to navigate college life more independently. Despite the fact that students with ASDs experienced delays in communication, executive functioning, and socialization, deep down, many parents reported that they felt their students needed to learn from their mistakes. One parent explained her struggle to encourage her son's independence with a decision regarding how many classes he should take. She shared that her student,

kept telling me, 'Mom, Mom I can do it, I can do it, I can do it.' And he was over 18 and I have a very specific idea about parents and 18 and how much you hold on and how much you let go. And I decided the worst he could do was fail, but the best thing he could do is really succeed.

Another parent shared, "This is going to be a whole new chapter for me; he's an adult, and I'm not going to be that so-called advocate anymore for him." The decision to step in when the student needed assistance posed a dilemma for many parents. On the one hand, explained a parent, "You want to build the independence and you want him to learn to take these things over... So sometimes I let him fall a little bit because that's a learning process." On the other hand, she continued, "I'm not interested in jeopardizing graduation over having him learn a lesson. So we've tried to balance."

Parents reported devising successful strategies to encourage students to take responsibility for making academic-related decisions while at the same time stepping in when needed. Some parents, for instance, asked to be copied on emails from the directors of disability programs. "She'll copy me on emails and things that she's sending to him so that I know to follow up," explained a parent. Then she would check in with her son: "Did you give [the director] what she needed?" Other parents made sure to accompany the student to meetings, but purposefully sat in the back of the office so that the student could become a more active participant in the conversation. One parent proudly noted the progress in her son's ability to independently meet with his college counselor. "He is now going to those meetings by himself. At first I went with him. Then we read the notes together, I sat out by the side and he did the talking. And the last time we said, 'You need to do this on your own." Another parent reported that her son developed the ability to become a self-advocate, a major accomplishment for any student, particularly one on the spectrum. At a meeting with a college counselor, the parent recalled her son's ability to self-advocate for needed accommodations:

I didn't say anything. I kind of sat in the back and he sat more like one on one with her. I was sitting on the couch. And he says, 'Well I need to sit in the front row. I need someone to take notes for me. I need extra time to do my homework. If the teacher could let me know in advance what the assignments were it would be helpful so I can already get done some of them before. And I can't take my test around other people. I need to have a quiet room.'

Encouraging their student's independence was not only a difficult transition for parents, but also difficult for their student who was used to their parent making many decisions for them. One parent explained the extent to which her son leaned on her to make decisions for him: "He kind of relies on me for, 'What should I do next?' I was like, 'OK you finished high school, now you go to college, just like your brother and sister.' 'Oh, OK, I'm going to college.'" Changing the norm was difficult for both parents and students; while parents reported the challenge of letting go, they also recognized the difficulty for their students to take the lead.

Challenges

Both parents and students faced challenges that complicated the transition experience for community college students with ASDs. The two major challenges that emerged from parents' reports were navigating the Federal Educational Rights and Privacy Act (FERPA), and finding supportive faculty. First, parents had to face major changes in accessing their children's educational records and participating in campus meetings with their child when they entered postsecondary education. In the high school system, parents were the primary advocates and decision-makers for their child. However, due to Federal Educational Rights and Privacy Act (FERPA), community colleges may not share student records with parents unless the student signs a waiver to allow the parents to access their records and participate in campus meetings. Many parents reported that they received the message loud and clear from administrators and professors to "back off, mom!" As one parent shared, "They would not talk to me. It's because of FERPA." To address this issue, most parents encouraged students to sign a FERPA waiver to allow parents access to educational records and information. A mom explained,

The first time we walked into the Disability Services office, I went with him. We sat down, the intake business. I created a form that said that I will be allowed to be present. He makes decisions, but if there are meetings or anything, nothing can be signed until full discussion with mother first, or father first. Though students signed FERPA waivers, parents were still not able to communicate directly with faculty members. "The professors don't want to talk to me. And I understand all the privacy issues and all that stuff. But even if [my son] signs off they don't want to deal with you."

Faculty members were a source of contention for parents and students with ASDs in other ways. Some parents reported feeling that faculty members entered unchartered territory when teaching students with ASDs. A parent explained, "Teachers at the college are not prepared to deal with his particular type of disability." Faculty members were not always aware of the difficulties students with ASD experienced in executive functioning and processing information during class lectures. One parent explained,

When the teacher's standing or the professor is standing up in the front of the class and going, 'Okay, besides the stuff on the syllabus, we also need to do this, this, and this, and I want this by this date and this by this date,' you've lost him [because of] auditory processing.

What makes asking for help from faculty difficult is that many students on the spectrum will not take initiative to communicate or interact with the professor, including disclosing their disability. "That is my concern, he has to be comfortable with approaching professors," shared a parent. Given that parents could not communicate with professors directly, they instead took an active role in accompanying students to the disability services office to find out which professors were supportive of students with disabilities. One parent made this a routine practice,

We always utilize the disability services office. We always go in before classes start... And we sit down and say: these are the classes he wants, who are the teachers who are friendly. Because if you don't do that you don't know what you are going to get.

This practice allowed parents and students to be proactive about developing positive experiences with faculty members.

Discussion

This study's exploration of the first-hand experiences of parents as they assist their student with ASD transition to community college offers detailed information about the roles that parents played and the challenges they experienced in those roles. While research on supporting students with special needs in secondary education highlights the importance of parental involvement, findings from the current study are consistent with previous research suggesting that parents continue to play a critical role in

their student's academic experience in the post-secondary setting (Morrison, Sansoti, & Hadley, 2009).

In summary, two primary roles were mentioned frequently by parents, namely, coaching students through interactions with campus offices and encouraging independence in their student. These findings are consistent with previous literature which found that parents anticipated that having a "job coach/life coach" would be helpful for their student, and that parents "expressed an on-going need to maximize their son's capacity to live independently, while maintaining a watchful eye for potential struggles" (Morrison, Sansoti, & Hadley, 2009, p. 83). Findings from the study also indicate that there were two primary struggles that many parents reported as they attempted to assist their students with their community college experience. These include, first, the regulatory limitations of FERPA and the implications for parental communication with constituents at the community college and second, their challenges communicating with faculty. While the challenges related to FERPA are unique to the post-secondary setting, findings regarding parents' difficulties interacting with school professionals and feeling alienated are consistent with previous research regarding difficulties faced by parents during transition planning (Defur, Todd-Allen, & Getzel, 2001).

Information gathered from these parents has significant implications for community colleges. As the number of students with ASD who attend community colleges continues to grow, new demands will be placed upon various support services on campus, as well as on faculty and staff. The roles parents played to meet the challenges provides valuable information regarding the type of assistance that is needed for these students and how community colleges can best support them and their parents. The following recommendations are based on the findings from parent interviews. These recommendations include developing an orientation focused on the level of support and interaction both students and parents can expect from campus offices; providing training sessions for students focused on the skills needed to access campus offices for assistance; identifying a case manager or support person for the student to access regarding any educational concerns that arise; offering training sessions for office staff regarding the unique challenges that students with ASD may face as they utilize their office services; creating training sessions for faculty regarding possible difficulties for students with ASD in the classroom; and facilitating structured opportunities for communication between institutions and parents.

One role that parents reported playing was helping their student to navigate campus resources. This finding suggests that it may be helpful for these students and their parents to participate in an orientation at the beginning of the school year which focuses on campus services available to students and locations of the student's classes. One parent explained, "He was a bit lost at the beginning; it was kind of hard for him to find his classes. I even went with him the second quarter. We spent 40 minutes walking around...maybe some sort of orientation would help." In addition, many parents mentioned the difficult balance required to assist their student in their interactions with campus services while, at the same time, advancing their independence. Thus, it may be helpful for the orientation to include suggestions from campus services regarding the role they believe parents might play in promoting student success.

Encouraging independence among students with ASD is an important goal and one where parents felt that community colleges could help in the transition to higher education. Parents indicated that it would be helpful for community colleges to train students on how to utilize office services to get their needs met independently. Given that students interact with many offices on campus and not solely the disabilities services office, this area may provide an opportunity for various campus offices to collaborate in the provision of workshops for these students. Workshops could address various issues that may have come up or that the student may face in the future and discuss how various offices can help in those situations.

Given the regulatory limitations of FERPA regarding the extent to which parents can communicate with particular constituents in the community college (e.g., offices and faculty), many parents reported that it would be helpful to have a support person on campus who could assist the student with any educational concerns that arise. One parent explained, "To me there needs to be a "quarterback"... or just a point person on campus that they can always go to." Another parent offered the following regarding the need for a mentor or support person, "I think there should be a liaison between the professors (or the TAs) and the student that basically advocates and makes sure that the student doesn't fall through the cracks. Because if they aren't able to advocate for themselves, and they're in an environment where the parents aren't advocating, who's going to advocate for them?" A key role for such a support person would be to assist students in communicating with faculty. Another parent explained, "The thing with my son and other kids with Asperger's, it's a communicationbased disorder. So when the counselors say, well you have to do the communication with the professor, it's the same as telling the kid in a wheelchair that he has to walk across the room to get the book. Why don't they understand that if I could communicate I wouldn't need help?"

Many parents reported having difficulty with campus office staff as they attempted to help their student access their services. This finding indicates that it would be helpful to provide training to educate office staff about the symptoms of ASD and the various struggles that stu-

dents with ASD may face as they attempt to access campus offices to have their needs met. Of course, parents are important sources of expertise in this endeavor. Indeed, community colleges may wish to consider opportunities for parents to play a more formal role, through on-going consultations for example, to advise institutions on advancing greater awareness, training and policy matters. Workshops could be led by community college faculty or staff who have expertise in assisting students with ASD. In addition, it may also be beneficial to invite parents to these workshops to offer first-hand knowledge and to give specific examples regarding the difficulties they and their students have faced. These workshops could also focus on helping staff recognize the parents' evolving role as they transition from supporting their student at the secondary to the post-secondary level.

The second challenge that many parents reported facing was enabling the student to interact with faculty who are not aware of the challenges associated with ASD. Thus, in addition to holding training workshops for office staff, it would likely be beneficial to offer similar training sessions for faculty. One parent shared, "It doesn't necessarily depend on the class structure for these kids to be successful. Just a little support, a little more understanding of what they may be dealing with...That would be my small piece of advice for the professors." These sessions could examine possible difficulties for students with ASD in the classroom. Furthermore, awarenessbuilding sessions might provide an opportunity for faculty to problem-solve or to discuss any issues that have come up in their interactions with students with these unique needs. One parent offers the following specific example, "A small example: a kid like my son can't sit in the back of the classroom so make a front seat or two seats available for their use. Resolve to have the front row seats so that they can be more present in the class. If my kid sits in the back he is not going to participate."

Lastly, given that many parents shared that they had a difficult time staying involved to support their student's community college experience (e.g., due to legal mandates such as FERPA), it is recommended that community colleges make every effort to communicate with parents of students with ASD in ways other than sharing specific protected information. For example, it may be helpful to offer quarterly meetings or a newsletter keep parents abreast about important information and upcoming events, as well as issues that their student may be having at that time (e.g., registering for the next semester, deadlines for financial aid, when mid-term grade notices have been given). These strategies would allow parents to feel connected and afford them the opportunity to discuss the specifics of these issues with their student. As one parent shared,

They [the students] still need support. They still need their family involved. They still need parents with them. That is I think the hardest thing for me is to work around the college and let them know that I am here. And that my son, yes, is responsible; however we are a team. We want to make sure that we are involved as much as possible.

Although the findings from this study offer valuable information regarding meeting the needs of students with ASD and their families in the community college environment, there are limitations inherent in its design as well. First, the study's sample included predominantly highlyeducated, middle-class families in one county in Southern California and therefore results from these parents' experiences may not generalize to other locations. Second, and more importantly, the study did not include the voices of the students themselves regarding their experiences at a community college. The purpose of the current study was to learn from the parents about their experiences because, as was suggested earlier, previous literature indicates that parents play a significant role in the academic experience of their child with special needs. However, it is critical that future research focus on including the voices of the students to understand the transition process from their point of view.

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