

Autistic Young Adults, Parents, and Practitioners Expectations of the Transition to Adulthood

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Abstract

Parental expectations are important for autistic youth during the transition to adulthood, but less is known about the expectations of other stakeholder groups. The current study examines similarities and differences in expectations among autistic youth, parents, and professionals. Data were collected through six focus groups with 24 participants (7 parents, 11 professionals, and 6 young adults on the autism spectrum). Thematic analysis was used to identify five themes: *Normative Hopes, Living with Uncertainty, Mismatch of Reality and Expectations, Impairments Shape Expectations, and Services Dictate Expectations*. Autistic youth expressed the most optimism for the transition to adulthood. All stakeholder groups touched on the tension between matching expectations with abilities; however, only professionals indicated a direct relation between expectations and abilities. Both parents and professionals highlighted the role of service availability in shaping expectations.

Keywords: autism spectrum disorder, transition planning, expectations, thematic analysis

Autistic Young Adults', Parents', and Practitioners' Expectations of the Transition to Adulthood

The transition to adulthood, also called emerging adulthood, is a developmental period occurring in the late teens and early twenties marked by identity exploration and subjective perspectives (Arnett, 2000). It is during this time that young people explore love, work, and worldviews; there is a lack of normative developmental milestones; and young people feel neither like adolescents nor adults (Arnett, 2006). This is a complex time for youth as they move into increasingly independent roles and identities along non-linear and non-uniform paths. This period is even more complex with the presence of a developmental disability like autism spectrum disorder (ASD). The transition to adulthood is a vulnerable time for youth on the autism spectrum¹ (Stoner et al., 2007).

Two of the greatest challenges facing autistic youth are the lack of appropriate services as part of secondary education and the lack of services once they leave high school. Several studies have shown that youth on the autism spectrum are unlikely to receive the support they need in secondary programs. For example, Kucharczyk and colleagues (2015) conducted focus groups in four states with 152 practitioners, parents, and other key stakeholders. Although a few respondents reported receiving support during high school, the majority emphasized the lack of appropriate support described as ranging from nonexistent to inadequate. In a multilevel model of youth on the autism spectrum ($n = 204$), especially those without co-occurring intellectual disability (ID), Laxman and colleagues (2019) found that youth experienced a reduction in services during high school. Taken together, these findings suggest that youth on the autism spectrum are less prepared than their peers to navigate emerging adulthood. This is despite a mandate to appropriately educate youth and prepare them for postsecondary education and employment as part of the Individuals with Disabilities Education Act (IDEA; 2004).

The IDEA (2004) mandates that Individualized Education Plan (IEP) teams develop activities—which can include instruction, related services, community experiences, and post-secondary objectives—to support a young person moving to post-school activities such as postsecondary education, employment, and adult services. There is considerable variability in school-based transition planning in terms of (a) the start of transition which can begin as early as middle school, but must begin by 16 (IDEA, 2004) and may go until, 18, 21, or 26 depending on the youth's needs and the state's laws; (b) theory behind the transition process (for a detailed analysis see Wehmeyer et al., 2019); and (c) activities which are included in transition plans (Office of Special Education and Rehabilitative Services; OSERS, 2017). As youth move out of school-based services, there are significant differences in the process of receiving services as compared to when youth were in school: (a) there is no single point of service entry, (b) each program has its own eligibility criteria, (c) the system of support is not coordinated, (d) there are overlaps in service provision, and (e) different programs define disability differently (Shogren & Wittenberg, 2020).

¹ We use identity first language or the phrase “on the autism spectrum” as these were preferred by the majority of our autistic participants.

Due to the struggles that youth on the autism spectrum face, research has sought to identify barriers and facilitators of success in the transition to adulthood. One facilitator that has been identified is parental expectations (e.g., Blustein et al., 2016; Chen et al., 2019; Holmes et al., 2018; Kirby, 2016). By examining autistic youth ($n = 1170$) who participated in the National Longitudinal Transition Study 2 (NLTS2), Kirby (2016) found that parental expectations mediated the relation between family background and functional performance with adult outcomes in the domains of employment, residential independence, and social participation. In this study, parental expectations were measured with two items asking the degree to which parents expected their child to have a job and live independently. This finding suggests that parental expectations are an important factor for improving youth outcomes. Furthermore, Holmes and colleagues (2018), found that parent expectations predicted parents' use of strategies that support the transition to adulthood such as talking about jobs, providing responsibilities, enrolling their child in preparatory programs.

There is some evidence from qualitative studies that parents are realistic in how they form their expectations of adult life. For example, a study of 18 parents found community mobility, community participation, living situation, peer relationships, personal safety, post-secondary education, self-care, and work to be important domains they considered when creating expectations; however, they also found these expectations tempered by fear and uncertainty such as whether their adult children could manage increased expectations or navigate new contexts (Chen et al., 2019). Additionally, in a large study of parents ($n = 1,065$) who have children with intellectual and developmental disability (IDD), parents were found to have nuanced markers for success such as valuing the fit of a workplace and opportunities for interpersonal relationships over employment metrics like pay and hours (Blustein et al., 2016). The nuance reflected by parents suggests that parents contextualize their expectations based on the unique needs and desires of their child.

Although these studies highlight the importance of expectations, there remain questions as to the role of expectations. For example, it is impossible to infer whether parent expectations are malleable such that parents help facilitate a reality in which their expectations are met. Or rather, that parents have a nuanced and realistic understanding of their child's skills, needs, and the community opportunities available to them. If expectations are a malleable factor that can influence youth outcomes, they can provide a valuable opportunity for educational efforts. If parents have a more complex understanding of what their child needs, their expectations can provide insights for how service should be provided. Additionally, previous research has focused on parental expectations; few studies have examined autistic youth and practitioner expectations regarding the transition to adulthood.

One study that did focus on youth used semi-structured interviews to how 31 high school youth conceptualized adulthood and pathways to adulthood (Anderson et al., 2015). Youth held normative expectations for adulthood (e.g., independence, maturity, and personal responsibility). Carter and colleagues (2014) used a survey to compare how parents and teachers assessed strengths and needs of students with IDD ($n = 134$). They found a significant discrepancy

between parents' and teachers' ratings of strengths and needs on more than half of the items on the scale in domains such as communication, further education, health, and employment. The discrepancy when assessing strengths and needs suggests the importance of soliciting multiple stakeholder perspectives.

At this time, parental expectations have been identified as (a) being related to parenting behavior in terms of preparing autistic youth for adulthood; and (b) predicting outcomes for autistic youth in adulthood. Compared to many of the barriers youth face (e.g., inappropriate services, lack of services, difficult to navigate eligibility requirements), expectations are malleable and can be raised through educational programs. There is much still to learn about the nature of parent expectations, the details of which can inform the development of more socially valid parent education programs. Additionally, if parent expectations have an important impact on transition-related behavior and outcomes, then the expectations of other stakeholder groups are important to understand. To our knowledge, no studies have examined the similarities and differences in the expectations of autistic youth, parents, and professionals regarding the transition to adulthood. A better understanding of the expectations of each stakeholder group could be useful to practitioners in planning transition services so that they meet the needs of youth and families. We asked the following questions:

1. What expectations do autistic youth, parents, and professionals have regarding the transition to adulthood?
2. How do the expectations of autistic youth, parents, and professionals compare?

Method

This study is part of an exploratory focus group study with a broader focus to explore the perceptions of parents, professionals, and autistic young adults regarding the transition to adulthood. In this study, we focus on the body of data regarding expectations. We received institutional review board approval from a Midwestern University. We used focus groups as they allow participants to share their perceptions and experiences, compare and contrast points of view, and generate ideas based on one another's experiences (Krueger & Casey, 2014).

Participants and Recruitment

We recruited participants purposefully to ensure key stakeholder groups were represented (Maxwell, 2012): parents of transition-aged youth on the autism spectrum, professionals, and young adults on the autism spectrum. For the purposes of this study, transition age meant between 14 and 30 because this study was conducted in a state where secondary school-based services can extend to age 26. The average age for youth participants and parent participants' TAY was 21.6. The average age was 56.1 for parents and 46.9 for practitioners. We recruited all participants from the same midwestern region. All potential participants who we recruited were eligible for the study and participated. See Table 1 for complete demographic information.

Table 1
Demographic Characteristics of Participants

Stakeholder group	Parents		Practitioners		Youth	
	n	%	n	%	n	%
Gender						
Male	3	42.9	2	18.2	4	66.7
Female	4	57.1	9	81.8	2	33.3
Race						
Black	1	14.3	-	-	1	16.7
White	6	84.7	11	100	5	83.3
Highest Degree						
High School	-	-	-	-	5	83.3
Bachelor	3	42.9	2	18.2	1	16.7
Graduate Degree	4	57.1	9	81.8	-	-
Annual Household Income						
\$20,001 – \$30,000	1	16.7	-	-	-	-
\$50,001 - \$75,000	1	16.7	-	-	-	-
\$75,001 - \$100,000	3	50.0	-	-	-	-
\$100,001 - \$200,000	1	16.7	-	-	-	-
Comorbidities ^a						
ADHD ^b	1	14.3	-	-	3	50.0
Anxiety	1	14.3	-	-	1	16.7
Cerebral Palsy	1	14.3	-	-	-	-
Dyslexia	-	-	-	-	1	16.7
Emotional Disorder	-	-	-	-	1	16.7
Epilepsy	2	28.6	-	-	-	-
ODD ^c	1	14.3	-	-	-	-
Seizure Disorder	1	14.3	-	-	-	-
Sleep Disorder	1	14.3	-	-	-	-
Tourette	-	-	-	-	1	16.7
None	2	28.6	-	-	1	16.7

Note. N = 23 (n = 7 for parents, n = 11 for practitioners, and n = 6 for youth).

^a Comorbidities are presented for both the youth participants and the parents’ transition age autistic children.

^b Attention deficit hyperactivity disorder

^c Opposition defiant disorder

We recruited parents via a community-based service provider ($n = 7$). To be included in the study, parents had to be an adult and have a transition-aged child diagnosed as being on the autism spectrum. None of the parents had a child who participated in the study. Two members of the research team attended a transition-focused parent meeting to explain the study and have parents enroll to participate.

We recruited practitioners through the professional connections of the research team ($n = 11$). To be included in the study, they had to be adults and work with autistic youth or families during the transition to adulthood in some capacity. There were two overlaps between the practitioners and other stakeholder groups: one practitioner was employed by the organization that youth participants were recruited through and one practitioner was employed by the organization that parent participants were recruited through. We intentionally recruited from multiple transition providers (e.g. independent living skills, higher education, employment). Many of the participants had held several positions throughout their careers related to transition, but at the time of their participation in the study there were three community non-for-profit program directors, one private clinic director, one state vocational agency manager, one autism behavioral consultant, one adult employment and daily living specialist, two benefits coordinators, one special education transition director, one special education coordinator, and one university disability resource specialist. We contacted professionals via email by a member of the research team and invited to participate.

We recruited young adults via a disability resource center at a university in the Midwest ($n = 6$). To be included in the study, autistic youth had to be adults registered with the disability resource center. We intentionally recruited from the disability resource center to ensure we recruited transition-aged youth with documented disability. A member of the research team provided the disability service center with information about the study and the disability service center passed the information along to prospective students. Interested participants then contacted the member of the research team.

Procedure

We conducted a total of six focus groups—two focus groups with each type of stakeholder. Each of the focus groups lasted approximately 90 minutes. One moderator with one co-facilitator/note-taker led five of the six focus groups. The sixth did not have a co-facilitator. Although the moderator was mainly responsible for facilitating the interview, when present, the co-facilitator would step in if any additional threads needed to be followed or questions were missed. We held the focus groups in a community conference room with each stakeholder group. The size of the focus groups varied between 3 and 7 participants, and was based on participant availability. Focus groups should be small enough that each participant can share their insights, yet large enough to elicit a range of experiences (Krueger & Casey, 2014). The moderator and the co-facilitator were researchers with counseling backgrounds who had expertise in autism and training in interviewing. The same moderator facilitated each of the parent and practitioner focus groups and both of the focus groups with autistic youth were led by a different moderator.

First, the moderator reviewed the consent forms and then the participants answered a demographic questionnaire. Next, we queried participants with a set of semi-structured open-ended questions that were sent to them prior to the meeting, encouraged them to share their experiences, and affirmed them for their participation. We followed Krueger and Casey's (2014) recommendations for question development; the questions were open-ended, designed to evoke conversation, and clear. Each focus group had three questions specifically about expectations

tailored for each group regarding: (a) what their expectations are; (b) what factors affect their expectations; and (c) the effects of their expectations. For example, in the practitioner group, we asked “What factors affect your expectations?” In the youth group we asked, “After you leave college, what do you want to do?” In the parent group we asked, “How do your expectations affect you and your family?” The facilitator followed idea threads introduced by participants or prompted them to explore further domains such as education, work, and relationships if they were not already discussed by participants. Additionally, based on the responses, the moderator may have changed the wording of the questions to highlight a part of the question not already touched upon or use the participants words to make the question clearer. As the focus groups were part of a broader project, if the participants discussed expectations at any point in the interview, their responses would be coded as expectations.

We compensated participants for their participation with a \$20 gift card upon completion of the focus group. All focus groups were audio-recorded then transcribed verbatim by a professional transcription service. Names were removed from the transcripts before coding and replaced with pseudonyms. The pseudonyms were changed each time results have been presented to reduce the likelihood that identities could be pieced together from multiple sources. There are 16 pseudonyms used in this analysis.

Data Analysis

We analyzed data using thematic analysis (Braun et al., 2015). A team of five researchers participated in the coding under the supervision of an expert in qualitative data analysis. All researchers were either doctoral students or doctoral-level researchers and had received training on the use of qualitative research methods. We conducted open-coding using a technique called episode profile analysis (Maietta et al., 2016) with each focus group being considered an episode. For each focus group transcript, two members of the coding team independently selected a series of powerful quotations and wrote analytic memos about each quotation. They then compared their quotations and memos to come to a consensus of quotes to create a quote inventory (Maietta et al., 2016). For each group, we used the two quote inventories to develop initial codes by the entire research team using constant comparative analysis (Glaser & Strauss, 1967).

To create each coding framework, we gave initial codes names and definitions. Several examples epitomizing each code were also included in the framework. We shared the framework with other research members who were not part of the coding team to provide critical feedback. From their feedback, we refined definitions and further differentiation was given to each code. We changed code names to better capture the intended meaning of the code. The coding framework was then used to focus-code all data from each transcript. We double coded all transcripts. One member of the coding team conducted the initial coding and then two different members of the coding team worked together to come to a consensus based on the initial coding. This led to the code definitions continuing to be refined, collapsed, and expanded. Once the codes had been finalized within each stakeholder group, we began to examine the codes across stakeholder groups for similarities, differences, and relationships to generate final themes (Braun

et al., 2015). To do so, we wrote analytic memos describing similarities and differences and using data to support these conclusions.

To further explicate our analytic process, we will outline the evolution of the theme *Living with Uncertainty*. The open coding process elicited 25 powerful quotations from the parent stakeholder group. Each of these powerful quotations were written about and discussed at length. We then looked for commonalities across the powerful quotations through a small-group discussion. Based on these quotes, the initial code was “We can’t expect, only hope” and was given a definition: Parents do not really have expectations for the future, but they do have things that they hope for. They feel like setting up expectations would be setting themselves up for disappointment. Anything that is going to happen for their children will be things they have to make happen.

We then worked on analyzing other stakeholder transcripts before returning to the parent focus groups to revise the code book. We had concerns that the code was difficult to understand. It was revised to “Living into Uncertainty” and the definition was broadened to include the following: they are also wrestling with trying to understand what possibilities are reasonable given their child’s abilities. We next met with a broader group of researchers who were not part of the coding team to talk about our codes in terms of the wording we selected, the definitions we developed, and the quotes we were using to support them. During this meeting, the interpretation of “Living *into* Uncertainty” remained unclear and we revised into “Living *with* Uncertainty” to include that some parents discussed uncertainty in terms of planning for after the parents death. We then focused-coded the transcripts using the code “Living with Uncertainty” as well as the other codes developed through the same process. We closely examined any quotes that we did not feel fit into our codes as well as codes with few quotes associated with them. We either expanded codes or combined codes to address these problems. From there we had a corpus of quotes related to “Living with Uncertainty.” Using constant comparative analysis (Glaser & Strauss, 1967), discussions, and memoing, we examined across quotes to further develop the code into a theme presented in the results section by identifying the dimensions, boundaries, and within as well as between group variations.

Credibility and Trustworthiness: Indicators of Qualitative Research Quality

In order to ensure credibility and trustworthiness, we followed several of the strategies outlined by Brantlinger and colleagues (2005). We triangulated *within* data which meant we had to have multiple informants contributing to each code. We also triangulated among investigators throughout open and focused coding by using a collaborative approach. During open coding, two members opened-coded each transcript and compared and contrasted coding to come to consensus on the quote inventories. The initial themes were decided by consensus between at least four research team members and also refined by consensus. Focus coding was done by consensus by two team members and then confirmed by two additional team members. As part of our collaborative process, researchers reflected on their own assumptions, beliefs, and values through analytic memoing and discussions during research meetings. We participated in peer debriefing in two ways. First, we invited peers to critique and discuss our initial codebook and

we revised our themes based on their feedback. Also, we presented our preliminary results at several national conferences in order to receive critical feedback from experts who are familiar with the process of transition for youth on the autism spectrum. We maintained an audit trail to document the specific times, dates, and research members involved in all steps of the coding process. Finally, we report our results using thick, detailed descriptions to provide evidence for our interpretations and conclusions.

Results

In response to questions about expectations during the transition to adulthood, youth on the autism spectrum, parents, and professionals described their expectations in very different ways from one another. This underscored different processes that youth on the autism spectrum, parents, and professionals utilize for creating expectations. Autistic youth expressed *Normative Hopes* when discussing the expectations for the transition to adulthood. Parents discussed *Living with Uncertainty* as the primary descriptor of their expectations for the transition to adulthood. Professionals described three themes regarding their expectations: *Mismatch of Reality and Expectations*, *Impairments Shape Expectations*, and *Services Dictate Expectations*. All five themes will be described in more detail, as will similarities and differences between each stakeholder group.

Normative Hopes: “I Just Want to do What I Love”

As autistic youth described their expectations regarding the transition to adulthood they described *normative hopes*: that they would find careers that were interesting and achievable, that they would have romantic partners and start families, and that they would be independent in their future lives. Beyond describing the areas in which they have plans for their future, in discussing normative hopes, participants described a process. The process that they described was also normative and included understanding strengths, receiving encouragement, being dedicated, having set-backs, participating in vocational opportunities, learning from the experiences of friends and family members, and being flexible.

In articulating their expectations for the future, participants described a normative process of how their hopes were shaped. They identified strengths, got encouragement, and were dedicated to their goals. For example, Lexi’s comment focused on identifying strengths, “I want to get into editing. I like editing videos and stuff because I’m good at that.” Like many young adults, Lexi chose her major based on her strengths. Participants discussed identifying their own strengths and having parents and teachers helping to identify strengths. Beyond identifying strengths, *encouragement* was also important to how youth shaped their expectations. For example, Susan identified herself as an artist and remembers encouragement from a teacher that continued to motivate her, “I remember I was in second grade. I didn’t know what I was going to do with my life and then my art teacher told me when I was about to give up an art project, ‘Don’t give up’.” In addition to external encouragement, personal dedication was important to the youth’s expectations for the future. This comment from Susan highlights *dedication* as she described wanting to go to a university, “It was love at first sight. I gotta go here...I had to take the ACT again just to get that one point to enter in.”

Participants had a wide range of goals that they were dedicated to achieve. Most focused on careers, but participants also discussed non-academic goals, including living on their own, having romantic relationships, and having families. For example, Ben talked about moving out of his parents' house, "In the summer, I'm actually hoping to get an apartment on my own by then. I'm living at home right now saving up for that." Although the participants in our groups often focused on their growth, it was not always a linear path as some described *set-backs*. For example, Ben discussed not always having wanted to go to college, "I had very prejudiced ideas about college. It's hard to say exactly where they came from. I think it was mostly my own anxiety...I thought I could educate myself better than any system could educate me, of course, it's not true it's ridiculous, right?" Ben went on to discuss how much he has enjoyed and appreciated his college experience.

There were other factors that shaped participants' career expectations. Participants often described *vocational experiences* as a factor contributing to their employment expectations. For example, Ben described how he decided he wanted to become a librarian, "I volunteered to be a librarian for my high school class... [Now] I work at the university library shelving books. I just love libraries. I really love books and I like working with people." Participants also used the *experience of friends and family members* to help shape their expectations, especially as they pertained to understanding what jobs actually entailed, how they might affect mental health, and put constraints on work-life balance. Using the experience of friends and family members to shape expectations is evidenced in this comment from Tyler when discussing switching majors, "I came into the school wanting to go to game design but then I realized it's horrendously competitive. One of my close friends was hospitalized because of exhaustion from working too hard on the stuff." As participants discussed their careers, they highlighted the importance of *being flexible* to respond to opportunities that may present themselves, as indicated in this statement from Ben, "I'm kind of at this stage where the idea roughly that sounds good, but if opportunities take me to other places, I'm open to that as well."

Throughout their responses, autistic youth expressed normative hopes in terms of what their future might look like and how they planned to achieve it. For the youth, setbacks and obstacles were not sources of anxiety. Rather, youth saw these as part of a normative process. The youth in our study were both optimistic and realistic.

Living with Uncertainty: "There's Too Much Uncertainty to Have an Expectation"

Like the youth on the spectrum, parents described their expectations in terms of hopes. However, whereas hope had a largely positive connotation for the youth, parents' hope reflected their uncertainty and anxiety. George discussed the uncertainty he experienced when considering the future,

"I would love to be able to have an expectation. That would be a wonderful luxury to have. I think the way the question should read is, 'What are your hopes?' Because you just live in this state of hope. There's too much uncertainty to have an expectation."

Thus, we characterized parents' expectations as *living with uncertainty*: they have concerns about understanding their child's potential, managing their child's expectations, and trusting that there are others that could provide care for their child.

Parents described struggling to *understand their child's potential* as one contributor to their uncertainty. This was indicated in this comment from Hank, "The problem is that I'm still convinced that there's a lot more potential locked in my child than I'm able to realize." Christina discussed the difficulty in understanding her child's potential as she became more aware that some of her expectations from when he was young were unlikely to come to fruition, "When he was little, I used to think he'd go to college and he'd be in some kind of an academic where he could be a little weird and whatever, but no. I mean, he doesn't have the communication skills at this point." She goes on to describe the emotional toll that this level of uncertainty takes, "It's emotionally hard to take apart your hopes versus what you realistically think will happen." Hank also discussed the challenges of trying to set realistic expectations, but his comments came from the concern that he may be underestimating his child's capabilities,

"Well here's the frustration, I've talked to parents that have launched their kids, they live independently now, or semi-independently. In almost every case before that happened the parents were, 'Well, he can't do that, she can't do this.' Once they're out on their own the parents are saying, 'Oh my god, I never thought that they could do this or that.'"

Paul shared his challenge in understanding his child's potential due to the complex interaction between his child's skills and limitations, "Everyone around assumes that everyone has a certain skill set...He has an amazing sense of taste and smell, which can be very good if you want to be a chef but he could never remember to turn the stove off, not reliably." George also focused on the interaction between skills and limitations. However, George emphasized the limitations of the support his child could receive,

"I'm cognizant that I often get frustrated because I think, 'Why can't somebody help my son?' Then there's also the part of me that says, 'There's only so much that really, maybe, can be done.' So that makes it hard, because you don't necessarily know what your expectations should be or what to even expect of these support groups."

In addition to understanding their child's potential, another contributor to a parent's uncertainty was managing their child's expectations. For example, Paul discussed how he believed his son's expectations were not realistic when he described trying to teach his son how to drive:

"If I tell him, 'No, you can't drive.' I might as well tell him, 'No, you're not getting to breathe.' To him that is an expectation he feels he has to have. So, we'll try and maybe we're down to reasonable levels of failure, but not what you would say is acceptable. That's really hard to manage. It's really hard. It's not small. You're not going to get there and here's a program, here's five hours a week. That's not going to get you there."

Parents were unsure if their own expectations were realistic and they also struggled to understand if their children's expectations were realistic and how to support them. Finally, parents described living with uncertainty in terms of their fears of what will happen to their

children when they are no longer able to care for them. Angie noted, "That's the common denominator of all parents or guardians is what's going to happen to them when I pass away." Christina also described her uncertainty in terms of her planning with her son, "You've got to be prepared for when mom's not here to do this for you." Rosie described how she also plans for her son's future without her, "I'm going to work really hard to have supports in place, have resources in place, and hopefully enough training with him so that he can be independent and live without me. Because that's the goal."

Taken together, these comments indicate that parents struggle to understand their child's potential due to how their child's trajectories change over time and the fear of underestimating their child. They are also unsure if the necessary supports will be available or possible, thus contributing to their concerns about their child's skills. Living with uncertainty took an emotional toll of themselves as a parent. Their children's own expectations for the future also lent an element of uncertainty.

Mismatch between Reality and Expectations: "Sometimes Parents get Skewed"

Practitioners also evoked the idea that expectations could be a struggle; specifically, parents' lack of realistic or informed expectations. Practitioners discussed parents' expectations as being a mismatch with reality in terms of having expectations that were too high based on their child's capabilities, or not possible due to a lack of community resources. Paula's comments reflect the idea that parents may set the bar too high, "Sometimes parental expectations are not reality based, they're very high and they haven't necessarily reconciled themselves with, 'What is going to happen with my child? What is realistic?'" In this comment, Paula is discussing what was realistic based on the child's potential as she goes on to say, "I hesitate to say, 'This is the top, this is the limit that you can reach for' ... [but] it becomes very difficult to navigate what's real - what's possible." Adriana also focused on the difficulty when parents have high expectations. However, Adriana focused on how parents did not realize that the supports do not exist to make those expectations a reality, "I see families that have high expectations and want that, but they don't have the supports, there's not the community supports to be able to support those expectations. So, it continually falls back on them." Audrey also discussed the lack of community resources and how there is a mismatch between parents' expectations and reality, "Families are just assuming, [because they] have been getting these services in school [that they will continue to get them]. [Parents ask,] 'Now who's giving us the services afterwards?' And in many cases, there are no services."

In the previous quote, Audrey discussed the challenges that arise when parents' have expectations that are not in line with reality due to a misunderstanding of the services that are available through adult service programs compared to school-based programs. In this quote, Audrey is expressing frustration that practitioners are not more forthcoming with the full spectrum of post-secondary outcomes and how outcomes can be matched based on an individual's needs:

"Do the families really believe that these kids are ever going to work or live independently? No, they don't. So, they are not on board, because we are not saying to

them ‘Yes, your kid is going to work. They may not work 40 hours a week, and they may not have a living wage, they may still have to have other supports, but they are going to work.’”

Although practitioners focused on parental expectations, they also discussed the complexity of how youth set their expectations. For example, Jennica said,

“For those seniors [in high school] who are trying to navigate, ‘Am I going to college or straight to employment or somewhere in the middle of that?’, trying to explain to them just because your friends are going to college doesn't mean that that's the track for you and I think that a lot of times that's difficult.”

Similarly, Paula described trying to support a student with having more realistic expectations, “So if we have a student who is 16, and almost non-verbal, but they write down they want to be a doctor. Okay, that's fine, there's nothing wrong with that, but then it's our job to help them understand what being a doctor is.” Whether taking a parent-centered or student-centered approach, in each of these cases, the practitioners are describing strategies they used to try to correct for the mismatch they perceive between expectations and reality.

Impairments Shape Expectations: “Based on the Continuum of Severity”

In viewing how parents described living with uncertainty and in how practitioners described the mismatch between reality and expectations, there was an implicit question as to the role that impairments make in the process of setting expectations. As evidenced in the previous themes, parents and practitioners discussed the challenge of understanding the role of impairments in shaping expectations. Autistic youth did not express impairments specifically, but did discuss trying to understand their own strengths and weaknesses. In each of the previous themes, the relative balance between the role of impairments and societal constraints was either ambivalent or more focused on the societal aspect. In contrast, this theme reflects the belief on the part of some practitioners who clearly stated the role of impairments in shaping expectations. For example, Christopher said, “Based on the continuum of severity you may be faced with just improving behavior within a residence versus on the very high end navigating the world of work, college, social and community relationships.” In this comment, Christopher was suggesting what he sees as the continuum of expectations one might have based on an individual’s impairments.

Similarly, Rhonda mentioned, “I think some other factors that affect my expectation is the individual's functioning level. I think we do have to consider there's a broad range and some folks may never be able to live independently.” Paula also commented on her conceptualization of the autism spectrum as having higher and lower ends, “There's such a large variety on the autism spectrum, and that impacts what you expect and how you proceed to work with individuals. When someone is higher functioning, those expectations for employment are much different than when someone falls lower on the spectrum.” Each of the responses in this theme suggested that some practitioners delineated individuals on the autism spectrum as being “higher functioning” or “lower functioning” and these designations influenced their expectations during the transition to adulthood.

Services Dictate Expectations: “It Would Depend on the Specific Service they were Receiving”

For youth on the autism spectrum and parents, the process of setting expectations was very personal. Youth’s expectations were influenced by their personal strengths, goals, and experiences. Parents’ expectations, albeit feeling uncertain, were based on their individual child’s wants, strengths, and needs. In contrast, practitioners often discussed their expectations in terms of the services they provided rather than from a person-centered perspective. For example, Shannon described how her field of pre-employment services dictated her expectations, “For me, specifically, working with pre-employment services, our hope is that after they’re done working with us, they’re moving on to that next step for that specific individual, whether it’d be volunteering, employment.” Practitioners often had a different process and shaped their expectations. To some extent, how they set their expectations and the services they provided were based on the service system or their professional discipline. For example, Paula discussed the constraints the service system could place on the services provided, “In a lot of ways it’s the system that you’re working within which tempers what you can actually do with someone or how you can spend those dollars to support them.” Paula also discussed how services dictated expectations,

“The beauty and the ugliness of the system is that oftentimes you do have an awful lot of flexibility in terms of what you can do. I would not want to give that up. At the same time, you also have these very specific policies about what you can and what you can’t do that drive your actions more often than not.”

The quote from Paula articulates the connection between expectations and behavior. As evidenced in previous themes, parents and youth express needs in terms of a dynamic interconnected system that weaves together life experiences, desires, strengths, and challenges. This theme presents an alternative view: although services may be quite dynamic within an organization’s purview, they are also constrained by the mission of the organization.

Discussion

Understanding the expectations of youth on the autism spectrum, parents, and practitioners is an essential component for understanding how to facilitate success with the transition to adulthood. Our results highlighted the need to elicit input across different stakeholders in order to make services more efficient and effective, as suggested by some of the existing literature (e.g., Accordo et al., 2018; Ellias & White, 2018). Results of our analysis further document similarities and differences in the expectations for the transition to adulthood across the stakeholder groups.

Similarities and Differences between Stakeholder Groups

One similarity is that all three groups discussed the role that the individual’s strengths and challenges of autistic youth play in shaping expectations. However, the tone and nature of how strengths and challenges were discussed was different for each group. The youth in our study were strength-and preference-based in how they discussed their expectations and did not address their impairments directly. Parents in our study discussed functional performance as a

source of uncertainty in terms of not always being able to understand their child's strengths and limitations and how their child would fit (or not fit) with the services that were available. The responses of the parents in this study are consistent with previous research, such as Kirby's (2016) NLTS study, which suggested that functional performance played a role in affecting the parental expectations in the areas of work, social participation and independent living.

Although parents did discuss the role their child's impairments play, they never went so far as to suggest that impairments play the primary role in determining their expectations. They also described impairments specifically and avoided generalizations like "high" or "low" functioning, nor did the autistic youth we interviewed talk about themselves in these terms. In contrast, some practitioners clearly based expectations on skill generalizations and implied that high expectations were only appropriate for youth they would consider to be "high functioning." The use of functioning labels is problematic for several reasons. First, "high" and "low" functioning are not clinical terms and thus they have imprecise definitions (American Psychiatric Association; APA, 2013). Second, the terms have been found to be an inaccurate descriptor when looking at relations between functional behavior, intelligence quotient, and age of diagnosis (Alvares et al., 2020). Third, the binary nature of "high" and "low" does not reflect the diversity of support needs in the autism community or how support needs differ within individuals, across contexts, and time. Finally, it suggests that only those least affected by their impairments are capable of achieving high expectations.

Each group discussed the complexity of the transition process and how that affected expectations. Autistic youth reported their expectations similar to how those without disabilities express expectations (Arnett, 2006). This is congruent with Anderson and colleagues' (2015) study which also showed autistic youth held normative expectations for adulthood. Youth in our study discussed expectations in academic and vocational domains as well as non-academic domains, such as living independently, having a romantic relationship, and having a family. The holistic needs of autistic youth is shared by other studies (e.g., Accardo et al., 2019) which suggested specific academic needs such as testing, academic accommodations, and social supports should be considered (Ashbaugh et al., 2017). Expanding on previous research, we were able to identify a normative process by which youth achieve their hopes.

As for parents of autistic youth, our results showed parents' expectations for their child often were uncertain due to the combination of not fully knowing what was possible as well as the extent of limitations. Chen and colleagues' study (2019) supported our results that while these parents have expectations for their child in areas such as community participation, safety, independent living, social relationships, education, these hopes and dreams were often tempered by fear and uncertainty. Furthermore, in considering the services that were available, uncertainty seemed to be caused by a fear that there would not be services available to meet their child's unique needs rather than a complete lack of services. The tension between expectations and limitations was not the emotional connotation of the autistic youth in our study, but it was similar to the emotional connotation of how practitioners discussed their expectations. Practitioners in our study suggested uncertainty compared to previous studies that indicated that employers and

employment specialists felt supportive in providing the necessary accommodations in order to facilitate successful employment for young adults with autism (e.g., Dreaver et al., 2019; Scott et al., 2017). This may be due to the range of professional disciplines represented in our sample.

Although all three groups recognized the challenges associated with the transition to adulthood, youth on the spectrum had the highest expectations of meeting their goals. Both parents and practitioners expressed more hesitation that youth on the spectrum would work and live in the community, given the impairments associated with autism and the constraints of the service system. This is an important insight, especially given that the perceptions of autistic youth are largely absent from the literature on transition expectations. One reason that youth on the spectrum were expressing optimism may be that these individuals were experiencing a well aligned person-environment fit. The person-environment fit describes the complex dynamic between personal needs and societal expectations (Henninger & Taylor, 2013). The youth in our study were college-students who were succeeding in that environment. Thus, they were participating in an age-appropriate activity and doing well. Youth may have also had high expectations due to their previous experiences, successes, family support, and community support. Another explanation is that the youth in our study had set high expectations for themselves based on their individual abilities and were working to meet those expectations. Only practitioners mentioned the idea that too high of expectations could be a risk. Including the subjective experience of youth on the autism spectrum when defining what it means to be successful with the transition to adulthood can enable youth, families, and professionals to set goals that are not just achievable, but also meaningful (Billstedt et al., 2011).

Strengths, Limitations, and Recommendations for Future Research

Our study illuminated the importance of examining the role of expectations on the process of transition from multiple perspectives as each stakeholder group had unique contributions. Although there were similarities across the perspectives, there were clear differences in terms of tone and focus. Other studies have highlighted the difference in stakeholder perspectives, however, they have focused on parents and educators (e.g. Carter et al., 2014). Our study adds to this literature by incorporating a wide range of transition-related practitioners as well as the perspectives of youth on the autism spectrum.

Despite the unique strength in the incorporation of multiple stakeholders in the conversation in understanding the transition process for autistic youth on the spectrum, future research is needed to address the limitations and to further explore the findings of our study. First, although our study gained multiple stakeholder perspectives, we did not utilize participatory strategies. Future research could involve stakeholders in the research process through strategies such as member checks, perspiratory action research design, or stakeholder research advisory board.

Our study asked about the general process of transition. We did not have theoretical saturation on how each of the stakeholder groups may or may not have different expectations based on the domain of adult life. Therefore, future research can explore how domains such as academic, vocational, interpersonal relationships, and health are integrated or independent

processes, thus could provide more in-depth understanding of how these pertinent transition domains can impact on them and how services can be better prepared. Also, all of our stakeholders are from the same state. Although they were from various regions and could speak to differences in service variability, participants from other regions may hold different expectations. Additionally, we did not have theoretical saturation across practitioner groups. From our study, we were not able to identify patterns between educators, community-based service providers, and vocationally focused providers. Future research can further identify how expectations throughout the service network influence the outcomes for youth on the autism spectrum during the transition to adulthood.

Our study only included youth on the autism spectrum who were pursuing post-secondary education. Future research should examine youth on the autism spectrum who have pursued other paths during the transition to adulthood as they may have substantively different expectations. Furthermore, because we recruited through the disability resource center, we cannot speak to the experience of college students who do not seek formal accommodations. Additionally, research can explore how similarities and differences among stakeholder perspectives transition teams affects both expectations and transition planning. Finally, our project was a snapshot of expectations. Future research should explore how expectations change and influence behavior over time as well as the factors that shape how they were formed.

Implications for School-based Transition Planning

The perspectives of youth emphasized both the universal and the individualized nature of their hopes and dreams. This finding underscores the need for individualized transition plans based on high expectations, matched with individualized supports, and meaningful and feasible goals. Other scholars have provided empirical support for individualized service planning (e.g. Karan et al., 2010). The parents' uncertainty regarding how to set appropriate expectations based on their child's strengths and challenges then advocate for necessary services, suggests the need for school-based parent education. There is emerging evidence that parent psychoeducation has been effective in improving transition outcomes for autistic youth (Curtiss et al., 2019). The youth in our study highlighted the importance of early vocational experiences. College-bound youth on the autism spectrum may not receive formal early vocational experiences due to students' academic focus, however, early vocational experiences have been found to improve employment outcomes for youth (Lee & Carter, 2012). This is one strategy that can be explored in future research and practice.

Implications for Adult-based Transition Services

For practitioners, their experience of being in the service system placed constraints on how they were able to view youth and families. Instead of focusing on what youth on the spectrum and their families needed, practitioners focused on what services their agencies could provide. The lack of focus on individual needs may contribute to services not being able to meet the high expectations of some youth and parents. Findings from this study suggest a re-envisioning of a comprehensive person-centered planning for the transition to adulthood. Previous studies have identified processes and strategies for supporting youth on the autism

spectrum and their families person-centered planning process (Hagner et al., 2014). Practitioners will need to find ways to advocate for change within their organizations so they are able to provide the services that make high expectations a reality. Additionally, the finding that generalizations about functioning dictated expectations suggests that practitioners need more awareness of how functioning labels and deficit orientations can limit youth outcomes.

Conclusion

Youth on the autism spectrum are facing objectively poor outcomes in adulthood (Roux et al., 2015) and much more work is needed to understand how to best support these youth so they may reach their full potential and achieve their goals. Due to their role in influencing outcomes, expectations during the transition to adulthood of multiple stakeholder groups are an important area for future research. The extant literature has focused on the expectations of parents with much less attention to the expectations of youth on the autism spectrum and practitioners who support the transition to adulthood be they educators or adult service providers. Results of our analysis add to the emergent literature on youth and practitioner expectations as well as further document similarities and differences in the expectations for the transition to adulthood across the stakeholder groups.

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