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Parent Perspectives on Supports and Barriers for Autistic Youth Transitioning to Adulthood

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Abstract

Knowledge is needed about specific supports and barriers for successful transitions to adulthood for autistic youth, especially from the perspective of parents, who are highly involved in transition preparation. We conducted a qualitative thematic analysis of previously conducted semi-structured interviews with 39 parents of 41 autistic adolescents to identify themes related to supports and barriers; we then used Bronfenbrenner's Ecological System's Theory to aid in interpreting the themes. We identified three main supports and four main barriers to the transition to adulthood from the parent interviews. The supports and barriers represent factors to consider at each theorized ecological level. Results point to opportunities to promote person-environment fit and support the transition to adulthood for autistic youth at multiple system levels.

Keywords

autism; adolescence; parents; transition; qualitative

Introduction

Historically, the main focus of autism services has been on developing and strengthening programs for young children. As autistic children grow into adolescents and adults, services and resources, especially those that incorporate the parent-child relationship, tend to dwindle (Dawalt et al., 2017). In adolescence, there is a marked shortage of available programming, leaving many of the needs of autistic youth unmet (Henninger & Taylor, 2013; Howlin & Moss, 2012). Inopportunately, adolescence is also a critical time when parents and

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Author Contributions:

Jenna Hoffman developed the idea for the project, analyzed the data, and drafted the manuscript. Anne Kirby conducted/oversaw all data collection; provided support for study conceptualization, analysis, and manuscript writing; and edited the manuscript. Both authors read and approved the final manuscript.

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youth confront preparation for adult life, including making decisions about postsecondary education, housing, and employment (Arnett, 2000; Hendricks & Wehman, 2009).

Data on post-secondary outcomes of autistic youth suggest that the transition to adulthood is difficult for individuals and families. Many studies report high rates of “poor” or “fair” outcomes with regard to independence and integration in society (Eaves & Ho, 2008; Steinhausen et al., 2016), as well as quality of life (Mason et al., 2018). These data indicate a high need for interventions for autistic youth that are designed to support the family system leading up to and during transition (Dawalt et al., 2017). Parents play a crucial role as they guide and make key decisions in the transition process, especially for this demographic. Taylor et al. (2017) note that parents serve as the “linchpin” of services for children with disabilities and are therefore ideal targets for intervention. Tapping into the parent perspective in order to understand the factors that support and inhibit families as they approach the post-secondary transition is essential to better equip practitioners and providers with the tools to enhance supports and minimize barriers. The current study examines supports and barriers reported by parents of autistic youth during qualitative interviewing about the transition to adulthood in an effort to illuminate the parent perspective and inform more holistic transition-related interventions in the future.

Bronfenbrenner’s Ecological Systems Theory

A theory that is helpful in organizing and understanding contextual factors affecting an individual is Bronfenbrenner’s (1979, 1994, 2004) Ecological Systems Theory. Although Bronfenbrenner’s theory and related model are highly complex (Tudge et al., 2009), for the purposes of this paper, we focus on the *person* and *context* aspects of the model to categorize the findings of this study, in order to make clearer delineations of how supports and/or barriers exist in several dimensions and across multiple levels of an individual’s life.

According to Bronfenbrenner (1979), within an individual’s ecological context there are four systems: microsystem, mesosystem, exosystem, and macrosystem. Bronfenbrenner’s model is often depicted as a center circle with concentric rings around it. The central component of the model is *person* or *individual*, which comprises a set of characteristics, namely physical, mental and emotional, and temperamental and motivational characteristics. The rest of the concentric rings in the depiction comprise the person’s *context*, which contains four distinct systems. Building out from the center is the *microsystem*, which includes activities, roles, and relationships directly experienced by the individual. An individual spends a significant amount of time in direct interaction with these contexts; examples include family, school, neighborhood, peer group, community group or work setting. The next level is the *mesosystem*, which is described as the relationship between two or more microsystems. This may include relationships that parents have to other entities directly interacting with the individual at the center, including the school, programs, or other families. Outward from there is the *exosystem*, which describes settings in which the individual does not have direct experiences but which have important influences on them. For example, a child may be affected by experiences in their parent’s workplace (e.g., events that lead to parental work-related stress), even though the child does not spend time in that setting. The outermost ring is the *macrosystem*, which is a broader context with common values or processes. Examples

of the macrosystem include cultural influences and broad social structures, including effects of socioeconomic status.

Contextual Influences on Transition

Existing research points to the relevance of Bronfenbrenner's model for understanding barriers and supports to the transition to adulthood for autistic youth. For example, there is a wealth of literature supporting the idea that a youth's school system (i.e., microsystem) plays an integral role in successful transition to adulthood (e.g., Chiang et al., 2012; Taylor & Henninger, 2015; Wehman et al., 2014). The quality and quantity of services offered (Camarena & Sarigiani, 2009; Hetherington et al., 2010), the school's post-secondary goals for the child (Pinder-Amaker, 2014), and the structure of the special education process (Hetherington et al., 2010) are all school-related factors that have been shown to influence the transition for autistic youth.

Furthermore, research suggests that experiences and opportunities associated with sociodemographic factors can also either support or inhibit transition (Kirby et al., 2016). For example, in our society (i.e., macrosystem), financial access can play a significant role in transition planning. This trickles down through the exosystem, mesosystem, microsystem, and ultimately to the individual. Thomas et al. (2007) identified that families with lower incomes tend to have more difficulty accessing services for their autistic children (i.e., mesosystem). Research by Taylor and Henninger (2015) found that the three most commonly reported barriers to receiving services in high school, according to survey responses from parents of autistic youth, were that services cost too much, were not provided in a geographic area that was convenient/accessible, and were not covered by their insurance type. Wei and colleagues (2015) also found that the most common barriers for autistic youth and their families was the lack of availability and information about services.

Study Purpose

Despite existing research indicating the influences of contextual factors on transition, there is little analysis of supports and barriers from the perspectives of parents of autistic youth informed by a theoretical framework. The current project involved secondary thematic analysis of qualitative interviews with parents of autistic youth to explore supports and barriers perceived by parents as related to the transition to adulthood. After thematic analysis, we used Bronfenbrenner's model to interpret the results in order to explore the potential needs for policies, interventions, and supports at different ecological system levels. This work can help to inform improvements to transition resources in order to facilitate supports and reduce barriers for families of autistic youth.

Methods

This manuscript describes qualitative analysis of interviews collected as part of three separate research studies led by one principal investigator. Each study involved individual interviews with autistic youth and one of their caregivers (separately) and focused on the preparation for adulthood among autistic youth and their families. The present analysis included the parent interviews only; recent manuscripts include analysis of the

corresponding youth interviews ([Author; Author]). The primary purpose of the interviews varied slightly across studies, though the core interview questions were consistent across studies. University institutional review boards approved each study, and we adhered to data security and informed consent/assent standards. This secondary data analysis aimed to explore parent perceptions of supports and barriers related to the transition to adulthood for their autistic youth.

Participants

The total participants for this analysis included 39 parents of 41 youth (88% male; 12–19 years of age) with a parent-reported autism diagnosis recruited from two U.S. states. Although any type of primary caregiver was eligible to participate, only mothers and fathers enrolled. We recruited participants through emails and printed flyers distributed to local organizations, clinics, and schools that serve autistic youth and/or support caregivers. None of the youth had exited secondary education at the time of interview, and most (>80%) were anticipating a secondary school diploma (this was an inclusion criteria for two of the three studies, indicated below). Each study is briefly described below, and demographics are provided by study in Table 1.

- Study A included seven parents of eight autistic youth interviewed in North Carolina in 2014 as part of a qualitative, descriptive study to examine parent expectations for their children's adult futures. Youth were required to have the verbal ability to participate in an interview (as determined by their parent), but no other inclusion criteria were imposed. (See [Author] for more information about this study.)
- Study B included fourteen parents of fifteen autistic youth interviewed in Utah in 2016 at the initiation of a longitudinal mixed-methods project about family experiences of preparing for adulthood during secondary school. Youth were required to be anticipating a secondary school diploma (versus a completion certificate). (See [Author] for more information about this study.)
- Study C included eighteen parent-youth dyads interviewed individually prior to participating in group interventions in 2017 and 2018. The intervention included a parent group focused on preparing youth for adulthood, and a youth group focused on adult life skills. As in Study B, youth were required to be anticipating a secondary school diploma and the study was also conducted in Utah. (See [Author] for more information about this study.)

Procedures

Each parent participated in a semi-structured interview either in their home or at a university clinic; interviews lasted 33 minutes on average (range: 12–72 minutes). The principal investigator or a trained research assistant conducted the interviews, which were audio recorded and transcribed verbatim prior to analysis. Participants had no prior relationship with the researcher. Interview procedures were similar across studies. Interview prompts included parent visions for the futures (i.e., *Tell me about what you currently imagine life after high school will look like for your child*), concerns for the future (i.e., *Are there aspects*

of your child's future that you are especially unsure of or concerned about right now?), and transition preparation activities (i.e., *Tell me about what sorts of things you, your child, and the rest of your family have been doing to prepare for your child's adult life*). We did not specifically ask about supports and barriers related to transition, but participant perspectives on these consistently arose during the interviews leading our team to conduct the present analysis.

At the time of the interview, parents also provided demographic information, completed the Social Responsiveness Scale (Study A used the 1st edition [Constantino & Gruber, 2005]; Studies B and C used the 2nd edition [Constantino & Gruber, 2012]), and completed other study-specific assessments. Families received financial incentives for completing relevant study procedures (ranging from \$20–25 US, as a gift card or check, across studies).

Data Analysis

We first conducted an inductive, semantic thematic analysis (Braun & Clarke, 2006) of the transcripts using a team-based approach of coding, categorizing, and developing themes (Coffey & Atkinson, 1996; Rubin & Rubin, 2005). We engaged in iterative readings of the transcripts with regular team meetings to develop themes. Both authors engaged in data analysis—the first author was a graduate student with prior experience assisting with qualitative coding and was trained to perform qualitative coding by the second author, a faculty member with extensive qualitative experience. The first author conducted all primary coding, and the second author reviewed and confirmed all final coded data segments. Any disagreements between authors were discussed until consensus was reached. We utilized multiple strategies to enhance trustworthiness in the analytic process (Lincoln & Guba, 1985), including an audit trail to document analytic decisions and multiple reviews of all codes and themes between the two researchers. Verbatim quotes and examples from individual participants are presented, as space allows, to further enhance trustworthiness (Brantlinger et al., 2005).

After finalizing the inductive codes and theme structure, we used Brofenbrenner's (1994) theory *a posteriori* to organize the themes according to the theorized ecological systems. As with the initial coding, the first author initiated this process and thoroughly reviewed each decision with the second author to reach consensus.

Findings

Through the data analysis process, we identified three themes related to supports and four themes related to barriers. The supports and barriers expressed by parents involved both individual and contextual influences on the transition to adulthood for the autistic youth. Quotes are labeled with a random identification number and the letter of the study the participant was enrolled in (A, B, or C).

Supports

The identified supports included (1) youth interests, positive experiences, and motivation, (2) parent connections and awareness, and (3) extracurricular programming.

Youth interests, positive experiences, and motivation.—Parents in our sample described how things they have witnessed about their youth, including youth interests, positive experiences, and motivation, gave them reason to feel optimistic about the future. For example, the vast majority of parents identified at least one interest of their child's that they hoped could potentially lead to or support future employment. Interests varied across the sample, but included things such as computer programming and coding, piloting, drawing, animation, and video game design. One parent described the following:

He has a lot of interests...very strong interests, of course, just in different areas. So, I think he has the ability to find something that he'll like. I've never really known which direction he's going to go... But you know, if it's something he loves, I think it's something he'll be successful at

(B11).

Many parents also reported that when their child had positive experiences, such as winning an award or receiving praise for their work on a project, it provided the child with a sense of success that parents hoped could carry over into other aspects of their life. Illustrating this point, one parent discussed how the praise her son received after his first attempt at welding helped to boost his confidence:

He was told he had done an amazing job. Like his first try was amazing, and [he] took that really to heart... [He] seemed very encouraged because he had these people telling him, 'That was a great first weld that you did'

(C1).

Although less commonly discussed, intrinsic motivation and drive to prepare for the future was also noted several times in the parent interviews as supports for youth. Motivation was often linked to interests or positive experiences, as children who had expressed an interest or aptitude for a certain skill or area of study or who had received recognition for something they had done were more inclined to be motivated to pursue those things.

Parent connections and awareness.—Some parents explained how their access to knowledge from established social connections or past experiences were supportive for their youth's transition. For example, some parents reported that they already possessed some degree of understanding of the education or service systems because of their job (e.g., teacher at the school) or educational background, which helped them to navigate these complex systems. Describing this, one mother stated: "My husband is a special ed. teacher, go figure. He teaches a unit class with kids just like [my son]...so I get information from there" (C5).

Parents also described receiving support from other individuals or groups that helped them navigate the transition process. One parent explained how other parents were supportive: "Just chatting with parents [of kids] around the same age and just kind of sharing and getting their ideas and what they went through. That was helpful" (B8). Other parents discussed how it can be a support to learn from the experiences of older siblings or to see people in the autistic community or with other disabilities be successful. One parent explained that when

her son saw that his grandfather could be successful while living with a disability, he was encouraged:

My father-in-law...had a...physical disability; his legs never developed, so he walked on crutches. And I mean, [my son] saw him walk, and...I think that taught him, you know, 'Gee, even though you have a physical disability, it shouldn't keep you from doing things'... So I think that's encouraging for [him] to see; you can overcome the things you need to [overcome], you know, your challenges

(A6).

Extracurricular programs.—The third support theme identified in the interviews was youth access to and participation in extracurricular programming, whether disability-related or not. Program structure and involvement varied widely, but many parents reported that their child's involvement in such programming was supportive in transition preparation because it helped increase self-confidence, social participation, and independence.

Some parents described participation in programs where their child learned computer skills, explored potential areas of employment, got exposure to employment settings or college settings, and learned other life skills. One parent explained:

The [3D modeling program at the university for neurodiverse youth] has been so great because it's given [my son] an idea of college. Because he's [traveling there on his own]. And he's been in a lot of the buildings up at [the university] and that's pretty cool, so he feels kind of comfortable with that. And he's been with a lot of professors...so that's good

(B8).

Another mother said, "He's been on the [biking] team and so my husband's been trying to teach him basic bike repair stuff. You know, just to find ways for him to be more independent" (B13).

Other parents identified volunteer and service opportunities as supports for their children as they prepared for adulthood. For example, one parent reported, "He's, he's doing some volunteer work right now. I'm trying to get him hooked up with a lot of different volunteer experiences so he knows what it's like to be out in the world" (A2). Another described, "Like I said, the [Boy Scouts] Eagle project helped me see that, 'Okay, he can do some stuff.' You know, he can handle this, he can go out of himself a little bit" (B13).

Barriers

The barriers to transition that parents identified included (1) limited awareness of resources, (2) difficulty accessing resources, (3) service mismatches, and (4) youth challenges.

Limited awareness of resources.—Parents described limited awareness of resources and services for autistic adolescents as a barrier to successful transition. Parents explained that they did not know where to find services, what kinds of services were available, or what certain services actually entailed. Illustrating this point, one parent said:

Quite honestly, I don't know of very many resources at all to help with this. And so most of everything we do, I just kind of stumble onto and start thinking, 'Oh, that's a problem, maybe we should do something about this.' And then [I] pretty much start reinventing the wheel, which is a whole ton of effort that probably doesn't need to happen

(B6).

Some parents reported that they knew that resources and services existed that could be helpful for their child, but were hesitant to approach or explore them because they felt like they "didn't know enough" (B10). Some expressed confusion and uncertainty about the role or purpose of certain services; for example, one mother admitted that she felt unclear about the role that the Social Security and Vocational Rehabilitation programs would play in her daughter's preparation for adulthood. She explained, "More assistance or guidance with Social Security would be great. Um, to me it's extremely confusing. And making it simpler, the better [laughs]. I'm not stupid by any means, but it's just like, it's so much." She then continued, "I'm kind of unsure [about] exactly where voc. rehab. is going to play a part in this" (B9).

Many parents voiced a desire for one central place where they could research all of the services, resources, and programs that were available. Other parents said that they would appreciate a coach, or someone to guide them and their child through adolescence and into adulthood. Almost every parent expressed some degree of frustration or exasperation about the amount of effort it takes to find resources, and made comments like, "I feel overwhelmed by the amount of knowledge I need to have to take him to the next step" (B7).

Difficulty accessing resources.—While lack of awareness of resources was mentioned far more frequently, some parents who did know about resources identified barriers to access. Among the participants who did identify barriers to access, the most frequently reported concerns were financial and geographical in nature. The following quote illustrates one parent's concerns about financial limitations:

The biggest [resource] that I feel he could really benefit from that I don't have access to um, because my husband works PRN and I'm a teacher...we're like paycheck to paycheck...I would like to get him in to some sort of counseling or some sort of group [therapy]

(B7).

Aside from difficulty in financial access, other parents reported that because they lived in a rural area, they had limited physical access to resources in the city.

Service mismatches.—Another identified barrier involved a disparity between the needs of youth and the services made available to them, specifically at school. Parents frequently discussed how the special education system was not providing the types of supports their child needed. For example, one parent explained, "The middle school has been awful. No counselors, no therapy, there's nothing unless you're in a wheelchair and nonverbal...we have got him to the point where we graduated from the services that they're willing to give" (B1).

Another parent described how her son would benefit more from life skills support, but all his goals were focused on academics:

I don't feel like [my son] is ever really going to master a lot of these academic goals that they set. And to me that doesn't matter...what matters is his life skills and social skills, and they don't provide quite enough of what I think he needs

(A4).

Outside the academic realm, parents also identified that most services they were aware of were designed for youth with higher support needs than their children. While discussing community resources, one parent, who is a social worker, said, "You know, being in the business and looking at the resources—there aren't a lot for teenagers who are high functioning adolescents. There really aren't" (B14). Parents feared that the lack of appropriate services at school and within the community hampered the growth of their child and represented missed opportunities for their child to prepare for adulthood.

Youth challenges.—In contrast to the other identified barriers, which were all extrinsic to the youth, the final barrier relates to challenges associated with the youth themselves. Many parents described their child's naivety or limited motivation or interest in preparing for the future as inherent barriers to a successful transition to adulthood. Some parents postulated that these challenges were due in part to the nature of adolescence, but also referred to them as challenges related to autistic traits.

Parents voiced concerns about their child's lack of understanding of adult responsibilities and inevitabilities, such as the value of money, and how this resulted in what were viewed as "unrealistic" expectations for the future. Many parents reported that their child seemed to live in their own reality, and others expressed that their child did not understand how decisions made now would affect the future. Exasperated, one parent said, "He's definitely not in the real world" (B10). Another parent, discussing her son's approach to job hunting, stated, "He thinks he only needs to apply for one job at a time and see what happens with that one application...although I have talked to him numerous times about the job search process, he just doesn't get it" (B14). Another said, "[His] understanding of the future is that he's going to design an app and he's going to get paid millions of dollars and that's going to take care of everything" (B7).

Other parents reported that their child did not have expectations for the future at all and that they showed little interest in preparing for the future. This is in contrast to parents who identified their child's interests as supports, as described previously. One parent said, "If there was anything that he showed interest in, we would figure out how to make it happen. He—he's just, just [does] not show interest in anything" (A5). A number of parents reported that their youth were more interested in activities like video gaming than doing anything to prepare for the future. When asked about what his son's future would look like, one father reported, "Um, staying at home, playing video games...As he is right now, he doesn't seem very enthusiastic about anything as far as getting a job, or getting a driver's license or anything like that. He's not motivated for anything" (B3).

Ecological Systems

Supports and barriers are summarized in Table 2, along with indication of how they align with Bronfenbrenner's theorized ecological systems. Figure 1 displays a visual representation of the supports and barriers at each ecological system level. At the individual, microsystem, and mesosystem levels, there was one support theme (youth interests, positive experiences, and motivation; extracurricular programs; parent connections and awareness) and one barrier theme (youth challenges; service mismatches [overlapped both microsystem and mesosystem]) each, respectively. Only barrier themes aligned at the exosystem and macrosystem levels (limited awareness of resources and difficulty accessing resources, respectively).

Discussion

Our analysis of parent interviews yielded seven themes—three support themes and four barrier themes, which we then mapped onto Bronfenbrenner's Ecological Systems Theory (1979). This allowed us to explore what kinds of individual and contextual factors parents described as supports and barriers. Each of the theory's levels of context surrounding an individual (i.e., microsystem, mesosystem, exosystem, and macrosystem) were evident in the identified themes and provide critical information about the nuanced layers of complexity parents face in their efforts to support autistic youth transitioning into adulthood. Bronfenbrenner's model has been used in other research that examines family involvement in transition planning for youth with disabilities, and proves to be a helpful tool to organize data and frame the discussion of supports and barriers that families encounter in this process (Hirano et al., 2018).

Individual Factors and Implications

In the center of Bronfenbrenner's model is the individual. In the current study, parents reported that characteristics of the child's unique personality, interests, and experiences could be supportive when considering preparation for adulthood. Many parents reported that their child's interests, which were wide-ranging from video game design to acting to welding, were encouraging because they offered hope that the child could perhaps turn that interest into a source of income in the future. In our sample, all parent participants saw at least one strength in their child, which they identified as supportive in preparing for adulthood—these youth strengths were examined more thoroughly in a separate paper (see [Author]). Considering youth interests is a best-practice for transition planning (Test et al., 2014); our findings reinforce the important role parents can play in this process by helping youth to identify their own strengths (Warren et al., 2021). Parents may find it beneficial to spend time facilitating their child's exploration of hobbies and activities in childhood in order to help them develop interests and build skills that may have broader utility in adulthood. This concept was reflected in a recent study by Kersten et al. (2020), wherein mothers of autistic youth provided opportunities for their children to experience diverse social environments in an effort to increase the child's level of comfort and confidence in community mobility.

In addition to positive experiences and strengths, each parent participant also discussed individual-level challenges that made preparing for adulthood more difficult. Some were specifically related to autism characteristics (e.g., social challenges) and others were more broad (e.g., lack of awareness about the “real world”). Perceived lack of interest and motivation—which are theoretically linked with decreased self-determination (Shogren et al., 2015)—were also described by some parents as limiting. Some existing research has demonstrated preliminary evidence for improving youth skills for transition including adaptive behavior and self-determination (Oswald et al., 2018).

While there are opportunities for parents to help create more opportunities to develop skills and experiences (e.g., Kersten et al., 2020), it is likely not supportive of youth mental health to focus all efforts on changing their intrinsic characteristics (Crane et al., 2019). As Anderson and colleagues (2018) described, focusing on behavior change in this population is less productive than focusing on environmental and contextual adjustments.

Contextual Factors and Implications

The *a posteriori* use of Bronfenbrenner’s model in our analysis allowed for particular consideration of what types of systemic levels may offer supports and/or barriers for autistic youth. We found that among the supports and barriers discussed by parent participants, supports were more centrally located in the model (individual, microsystem, and mesosystem levels), while barriers were identified at every level. This suggests that parents understand and take opportunities to maximize supports within their most accessible spheres of influence, but may feel ill-equipped to broach broader systems. While endeavoring to make change at local and family levels is important, enhancing supports within these broader systems—e.g., healthcare and educational policies—is critical to a holistic approach to improving the transition process.

At the microsystem level, participants described extracurricular activities as supportive of preparing for the transition to adulthood because they offered opportunities to socialize and learn important skills. Some of the programs described by parents were disability-specific (e.g., a 3D modeling program for neurodiverse youth, an adaptive theatre program for people with disabilities) while others were not (e.g., Boy Scouts, digital media camps). Prior research has demonstrated that social isolation can be common, as autistic youth have low rates of participation in social and recreational activities, except when it comes to disability-focused programs (Shattuck et al., 2011). In the current study, parents expressed that both disability-focused and general programming were useful for youth and acted as supports for transition. Wehman et al. (2014) indicate that participation in programming outside the home can promote youth self-determination, which is a critical quality for youth to develop in preparation for transition to adulthood.

Therefore, both disability-focused and general programming should be made accessible to autistic youth—including enhancing financial accessibility as well as ensuring a socially supportive environment that can accommodate their unique needs. Just as efforts are being made to educate workplace staff and employers (e.g., Scott et al., 2020), education efforts focused on extracurricular programming for youth may also enhance transition success.

Issues related to service access, awareness, and appropriateness were identified at multiple system levels. At the microsystem and mesosystem levels, parent participants described significant mismatches in the types of services available versus the types of services their child needed. In particular, many described that their child was not viewed as having severe enough problems to warrant access to services, or if they did receive services, their unique needs would not be addressed. This concept aligns with existing literature demonstrating that autistic youth without intellectual disability can fall through cracks in the service system (Hedges et al., 2014; Taylor & Seltzer, 2011) and reinforces the need for autism-specific services and supports that can benefit autistic youth with a wider range of needs.

Notable barriers at the exosystem and macrosystem levels related to parents' limited awareness of resources, as well as difficulty accessing resources. These findings align with those in multiple research studies, particularly Hirano and colleagues' (2018) metasynthesis of transition barriers for youth with various disabilities based on the perspective of parents. Additionally, Taylor and Henninger (2015) reported numerous issues with service access for autistic youth, including not receiving services that were needed, lack of availability (including geographic and financial accessibility), denied eligibility, and poor quality of services. Thomas et al. (2007) found that access to resources and services was limited for certain groups, including those living in non-metropolitan areas. They also found that increased income correlated to increased use of some services (Thomas et al., 2007). Further, studies have demonstrated that low-income and minority autistic youth have less independence in post-secondary outcomes (e.g., Chiang et al., 2013; Roux et al., 2013). Recognizing and ameliorating these access barriers is critical for reducing disparities.

One identified benefit related to services was parents' own connections and awareness—specifically, some parents felt they had privilege in the transition process because of their social and/or professional connections. While this emerged as a benefit in the present analysis, it is clear that it would conversely be a barrier for many other families—including families not included in this analysis. Some preliminary intervention programs support improving parent awareness of available services (e.g., DaWalt et al., 2018; Taylor et al., 2017); these types of programs hold promise for improving individual family access. However, it is apparent that there are tremendous hurdles in awareness and access that need to be eliminated at a systemic level in order to promote equitable service access for autistic youth from a variety of backgrounds.

These results point explicitly to the need for policy improvements and funding streams to support autistic youth. While government-sponsored resources have provided opportunities for greater access to services for families of younger autistic children (e.g., early intervention and school-based services), as the child enters their adolescent and young adult years, the relevant services and resources available for autistic youth are extremely limited (Howlin & Moss, 2012). Federal and state governments are best positioned in the U.S. to support services for all autistic youth; however financial and policy supports at the macrosystem level must permeate through the other system levels to support cross-system integration. For example, to be effective, funding for services from the federal and state level must be actualized through evidence-based programs run by appropriately trained service providers at the local level. Currently, programming varies greatly in different states. An

analysis of 2016 reports revealed that only ten U.S. states had comprehensive plans for improving employment for autistic adults (Roux et al., 2019). Future research would benefit from utilizing an implementation science approach for effective translation of research findings into policy improvements (e.g., Ruble et al., 2018; Snell-Rood et al., 2020).

Limitations

Although parents expressed widely varying goals for youth and were recruited from two different U.S. states, there was restricted diversity in the sample. In particular, the racial and ethnic diversity of the study participants does not reflect the broader population. Furthermore, we specifically recruited youth anticipating a high school diploma in two of the studies and required youth to participate in a verbal interview. Therefore, supports and barriers specific to autistic youth with more significant needs, those anticipating a completion certificate, and those with limited speaking ability, are not reflected in this paper. Another limitation is that, due to our analysis being completed after interviews were conducted, the interviews did not specifically include questions about supports and barriers, nor were aspects of Bronfenbrenner's model probed during interviews. Thus, there may be information relevant to this analysis that parent participants would have added had they been directly asked.

Furthermore, it is important to acknowledge that while some parents discussed supports and/or barriers that they had previously or were currently experiencing, others discussed anticipated supports and/or barriers. Therefore, the perceptions of parents included both past, present, and potentially future supports and/or barriers, which should be taken into consideration when interpreting the findings.

Finally, because the interviews were conducted as part of three distinct studies, slight differences in recruitment and procedures could have affected the findings. In particular, because Study C was an intervention study, these participants may have differed somewhat from the rest of the sample. Specifically, because they enrolled in a program to support transition, they may have been more likely to discuss barriers than supports for the transition process. Despite these limitations, our findings from in-depth qualitative interviews with 39 parents of autistic youth are robust and reveal common themes about their perceptions of supportive and non-supportive factors related to preparing for the transition into adulthood.

Conclusion

The information drawn from this set of parent interviews illustrates how supports and/or barriers for the transition to adulthood exist within multiple contextual levels for autistic youth. For autistic youth on the cusp of adulthood, parents expressed that obstacles to a successful transition existed for the adolescents as individuals; within their family, school, and peer groups; and within their wider sociocultural contexts. However, they also identified supportive factors at multiple levels and recognized opportunities to optimize them. In order to facilitate a successful transition to adulthood, it is important for legislators, professionals, and other stakeholders in healthcare, educational, and community settings to better understand and integrate parent perceptions into services to minimize the barriers and maximize the supports in each of these systems.

Declarations:

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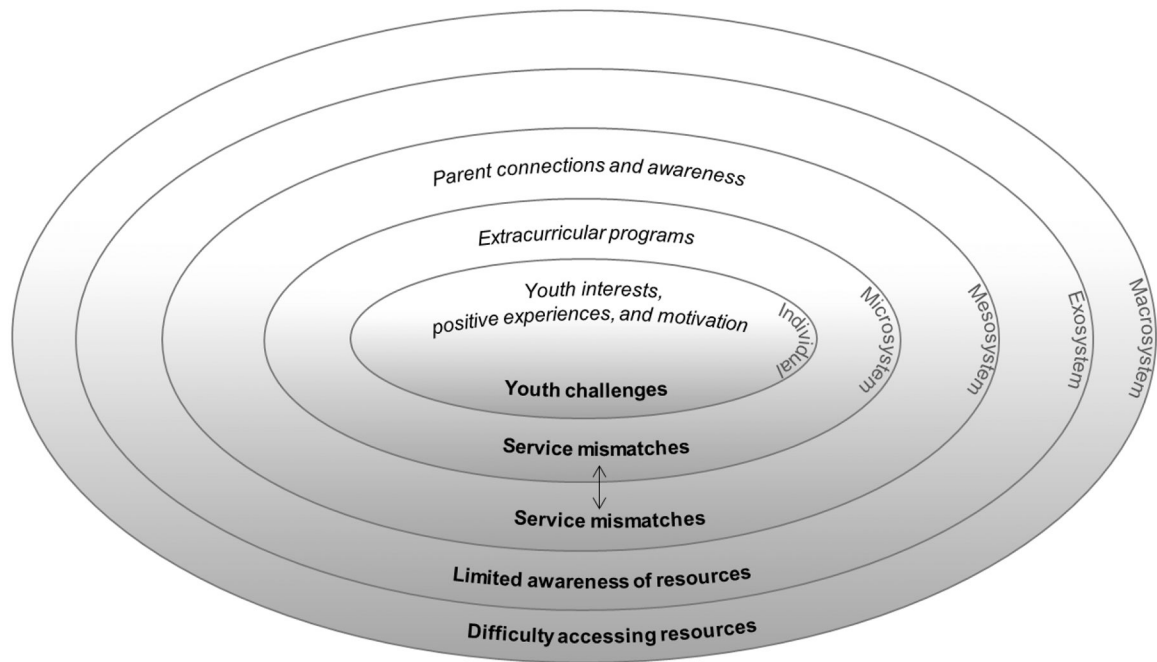


Figure 1. Thematic Results Mapped onto Bronfenbrenner’s Ecological Systems Theory
Note. This visual representation is based upon Bronfenbrenner’s (1994) Ecological Systems Theory, with our thematic results displayed within the respective ecological system levels (labeled on the right side of the figure). Themes identified as supports are displayed in the top half of the figure in italic lettering, and themes identified as barriers are displayed in the bottom half of the figure in bold lettering.

Table 1

Demographic Information about Parent Participants and Youth, specified by study

	Study A	Study B	Study C
Parent sample size	<i>N</i> = 7	<i>N</i> = 14	<i>N</i> = 18
Parent/caregiver sex/gender ^a : female <i>N</i> (%)	7 (100%)	13 (93%)	17 (94%)
Parent age <i>M</i> (<i>SD</i>)	49.9 (6.0)	46.4 (5.2)	43.4 (5.2)
Parent ethnicity: Hispanic <i>N</i> (%)	0 (0%)	0 (0%)	1 (6%)
Parent race: <i>N</i> (%)			
Black/African American	2 (29%)	0 (0%)	0 (0%)
White/Caucasian	5 (71%)	14 (100%)	18 (100%)
Other	0 (0%)	0	0 (0%)
Annual household income: <i>N</i> (%)			
<\$30,000	2 (29%)	1 (7%)	1 (6%)
\$30,000 - \$79,999	3 (43%)	2 (14%)	10 (56%)
\$80,000 - \$149,999		7 (50%)	4 (22%)
\$150,000	2 (29%) ^a	4 (29%)	3 (17%)
Youth sample size	<i>N</i> = 8	<i>N</i> = 15	<i>N</i> = 18
Youth sex/gender ^a : male <i>N</i> (%)	7 (88%)	14 (93%)	15 (83%)
Youth age in years: <i>M</i> (<i>SD</i>)	15.6 (1.7)	15.5 (0.9)	15.7 (1.3)
Youth ethnicity: Hispanic <i>N</i> (%)	0 (0%)	2 (13%)	2 (11%)
Youth race: <i>N</i> (%)			
Black/African American	4 (50%)	0 (0%)	0 (0%)
White/Caucasian	4 (50%)	15 (100%)	17 (94%)
Other	0 (0%)	0 (0%)	1 (6%)
Youth autism severity			
Within normal limits	0 (0%)	4 (27%)	0 (0%)
Mild	4 (50%) ^b	4 (27%)	2 (11%)
Moderate		5 (33%)	3 (17%)
Severe	4 (50%)	2 (13%)	13 (72%)

Note. Data from three studies were combined for the current analysis. Some data was unavailable due to variations in data collection across studies:

^a the demographics form for Study A inquired about “sex” for youth and parents; Studies B and C inquired about “gender” and provided an “other” option with space to self-describe, though no parent participants selected that gender option for themselves or their child.

^b only three income categories were presented in Study A;

^c the first edition of the Social Responsiveness Scale (used in Study A) only distinguishes three severity categories (mild and moderate are combined).

Table 2

Summary of Qualitative Themes

Theme	Examples	System Level*
Supports		
Youth interests, positive experiences, and motivation	Youth interests in areas such as animals, computers, theatre, writing; youth positive experiences and receipt of positive feedback about their skills; youth excitement about aspects of adulthood	Individual
Parent connections and awareness	Parents who work at universities and know the system; parents work in school system and understand transition process; parents connected to local organizations; parents observing other autistic people or with other disabilities being successful adults	Mesosystem
Extracurricular programs	Youth participation in activities that parents feel can build useful skills for employment, socialization, or other life skills, such as scouts, band, sports, and some autism- or disability-specific groups	Microsystem
<u>Barriers</u>		
Limited awareness of resources	Lack of awareness and understanding of available resources, including those provided at the state level	Exosystem
Difficulty accessing resources	Living in rural settings with limited access to programming that exists; financial barriers to accessing services	Macrosystem
Service mismatches	Systems in place but not all involved parties know how to implement them; services targeting only those with more severe disabilities; services not addressing the areas of greatest need	Microsystem, Mesosystem
Youth challenges	Youth not engaged in planning for their own future; emotional, behavioral, and motivational challenges; unrealistic expectations	Individual

Notes.

* System Level refers to ecological systems as defined by Bronfenbrenner (1994).