

Barriers to Receipt of Services for Young Adults With Autism

Connie Anderson, PhD,^a Alexis Lupfer, MA,^a Paul T. Shattuck, PhD^b

abstract

OBJECTIVES: In this study, we examine experiences of families of young adults (YAs) on the autism spectrum to better understand dynamics leading to poor YA outcomes.

METHODS: Twenty parents of YAs with autism spectrum disorder (ASD) who had completed high school in the past 15 years took part in a 90-minute interview. They described their YA's experiences at the transition from high school and current status with regards to services or postsecondary education. Qualitative interviews were digitally recorded, transcribed, and analyzed by using the constant comparative method associated with a grounded theory approach.

RESULTS: Few adults with ASD were receiving autism-specific assistance no matter their level of cognitive functioning. Existing systems, such as service agencies and college disability support offices, had seldom been designed to meet their needs. Some families gave up on services, some used self-directed services they had to manage themselves, and others paid out of pocket for services they could access no other way. Inadequate services often led to YA failure and worsening of symptoms. The majority of families bore the financial and emotional brunt of finding or creating services and community experiences to meet their adult child's needs.

CONCLUSIONS: Parent narratives highlight the difficulties that are faced as families attempt to access appropriate services for YAs on the autism spectrum at all levels of functioning. These insights can help pediatricians understand family concerns and develop anticipatory guidance strategies. More research is needed to identify potential solutions to challenges faced by specific subgroups of YAs with ASD.

^aDepartment of Interprofessional Health Studies, Towson University, Towson, Maryland; and ^bA.J. Drexel Autism Institute, Philadelphia, Pennsylvania

Dr Anderson conceptualized and designed the study, conducted research interviews, contributed to analysis and interpretation of the data, and drafted the initial manuscript; Ms Lupfer contributed to analysis and interpretation of the data; Dr Shattuck contributed to interpretation of the data and critically reviewed the manuscript; and all authors approved the final manuscript as submitted.

DOI: <https://doi.org/10.1542/peds.2016-4300G>

Accepted for publication Sep 26, 2017

Address correspondence to Connie Anderson, PhD, College of Health Professions – Dean's Office, Towson University, 8000 York Rd, Towson, MD 21252. E-mail: connieanderson@towson.edu

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

Copyright © 2018 by the American Academy of Pediatrics

FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

FUNDING: Funded by the College of Health Professions, Towson University, and the A.J. Drexel Autism Institute.

POTENTIAL CONFLICT OF INTEREST: The authors have indicated they have no potential conflicts of interest to disclose.

Autism spectrum disorder (ASD) is a neurodevelopmental condition involving social-communication deficits and restricted, repetitive behaviors, activities, and interests.¹ In recent years, the reported prevalence of ASD in the United States has continued to grow, likely due in part to a broadening of the disorder's definition and increased awareness.² This growing population of children diagnosed with ASD is approaching adulthood. After exiting high school, they lose entitled special education services and enter a less secure adult landscape where supports and services are fewer and harder to access. Each state has a different array of adult programs and agencies that families and their adult children must learn to navigate.

Research on young adults (YAs) with ASD paints a fairly dismal picture, describing limited services,³ restricted inclusion in community activities,⁴ and a decreased likelihood of living independently compared with YAs with learning, intellectual, or emotional disabilities.⁵ Participation in education and employment appears to be similarly limited. Over 50% of youth had no participation in either employment or education during the first 2 years after high school.⁶ Other evidence suggests there is a decline in the level of vocational and educational engagement over time, not just a temporary disruption at transition.⁷ The authors of these studies, many using national survey data, have successfully described the prevalence of poor outcomes.⁸ However, we still do not know why so many YAs with ASD remain disconnected after high school or what impact co-occurring physical and mental health conditions may have.

Our objective in this qualitative study is to better understand what processes lead to poor postsecondary outcomes for YAs with ASD as well as to begin to discern how these may differ by presentation of ASD (eg,

cognitive functioning, behavioral-psychiatric issues, degree of social impairment).

METHODS

This study was reviewed and approved by the Towson University Institutional Review Board. Qualitative research methods are ideal for exploring the life circumstances of a group of people whose situation is not well understood.^{9,10} We therefore invited families to tell us their stories and then explored these to inductively discover distinct categories of experience and how these relate to variability in YA outcomes.

Participants and Setting

We interviewed 20 parents of YAs with ASD. Our recruitment entailed sending study information to autism advocates and organizations as well as personal contacts of the first author throughout Maryland and the District of Columbia. To participate, a person had to be a fluent speaker of English and the parent of a YA with ASD who had left high school in the past 15 years. The YA could have been either "certificate" or "diploma" bound in high school. Those on a certificate track (intended for students with intellectual disability [ID]) had usually left school at approximately age 21, whereas those on a diploma track had usually left at approximately age 18.

Qualitative Interviews

Because looking back at their "autism journey" had the potential to evoke strong emotions, interviews were conducted in a private space, usually at the participant's home. Parents also completed a questionnaire providing basic information on family demographics as well as their YA's diagnosis, high school setting, and current services. To avoid unwittingly narrowing the scope of

a family's story, interview questions were open-ended. For example: "What were you going through as your son/daughter approached the end of high school? What happened afterward?" Most parents needed little prompting to tell their story, speaking with passion for an average of 90 minutes. Interviews were recorded and transcribed.

Data Analysis

Demographic, diagnostic, and other data from the questionnaire are summarized in Table 1. Textual data were analyzed by using Atlas.ti qualitative analysis software. We employed a grounded theory approach to inductively identify categories of experience reflecting YA and family life circumstances.^{11,12} The related constant comparative method involved coding data in several stages as the research team identified similarities and differences in outcomes, beliefs, meaning, and other factors within and across groups of participants.^{11,13,14} Once major themes were identified, the first 2 authors independently coded each transcript, discussing and reconciling any discrepant codes and analyzing any negative cases (ie, those that did not fit emerging themes). Considering the small number of interviews, and the diversity of the sample, even experiences that were not reported frequently were considered if they were salient, that is, potentially crucial to understanding the questions at hand.¹⁵ Saturation, the point at which concepts have been richly developed and no new themes are emerging, was achieved for this overview of outcomes.¹¹

Investigator triangulation was achieved by initial separate analysis of data by 2 team members with contrasting professional backgrounds. Confidence in findings based on family interviews was further enhanced by peer debriefing as well as confirmatory feedback from community members and

TABLE 1 Characteristics of YAs With ASD and Their Families

Characteristics	Families Interviewed (n = 20)
Interviewee: mother versus couple	
Mother only, n (%)	17 (85)
Maternal age, mean (SD)	55.4 (4.8)
Family income (\$), n (%)	
25 000–49 999	2 (10)
50 000–74 999	1 (5)
75 000–99 999	1 (5)
100 000–149 999	6 (30)
150 000 or more	10 (50)
YA age, mean (SD)	24.0 (3.5)
Sex: male, n (%)	15 (75)
Race: white, n (%)	18 (90)
Ethnicity: non-Hispanic, n (%)	20 (100)
Current ASD diagnosis, n (%)	
Autism	7 (35)
Asperger's	6 (30)
PDD-NOS	3 (15)
Other ASD	4 (20)
Age at ASD diagnosis, n (%)	
0–3.99 y	10 (50)
4–7.99 y	3 (15)
8 or older	7 (35)
Intellectually disabled, n (%)	8 (40)
High school track: certificate versus diploma	
Certificate, n (%)	7 (35)

PDD-NOS, pervasive developmental disorder-not otherwise specified.

professionals at conferences and presentations.¹⁶

RESULTS

Parents' accounts often encompassed their entire "autism journey," from a child's diagnosis through the school years and into adulthood. Our focus will be on the transition from high school and the 2 systems families most often discussed in connection with this: public agencies and institutions of postsecondary education. Major topics, themes, and subthemes drawn from the families' accounts appear in Table 2.

Note: All names have been changed to protect participants' privacy.

A Jarring Transition

Whether the relationship with the school system had been collaborative or adversarial, parents described the shock that came with the abrupt end of the daily engagement and built-in community associated with attending secondary school. Said the mother of 30-year-old Kyle:

You walk outside the public school system, you hear the doors slam behind you. They are iron, steel doors. They are not letting you in. That money's over. And you're in a world of like: What just happened?

The transition process itself was often depicted as overwhelming. Parents rarely felt they had been adequately prepared for the world of disjointed services that awaited them. Twenty-two-year-old Tommy's mother declared:

I watch transition specialists [who work for the school district], because I go to lots of IEP [Individualized Education Plan] meetings, who walk in and hand the parent a folder and it is full of just a whole bunch of flyers and paperwork and information from 95 different agencies. And the parents are like: What do I do with this?

Most state and federal programs for adults with disabilities do not begin until age 21. Those who left school before 21 faced the most glaring gaps. One mother with a son who had both ASD and severe mental health issues lamented the deterioration of his condition after high school and the fact that he was not alone in this:

We have a boatload of kids who graduate with a diploma before the age of 21 or even leave with a certificate before the age of 21. And they really, really need to have... services then and they do not. And it just kills me. Because like I said, that gap year was, we had gotten him back together and then he broke again... How many times can Humpty Dumpty fall off the wall?

Services: Access and Appropriateness

Two major themes emerged surrounding adult services: difficulty accessing such services and the fact that programs were often inappropriate; they were a bad match for the needs of a young person and their family.

Access Issues

Applying for services was a major undertaking. Once funding was received through a screening agency such as Maryland's Developmental Disability Administration, parents had to find one of dozens of service-providing agencies that was both a good match for their adult child and willing to take them. A few fortunate families found a competent agency that met their requirements. Jennifer's mother found one with just the right mix of employment- and enrichment-based activities:

What they do fits with what my daughter needs. Some of the agencies it is an either/or. You are either thrown out to the work force with a little bit of support and they do not have much of a day program. Or you are in a day program where you sit around most of the day; it is glorified babysitting. Well, neither one of those fits this agency.

Not all were as lucky. Those with higher IQs rarely qualified for services despite the significant challenges they faced, whereas those with medical issues or troublesome behavior (eg, meltdowns, aggression, elopement) qualified but were difficult to place. Four families opted for self-directed services (a program that permits families to use state-provided funds at their discretion for services of their choosing). It is a double-edged sword, providing freedom to

TABLE 2 Topics, Themes, and Subthemes Identified Through Family Interviews

Major Topic	Theme	Subtheme
Services	Access issues	<ul style="list-style-type: none"> ● Overwhelming number of systems ● Arcane rules and/or limited information ● Hard to qualify ● Limited providers, wait lists, gaps, and/or YA not wanted ● Lack of transportation ● Expensive and/or self-pay when waiting or not qualified ● Intake process not ASD-friendly
	Program issues	<ul style="list-style-type: none"> ● Underfunded and/or lack of capacity ● Bureaucracy (mountains of paperwork, procedures) ● Square peg in a round hole; programs not ASD-friendly ● Formal goals unmet; little accountability ● Families have to educate and/or take over (from agencies) <ul style="list-style-type: none"> ● Self-directed services
	Staff issues	<ul style="list-style-type: none"> ● Low pay and/or high turnover ● Untrained and/or lack ASD knowledge ● Incompetence <ul style="list-style-type: none"> ● Not meeting YA's goals ● Not in tune with YA's needs ● General (losing paperwork, missing deadlines, ignoring calls)
College	Student not ready	<ul style="list-style-type: none"> ● "Fantasy" of college and/or being in sync with peers ● School, parents, YA ● Place to belong, be engaged when not ready for work or the real world and services don't exist ● Socially-emotionally behind peers ● Unrealistic plans ● EF poor or difficulty dealing with lack of structure ● Trouble self-advocating, asking for help
	College not ready	<ul style="list-style-type: none"> ● Disability Support not specifically equipped for ASD ● Typical services (note takers, extra time on tests) insufficient ● Don't address social, EF, and other issues ● Can only help if alerted (and YA may not alert until crisis point)
	Social difficulties	<ul style="list-style-type: none"> ● Social deficits associated with ASD glaring ● Don't fit in with typical peers at college ● Isolation ● Dangerous behavior; vulnerability
	College success factors	<ul style="list-style-type: none"> ● Making progress at own pace; slow growth ● Reduced course load ● Community or small college close to home as stepping stone ● Need for support, scaffolding, practice ● Importance of setting, "quirky" culture, small campus

design the program the family feels is appropriate while placing the full burden of managing it on their shoulders. Twenty-three-year-old Connor's mother chose this after a fruitless search for a service provider:

It's just not worth putting a square peg into a round hole. There were a lot of programs that were not willing to take him because he is considered low-functioning. He has a history of behavior issues. He has seizures. He's a difficult client to take on. So...they were saying, "We don't think we can handle him." And, I'm okay with that, because if you think you can't handle him, you probably can't.

Taking on self-directed services meant cold-calling businesses,

trying to find a small job or volunteer position, as well as advertising for, interviewing, and training people to take a YA out in the community. This left little time for a parent's own pursuits, including paid work.

Individuals with ASD often suffer from co-occurring mental health conditions.¹⁷ Families of YAs with comorbid mental illness encountered a difficult problem. They were batted back and forth between agencies serving the mentally ill or developmentally disabled. Tommy's mother explained the obstacles she

faced trying to get him a qualified therapist through the public system:

So I needed a single provider...with enough knowledge and expertise for a significantly dually diagnosed kid and who takes Medical Assistance. And I cannot tell you how many intakes we went to and after maybe an hour or 2 hours or tons of paperwork, they would go, "Oh yeah. We do not have that expertise. We really cannot do the autism." And I was like could somebody have told me at that initial phone call you cannot do the autism? Because that was 3 hours of our life we are never going to get back. I cannot tell you how many of those intakes I walked away from in tears...

Program and Staff Issues

Families described agencies as chronically underfunded, entrenched bureaucracies that faced many system-wide issues including difficulty keeping qualified staff. These agencies had often evolved to serve people other than those with ASD, and this could lead to a variety of problems. An intake process that was too noisy, crowded, or otherwise demanding could sabotage admission to a program. Likewise, placements that were offered were not always appropriate. The mother of a 21-year-old with ID commented:

It was another huge center with an open room. They did show me a room where they said that they could possibly find him jobs. Again, nobody could give me direct answers...They basically sit in there. Some of them are fine with that. Craig would not be. They had computers in the corners. They have a ton of people in wheelchairs because it is for cerebral palsy. I was concerned about that because of Craig running. Wheelchairs and him do not always mix very well.

Parents of the cognitively able were more likely to engage first with a vocational rehabilitation agency. One mother tried to access employment support services through such an agency for her son Jack, a diploma-holding, history-loving 27-year-old. She was not impressed.

The lady said, "Well, we can find something." So she types in and says, "Here it is: Parks, Wildlife and Fisheries Management." I said, "What does that have to do with history?" and she said,

“There has to be history about fish.” I thought we had gone into the Twilight Zone... We just got so frustrated that we wound up not going back. They were not going to do anything.

Many parents mentioned incompetent staff, citing low pay and lack of training as the reason for high turnover rates. They tied these to an inability to meet the goals set forth in a young person’s Individual Plan (IP) (the adult version of an Individualized Education Plan). Jack’s mother described trying to keep a consistent service coordinator on her son’s case:

The turnover is so bad because they only pay about \$10 to \$15 an hour... We had a woman who had a degree in journalism. There was a guy with a degree in psychology, but he was only there 2 months. Then we had a couple of other people that we only talked to on the phone. Then one gal came out, she was pretty together. I do not know what her background was, but we only had her one month. She wrote a great IP but then the next month another guy came. He had a degree in art...

Postsecondary Education

Ten of the 20 YAs had planned on attending college as high school drew to a close. Most who succeeded at managing college coursework for a semester or more had support beyond that provided by the typical Disability Support Services office found on college campuses; they were living at or near home with parents who were actively involved. If far from home, these students had chosen a smaller campus with a culture accepting of those who are different. Two intertwining themes emerged surrounding those who did less well: students were not always ready for the demands of college, and colleges were not always equipped to provide the support they needed.

There were a number of reasons cognitively able students with ASD encountered difficulties at community or 4-year colleges. These included the social blindness that is at the heart of ASD, a kind of

social-emotional immaturity likely related to the cumulative effects of that blindness, executive functioning (EF) deficits, and anxiety. Matt’s mother explained that his anxiety interfered with his ability to get through the community college placement test:

It took us 2 years to get him willing to take the test... There were all these rules and that would get him so freaked out he literally one time ran screaming down the hall just as he was about to go in the room. He was going “I can’t, I can’t!” arms flailing, running out of the building.

Katie’s mother decided to delay college a year after a cautionary tale from a Disability Support specialist during a campus visit:

She was very shrewd. She told us a story about a young man with Asperger’s who was very brilliant. He was doing wonderfully in all his classes until the last 2 weeks of the semester when he just stopped going to class and didn’t leave his room. And he never came to ask them for help. He went into some kind of depressive funk, and he failed his classes, and he had to drop out...and I could easily see that happening to her, that she could sort of hold it together for a certain amount of time and then the bottom’s just going to fall out.

Sadly, even after the gap year, the bottom did fall out. Katie failed at college even with an expensive, private pay support program in place. Matt, another bright individual who had gone out of state to school, returned depressed and suicidal after struggling in a program that demanded negotiation of complex group dynamics. Said his father:

I went [to visit] and I could tell he was not fitting in. I mean he was there. He knew their names but he had no close friends. By that time in college, I had a lot of close friends. He was struggling mightily with calculus...He does not understand it and I think math is one of the inherent learning disabilities that he has... Just being away, overwhelmed, not a lot of friends, his life dream...was slipping away. And he knew it.

DISCUSSION

In this study, we explore the disheartening realities behind grim national level statistics on outcomes

for YAs across the autism spectrum. Families often feel there was only cursory effort on the part of the public schools to prepare them for transition. Once engaging with post-high school systems, whether an agency running a day program, a vocational rehabilitation service, or a college Disability Support office, they frequently find these were not designed with the complexities of ASD in mind. Young people on the autism spectrum generally have multiple needs no matter their level of cognitive functioning, and when the social blindness and repetitive behaviors of ASD are combined with seizures, aggression, anxiety, EF issues, or other challenges, appropriate support provided by adequately trained people is difficult to secure.

On the basis of the life experience of these 20 families, it appears that only those with ID and the mildest of behaviors easily find suitable services, perhaps because they best fit a preexisting mold or are easier to accommodate. Those who sometimes display aggressive behaviors or meltdowns may not be wanted by service providers, whereas those with co-occurring psychiatric issues may be bounced between mental health and developmental disability agencies. Meanwhile, the academic strengths of the cognitively able mask real deficits that may be ignored by high schools and families alike as they engage in what 1 mother called “a collective fantasy” about going to college with same-aged peers. College sometimes can be navigated successfully but only if the student is at least minimally ready and receives support that goes beyond notetakers and extra time on tests (ie, the services Disability Support Service offices usually provide).

When services and supports are lacking, families bear the burden by worrying, advocating, paying out of pocket for services if they have the funds, managing self-directed

services, and picking up the pieces if it all goes wrong.

The primary limitation of this study is that it was based on a small convenience sample; experiences and opinions reported cannot be presumed to apply to other populations of families with a YA on the autism spectrum. In addition, most participating families were white, 80% had an annual income of >\$100 000, and all came from a limited area. Future researchers addressing this topic should strive to collect representative samples that reflect racial, economic, and geographic diversity.

ABBREVIATIONS

ASD: autism spectrum disorder
EF: executive functioning
ID: intellectual disability
IP: Individual Plan
YA: young adult

REFERENCES

1. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. 5th ed. Arlington, VA: American Psychiatric Publishing; 2013
2. Christensen DL, Baio J, Van Naarden Braun K; Centers for Disease Control and Prevention (CDC), et al. Prevalence and characteristics of autism spectrum disorder among

children aged 8 years—Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2012. *MMWR Surveill Summ*. 2016;65(3):1–23

3. Shattuck PT, Wagner M, Narendorf S, Sterzing P, Hensley M. Post-high school service use among young adults with an autism spectrum disorder. *Arch Pediatr Adolesc Med*. 2011;165(2):141–146
4. Gray KM, Keating CM, Taffe JR, et al. Adult outcomes in autism: community inclusion and living skills. *J Autism Dev Disord*. 2014;44(12):3006–3015
5. Anderson KA, Shattuck PT, Cooper BP, Roux AM, Wagner M. Prevalence and correlates of postsecondary residential status among young adults with an autism spectrum disorder. *Autism*. 2014;18(5):562–570
6. Shattuck PT, Narendorf SC, Cooper B, Sterzing PR, Wagner M, Taylor JL. Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics*. 2012;129(6):1042–1049
7. Taylor JL, Mailick MR. A longitudinal examination of 10-year change in vocational and educational activities for adults with autism spectrum disorders. *Dev Psychol*. 2014;50(3):699–708
8. Roux AM, Shattuck PT, Rast JE, Rava JA, Anderson KA. *National Autism Indicators Report: Transition into Young Adulthood*. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University; 2015
9. Charmaz K. Grounded theory in the 21st century: applications for advancing social justice studies. In: Denzin NK, Lincoln YS, eds. *The Sage Handbook of Qualitative Research*. 3rd ed. Thousand Oaks, CA: Sage Publications; 2005:507–535
10. Morse JM. *Qualitative Health Research: Creating a New Discipline*. 3rd ed. Walnut Creek, CA: Left Coast Press; 2012
11. Corbin J, Strauss A. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. 4th ed. Thousand Oaks, CA: Sage Publications; 2015
12. Glaser BG. Conceptualization: on theory and theorizing using grounded theory. *Int J Qual Methods*. 2002;1(2):23–38
13. Glaser BG. The constant comparative method of qualitative analysis. *Soc Probl*. 1965;12(4):436–445
14. Boeije H. A purposeful approach to the constant comparative method in the analysis of qualitative interviews. *Qual Quant*. 2002;36(4):391–409
15. Buetow S. Thematic analysis and its reconceptualization as ‘saliency analysis’. *J Health Serv Res Policy*. 2010;15(2):123–125
16. Lincoln YS, Guba EG. *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications; 1985
17. Joshi G, Petty C, Wozniak J, et al. The heavy burden of psychiatric comorbidity in youth with autism spectrum disorders: a large comparative study of a psychiatrically referred population. *J Autism Dev Disord*. 2010;40(11):1361–1370

Barriers to Receipt of Services for Young Adults With Autism

Connie Anderson, Alexis Lupfer and Paul T. Shattuck

Pediatrics 2018;141;S300

DOI: 10.1542/peds.2016-4300G

Updated Information & Services

including high resolution figures, can be found at:
http://pediatrics.aappublications.org/content/141/Supplement_4/S300

References

This article cites 11 articles, 1 of which you can access for free at:
http://pediatrics.aappublications.org/content/141/Supplement_4/S300#BIBL

Permissions & Licensing

Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at:
<http://www.aappublications.org/site/misc/Permissions.xhtml>

Reprints

Information about ordering reprints can be found online:
<http://www.aappublications.org/site/misc/reprints.xhtml>

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN®



PEDIATRICS[®]

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Barriers to Receipt of Services for Young Adults With Autism

Connie Anderson, Alexis Lupfer and Paul T. Shattuck

Pediatrics 2018;141;S300

DOI: 10.1542/peds.2016-4300G

The online version of this article, along with updated information and services, is located on the World Wide Web at:

http://pediatrics.aappublications.org/content/141/Supplement_4/S300

Pediatrics is the official journal of the American Academy of Pediatrics. A monthly publication, it has been published continuously since 1948. Pediatrics is owned, published, and trademarked by the American Academy of Pediatrics, 345 Park Avenue, Itasca, Illinois, 60143. Copyright © 2018 by the American Academy of Pediatrics. All rights reserved. Print ISSN: 1073-0397.

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN[®]

