

2018-11-16

# Parents' future visions for their autistic transition-age youth: hopes and expectations

---

Jennifer Chen, Ellen S Cohn, Gael I Orsmond. 2018. "Parents' future visions for their autistic transition-age youth: Hopes and expectations.." *Autism*, pp. 1362361318812141 - ?. <https://doi.org/10.1177/1362361318812141>  
<https://hdl.handle.net/2144/34351>

*"Downloaded from OpenBU. Boston University's institutional repository."*

## Parents' future visions for their autistic transition-age youth: Hopes and expectations

Jennifer Chen, Ellen S. Cohn, & Gael I. Orsmond

Department of Occupational Therapy, Boston University, Boston, MA, USA

**Citation:** Chen, J., Cohn, E.S., & Orsmond, G.I. (2018). Parents' future visions for their autistic transition-age youth: Hopes and expectations. *Autism: The International Journal of Research and Practice*. E-pub ahead of print. doi: 10.1177/1362361318812141

### Abstract

Researchers have documented that young adults with autism spectrum disorder (ASD) have poor outcomes in employment, post-secondary education, social participation, independent living, and community participation. There is a need to further explore contributing factors to such outcomes to better support successful transitions to adulthood. Parents play a critical role in transition planning, and parental expectations appear to impact young adult outcomes for autistic individuals. The aim of this study was to explore how parents express their future visions (i.e., hopes and expectations) for their autistic transition-age youth. Data were collected through focus groups and individual interviews with 18 parents. Parents' hopes and expectations focused on 8 primary domains. Additionally, parents often qualified or tempered their stated hope with expressions of fears, uncertainty, realistic expectations, and the perceived lack of guidance. We discuss our conceptualization of the relations among these themes and implications for service providers and research.

### Keywords

Adolescent, transition, parent, hope, autism

Researchers have documented that individuals with autism spectrum disorder (ASD) have poor adult outcomes in employment (Shattuck et al., 2012), post-secondary education (Shattuck et al., 2012), social participation (Orsmond, Shattuck, Cooper, Sterzing, & Anderson, 2013), independent living (Anderson, Shattuck, Cooper, Roux, & Wagner, 2014), and community participation (Myers, Davis, Stobbe, & Bjornson, 2015). However, the reasons for these poor outcomes are not well understood. Given the likelihood that multiple, complex, and interrelated factors contribute to adult outcomes, researchers and service providers are seeking to better understand the potential factors. Such understandings may be useful to efforts supporting autistic individuals<sup>1</sup> and their families during the transition into adult life.

For autistic youth, parent support is a critical component in the transition to adulthood. Hatfield, Falkmer, Falkmer, and Ciccarelli (2017) interviewed parents of autistic adolescents, and reported that parents felt the transition planning process was their responsibility. Research indicates that once youth exit the school system, parents often search for services, manage service quality and coordination, and seek meaningful activities for their autistic young adults (Smith and Anderson, 2014). Additionally, parents

may assist with daily life tasks and activities (Cheak-Zamora, Teti, & First, 2015).

Several studies show that parental expectations may significantly impact adult outcomes for autistic individuals (Carter, Austin, & Trainor, 2012; Chiang, Cheung, Hickson, Xiang, & Tsai, 2012; Doren, Gau, & Lindstrom, 2012; Kirby, 2016). For example, Carter, Austin, and Trainor (2012) found that parents' expectations during high school regarding students' capacities to obtain employment or to be self-supporting in the future were associated with whether students with severe disabilities, including autism, worked within two years after high school. Similarly, Chiang et al. (2012) reported that parents' post-secondary education expectations prior to transition were a significant predictor of their autistic young adult's participation in post-secondary education. More recently, Kirby (2016) identified that parents' expectations mediated the effect of family background and functional performance on young adults' achievement of several adult outcomes. Kirby's finding highlights the importance of further exploring parental expectations; the association between parental expectations and youth's outcomes appears complex. To explore the relationship between parents' expectations and youth's outcomes, Holmes, Kirby, Strassberg, and Himle (2018) conducted a study regarding potential predictors of

parents' expectations for their autistic adolescent's adult life, as well as whether parents' expectations predicted the family's engagement in certain transition preparation activities. Their findings suggest that youth factors such as ASD severity, IQ, and gender could predict parents' expectations. Additionally, the researchers reported that parents' expectations predicted engagement in some transition preparation activities. For example, parents who expected their adolescent to live independently in the future were more likely to assign their son or daughter chores and other responsibilities.

Existing research on parents' perspectives on the future for their autistic adolescent has largely focused on specific measurable outcomes, such as being employed, having friendships, and living independently (Henninger & Taylor, 2013). However, researchers have noted the importance of investigating parents' perspectives more broadly to understand the range of topics that families identify as important. For instance, Henninger and Taylor (2014) conducted an online survey asking parents of youth with intellectual and/or developmental disabilities to define a successful transition to adulthood. Parents' views of a successful transition were broader than traditionally-measured outcomes (i.e., post-secondary education, employment, independent living, friendship). Parents valued outcomes such as a "constructive relationship with community," "accessibility and transportation," and "psychological well-being" (p. 103). Similarly, Poon, Koh, and Magiati (2013) surveyed parents of youth with ASD, intellectual disability, or multiple disabilities regarding the importance and likelihood of a range of adult outcomes, and found that parents did not rate education, employment, and independent living as the most important; rather, they rated safety and happiness as the most important. Recently, Sosnowy, Silverman, and Shattuck (2018) interviewed parents and autistic young adults about their valued adult outcomes, and reported that achieving traditional outcomes, such as employment and independent living, was important to families, yet such achievements were also perceived as means to other goals, such as social relationships and long-term security.

Although parents may identify certain adult outcomes as important, researchers have found that parents may not expect their adolescent to realistically achieve their desired outcomes. In the study by Poon and colleagues (2013), parents rated the importance of specific outcomes higher than they rated the likelihood of those outcomes. Ivey (2004)

surveyed parents of autistic youth about their desired adult outcomes, and also found that parents rated the importance of outcomes significantly higher than their likelihood. Relatedly, Camarena and Sarigiani (2009) examined parents' educational aspirations for their autistic adolescents, and reported that parents hoped their adolescent would pursue post-secondary education, yet were concerned about the availability of adequate resources in college.

Parents' concerns about their adolescent's future has been a recurrent theme in the literature for autistic youth, and may be related to why parents question the likelihood that their adolescent will achieve the outcomes that they value. In fact, in studying the employment-related expectations, concerns, and priorities of parents of youth with intellectual and developmental disabilities, Blustein, Carter, and McMillan (2016) found a similar gap between parents' perceived importance and likelihood of community employment outcomes, and suggested that parents' concerns may influence the discrepancy. Blacher, Kraemer, and Howell (2010) found that parents of autistic young adults were more worried about the transition to adulthood than were parents of young adults with Down syndrome, cerebral palsy, or other learning disabilities. The heightened concerns of parents of autistic individuals may be impacted by the transition services received by families. For example, Cheak-Zamora, Teti, and First (2015) described that parents of autistic youth were concerned and anxious about the transition to adulthood largely due to the lack of appropriate services to support their adolescent's needs. Shogren and Plotner (2012) found that parents of autistic high school students, compared to parents of students with other disabilities, were least likely to report transition planning as useful.

There is a need to further explore how parents view the future for their autistic youth, particularly during the transition years (i.e., high school). By the time students receiving special education services turn 16, schools are mandated to work with parents to develop transition plans (Individuals with Disabilities Education Improvement Act, 2004). High school can also be the ideal time for families to help adolescents develop life skills and gain knowledge of potential future opportunities and adult services. The current analysis was conducted to investigate how parents of autistic high school students discuss and envision their youth's future in adulthood. Qualitative methods allowed for exploration of nuances and complexities in how parents talked about the transition. The goal

of this analysis was to address two research questions:

1. What adult life domains do parents consider for their autistic adolescent's adult life?
2. How do parents describe their future visions for their autistic adolescent's adult life?

## Method

### *Participants*

Participants in this analysis were a subset of parents who participated in a study of parents of youth with a range of disabilities, which included 25 parents of youth with social, emotional, and cognitive disabilities (e.g., traumatic brain injury, mental health conditions). Eighteen of the 25 participants were parents of autistic youth and were included in this analysis.

*Recruitment.* Participants were purposively recruited through community organizations, clinics, and schools in Massachusetts. For this analysis, we included parents of students (ages 14-22) who were receiving, or in the past had received, special education services under the disability category of autism. Parents were excluded if their student used a wheelchair for mobility, because the transition to adulthood for these youth may have different challenges. Phone screens were conducted to determine eligibility, and Individualized Education Programs were collected to confirm receipt of special education services under autism. Participants completed a written consent form and demographic questionnaire. Parents received a \$10 gift card for participating.

*Sample.* The sample included 16 mothers and two fathers. For one individual interview, both the mother and father participated. The majority of participants self-identified as white and non-Hispanic; one participant identified as Cape-Verdian and one as African-American. Participants' household incomes ranged from \$30,000 to over \$160,000. Youth ranged from 14 to 21 years old ( $M = 17.4$  years old), and included 15 males and two females. Youth were attending both public and private schools (see Table 1). Pseudonyms are used.

### *Data collection*

Six focus groups and three individual interviews were conducted. Individual interviews were conducted for parents who expressed interest but were unable to attend the focus groups. Focus groups and interviews were facilitated by one of the three authors, with an additional researcher to assist, complete field notes, and ensure that the topics in the semi-structured interview protocol were covered. All authors have clinical interview training (occupational therapy or psychology), and have varying levels of experience with qualitative interviewing. Focus groups ranged in size from two to six participants and lasted from 45 minutes to 2 hours. Individual interviews lasted approximately 1 hour. Focus groups were conducted at community agency or organization locations (e.g., autism resource center), and interviews were conducted at participants' homes.

Focus groups and interviews followed the same semi-structured interview protocol, and covered the same topics. Questions were developed by reviewing the literature on parents' perspectives on the transition to adulthood for autistic youth (e.g., Poon, Koh, & Magiati, 2013; Wagner, Newman, Cameto, Javitz, & Valdes, 2012). Parents were asked to discuss: (a) youth's current daily activities and functional living skills; (b) hopes for their youth's future and the skills necessary to achieve their hoped-for outcomes; (c) how they have prepared their youth for adulthood; and (d) their experiences with supports and services provided to address their youth's functional living skills.

### *Data analysis*

The research team for this analysis included a professor with clinical psychology training, an occupational therapy professor, and a doctoral student with occupational therapy training. To establish trustworthiness (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005), the three researchers met regularly to reflect on the data and analysis. We kept an audit trail of all analytic decisions. In this paper, we included verbatim quotes from participants to provide transparency and evidence for our interpretations.

Data analysis was informed by analytic approaches congruent with grounded theory. We used a constant-comparative method of data analysis and multiple levels of coding, including initial coding, focused coding, and axial coding (Charmaz, 2014). Audio recordings of the focus groups and interviews

**Table 1.** Participant Background Information

Parent	Youth	Youth's gender	Youth's Age	Grade	Type of School/Program
Focus Group 1					
Diana	Nick	Male	21	Not graded*	Private school, transition program
Tracy	Lauren	Female	21	Not graded	Private school, transition program
Focus Group 2					
Judy	Robert	Male	17	12 <sup>th</sup>	Public school, substantially separate classroom
Melanie	Adam	Male	20	Not graded	Private residential school for students with developmental disabilities
Jodie	Ben	Male	17	12 <sup>th</sup>	Public school, substantially separate classroom
Focus Group 3					
Evan	Justin	Male	19	12 <sup>th</sup>	Private residential school for students with developmental disabilities
Focus Group 4					
Amy	Lucas	Male	17	12 <sup>th</sup>	Public school, inclusive classroom
Focus Group 5					
Maggie	Matthew	Male	14	8 <sup>th</sup>	Public school, substantially separate classroom
Audrey	Celine	Female	18	11 <sup>th</sup>	Public school, substantially separate classroom
Alison	Andrew	Male	18	12 <sup>th</sup>	Public school, substantially separate classroom
Emily	Nick	Male	20	12 <sup>th</sup>	Public school, life skills program
Focus Group 6					
Christina	Paul	Male	14	9 <sup>th</sup>	Public vocational technical school
Christine	John	Male	16	11 <sup>th</sup>	Public school, general education
Sharon	Kenneth	Male	15	9 <sup>th</sup>	Public school, mostly general education
Individual Interviews					
Sarah	Josh	Male	14	9 <sup>th</sup>	Private school for students with disabilities
Vicky/Mark	Jeffrey	Male	18	12 <sup>th</sup>	Private school, dual enrollment at community college
Kathy	James	Male	17	12 <sup>th</sup>	Public vocational technical school

Note. "Not graded" indicates that the classroom/program is not designated to be at a specific grade level.

were transcribed verbatim by graduate student research assistants. NVivo software was used for data management and analysis.

Transcripts were first coded to identify parents of autistic youth; data from parents of youth with other diagnoses were not included in this analysis. Then, any passage in which parents discussed their perspectives on their son or daughter's future was coded as "hopes and expectations." Each member of the research team independently reviewed data identified as "hopes and expectations," and then compared their initial interpretations of the data. Two initial patterns were apparent to the team: (a) parents' hopes and expectations could be categorized into domains of adult life; and (b) coding "hopes and expectations" was too broad, as hopes were, at times, discussed differently than expectations. We recognized that hopes and expectations may not be synonymous constructs, as parents sometimes described their

desired vision for their son or daughter, and then immediately qualified their statement; we labelled these passages as *qualifying statements*. This observed distinction between hopes and expectations prompted additional coding of hopes and expectations into separate codes. The research team discussed and agreed upon initial operational definitions of all codes, refined throughout data analysis (see Table 2). *Hope* was defined as a "future vision that is desired, positive, and ideal"; *expectation* was defined as "future vision that the parent believes will or could be achieved." These definitions were used to recode the data and further explore why parents' hopes and expectations, upon first impressions, did not seem to align. We then identified additional prominent themes, including parents' discussions of fears, uncertainty, and the lack of guidance or resources. Further exploration of these themes helped guide our understanding of the

qualifying statements and the idea that some parents' hopes may not align with their expectations.

## Results

### *Domains of Adult Life*

To answer the first research question, we identified the life domains that parents discussed when talking about their adolescent's adult future. Eight domains were identified: community mobility, community participation, living situation, peer relationships, personal safety, post-secondary education, self-care, and work. See Table 2 for descriptions and exemplars of the domains.

### *Parents' Description of Future Visions*

*Qualifying statements.* For the second research question, we explored how participants described their future visions for their adolescent's adult life. In doing so, we recognized a pattern among parents' expressions of their hopes. In multiple instances, parents stated their hopes for the future, and then immediately qualified or tempered their statement – often expressing fears, uncertainty, or realistic expectations about the desired outcome. The identification of these qualifying statements prompted the research team to consider that parents may not confidently expect that the adolescent would be able to achieve what parents ideally hoped. Examples of qualifying statements are described below; additional instances are marked by asterisks in Table 2.

For example, when discussing the future for her 16-year-old son, John, Christine stated that she hopes John will find a social group. Immediately, she raised her concern that he may become depressed if he does not develop connections with others.

...I am hoping that he will find his niche with other people. He really needs to connect with other people. Otherwise, honestly, I could see John, he becomes extremely depressed. I worry about him. He doesn't just have autism, he's got all kinds of complex things going on, and that's my worry is that as an adult, how's he gonna do it?... I worry about that...

Similarly, Vicky stated that she hopes her 18-year-old son, Jeffrey, will be happy in the future, and explained what "happy" meant to her. But then Vicky shifted to expressing her fear that Jeffrey will assume

an adult role based on a cultural stereotype of autistic adults.

I just hope that, in the end, I want him to be happy. And happy is... he needs to have a job that he enjoys, and that he makes enough money that he can enjoy himself. And that's all I care... My fear is I don't want him to be living at home, working at [a grocery store] for the rest of his life. That's what I fear. There is that stigma of Asperger's or autistic adults just huddling up and playing video games and then going into their menial-task job and that's it. And that's what I fear.

Vicky's example was powerful in illustrating the influence of socially-constructed images of autistic adults on her thoughts about the future. Kathy, mother of 17-year-old James, discussed her concern that also appears to be influenced by an external factor – employers' perspectives on autistic employees. In response to a question about hopes for James' future in the next five years, Kathy shared:

I'd like him to get a job that he likes... and that he'll be able to support himself... Because he's at [a bank] now and he likes it. And he's real proud of that... he has to do a weekly report to the school of what he does. And every day on the report it was "move boxes, enter data, file." Every day... I brought it up with the teacher and she said, "No that's not the only thing he does. He does other things." But in the back of my mind, I'm thinking, it could be the only thing he does. And that's what I worry about with his job – is he going have a low-paying job just because they don't want to give him more? Or he can't do more? Or he doesn't have the skills to do more than one thing at a time?

While Vicky feared the potential of her son conforming to a negative stereotype of autistic adults, Kathy worried about the influence of how others will view and treat her son, rather than her son's individual capabilities.

Unlike the previous examples in which parents expressed their hopes and immediately qualified their hopes with fears, Amy described her desire for her 17-year-old son, Lucas, to attend college, but tempered her hope with a statement of uncertainty.

**Table 2.** Operational definitions and exemplars.

Code & Definition	Example
Future visions	
<i>Expectation:</i> Future vision that the parent believes will or could be achieved; includes expectation that an outcome will not occur	<i>I foresee him, because of his rigidity and because how much he likes rules and how things should be perfect, I think he would do well in some niche. He's very good with computers. (Amy)</i>
<i>Hope:</i> Future vision that is desired, positive, and ideal	<i>I suspect my son will be living with me in five years. What I would say, in ten years, I'd like to see him not. Because he wants to. He doesn't want to live with me for the rest of his life. (Jodie)</i>
Domains	
<i>Community Mobility:</i> Ability to access and navigate the community, through public or private transportation	<i>But my hope for next year will be that he'll have learned how to drive, will get some way, shape, or form an access to a car, and that he can transport himself to and from [school] and/or work, and/or community college... (Vicky)</i>
<i>Community Participation:</i> Engagement in the community; includes community-based activities and social interaction with individuals/groups in the community	<i>So that's one of the goals we're having actually right now at school... helping him learn how to interact with... the cashier at the store... they practiced beforehand how to make small talk while paying for your item instead of just looking at the floor or something... Those are really important things that I want him to get used to. (Sarah)</i>
<i>Living Situation:</i> Where the youth will live in the future	<i>Robert isn't ready to live away yet, but that is our goal. The plan is for him to be able to go and participate someplace where he can gain the independence that he needs in order to be as independent as possible. (Judy)</i>
<i>Peer Relationships:</i> Friendships; relationships with peer groups	<i>My vision for him in five years is that he has a best friend. Honestly. That's my vision for him. I think if he didn't go to college or anything else, for [my son] to have a best friend would be amazing. (Christine)</i>
<i>Personal Safety:</i> Safety from physical or emotional harm; ability to avoid, prevent, and/or adequately respond to hazardous situations and environments	<i>I would pretty much say that if you ask any parent, safety's going to be first. More so than folding the laundry, safety. My son has absolutely no sense at all. (Melanie)</i>
<i>Post-Secondary Education:</i> Enrollment in college- or university-level courses	<i>*Five years, graduate high school... definitely graduate, he wants to graduate when he's a senior. And then maybe take some college courses and work part-time... I don't think he could ever go to college independently full-time, like go live in a dorm. So get him into some type of, you know, supported college. He wants to get his college degree. (Sharon)</i>
<i>Self-Care:</i> Taking care of oneself, including physical health (e.g., maintaining diet/medications), emotional well-being (e.g., happiness), and life skills (e.g., cooking, brushing teeth)	<i>*...One of the things that's really important for us too is...health and well-being... being physical, going to the gym, doing what everyone else does to stay healthy. Because he has a very limited diet, and again that makes it very hard for him to live on his own because if you only eat peanut butter sandwiches... I mean you can survive! But that's not healthy. (Jodie)</i>
<i>Work:</i> Commitment to work; paid or unpaid; part-time, full-time, or temporary; volunteering, internships, or vocational training	<i>*That would be my number one goal – to have Lauren have some kind of meaningful work. I really don't know what that will look like in five years or how capable she'll be. She's got a long way to go, working at a [pet store], or being a pet groomer, having her own pet-sitting business, something like that, is probably my number one goal. (Tracy)</i>

Note. Quotes marked with an asterisk (\*) are also examples of “qualifying statements.”

I want post-secondary [education]. But if he can't drive, and he might not... I didn't know how well he would do in a college setting... I figured he needed to know public transportation... as an option as well. So all of those things and just navigating the community and being safe... my goal is for him to continue to practice to drive – he's in driving school – to see if that will give him an avenue of independence.

Examples such as Amy's led us to examine uncertainty in greater detail. We then developed a proposition that parents' uncertainty about the future may limit or shape the way that parents discussed their future visions, in particular their hopes.

*Uncertainty and the lack of a roadmap.* We questioned why the qualifying statements occurred, and hypothesized that the repeated occurrences reflected important underlying experiences and

perspectives of the parents. Accordingly, we identified two recurrent and likely related themes across the data set: (a) parents were uncertain about their adolescent's future; and (b) parents felt that they did not have guidance – in their words, a “roadmap” – to prepare their adolescent for life after high school.

*Uncertainty.* Parents often expressed uncertainty about how to envision their youth's future. Returning to Amy's hope that her son Lucas will attend college, she elaborated on her uncertainty about his ability to manage college life:

It's hard to know what he's going to need... because high school is so...there's a teacher and their co-taught teacher and... they're driven by these standards ... I feel like they want to see them finish. They want to see them get through, whereas in college it's independently you have to get through like, “You didn't do your assignment... I don't care... there's your grade point average.”... I don't know if we're ready for him to live away... I can't imagine what life is like post-secondary...Being able to get up in the morning, what do you have to do? How do you - where do you have to go? How do you get there?

Amy expressed uncertainty about how her son would navigate new contexts and the demands of college, which seemingly influenced her ability to confidently picture her son's success in a college setting. Later during the focus group, Amy further expressed her concern:

He struggles with the outside-of-the-box thinking... But how will that play out in a real world?... I'm nervous how this will play out in real life. I can foresee how it plays out where he walks downtown... and he had a light to walk but an emergency vehicle came... And he thought... “No, I have the right to walk.” So it's those things in life...

*Lack of a roadmap.* Parents also felt they did not have guidance in preparing their adolescent for the future. Parents often described experiences of not knowing how to search for resources, programs, and services, as well as lacking assistance in navigating the multiple service systems (e.g., government, education). We posited that the lack of guidance may lead to even greater uncertainty about the future.

Christine explained that the constant occurrence of new challenges in high school

increased ambiguity and altered her “roadmap” for the future, thus revealing the fragility of her vision for the future.

You don't have a roadmap and your map changes constantly... You thought everything was great a year ago, and then, it's just extremely difficult. I think my fear for [my son] is that he is so high functioning. Who's going to check in with you after college? Unless you continually go to school the rest of your life. How's life going to be? What's life going to do? He will mature. But I don't know what, I don't know what [his] future looks like... I don't know in five years.

In addition to a constantly changing roadmap, parents described the challenges associated with seeking services and resources to help them plan for the future. For example, Alison, the mother of a high school senior, explained: “No one tells you anything. Mostly everything I've ever found out is from another parent. How I found every service that he's ever got.” Similarly, Evan, the father of a 19-year-old male at a residential school, explained how he felt alone in preparing his son for the future:

As a parent you're totally on your own. I don't know if there are people you can hire and do this, but I don't know, I haven't come across anybody. It seems like parents have to do this for themselves.

Jodie, mother of 17-year-old high school senior Ben, explained that although she was in contact with other parents of autistic youth through a support network, her son's unique characteristics and needs still prompted her to “reinvent the wheel”:

What's really so difficult is what your daughter's needs and my son's are so different, you can't just clump them and say, “Okay we're doing this”... I have to reinvent the wheel after [another parent has] reinvented the wheel and you're reinventing it and you are... there's no big group saying, “Okay this is the next step!” It's just, we're all making it up as we go along and there's no overall resource. We need a guide because we're going to be guiding our children.

Parents appeared frustrated by having to continuously search for transition-related support, and these experiences appeared to alter what parents expected of their son or daughter's future. Not having reliable resources to help navigate the complex

transition may have posed difficulties for parents to piece together fragmented information and experiences to compose both a realistic and desired expectation for the future.

## Discussion

The current analysis provides insight into the experiences and perspectives of parents preparing their autistic transition-age youth for adulthood. Specifically, the findings show the delicate intertwining of parents' experiences with how they envision the future. Ultimately, the goal of transition planning is to support families' desired outcomes (i.e., hopes); yet, this analysis suggests that parents' hopes may be greatly confounded by fears, uncertainty, realistic expectations, and lack of guidance. Thus, acknowledgement of parents' multi-faceted experiences, both in research and service provision, may help guide families toward both desired and realistic visions.

Other researchers and theorists have sought to understand expectations of outcomes in important life areas. For example, Wigfield and Eccles (2000) developed the expectancy-value theory of achievement motivation. This theory proposes that expectations and subjective values regarding certain tasks or outcomes are directly related to the decisions to pursue outcomes, persistence and effort toward outcomes, and actual performance. The theory also posits that past experiences contribute to the development of an individual's expectations and values. Parsons, Adler, and Kaczala (1982) applied expectancy-value theory in a study of parents of typically-developing children and adolescents, and reported that parents' expectations and beliefs influenced their children's own expectations and self-concepts.

In applying expectancy-value theory to the findings from the current analysis, the eight domains of parents' future visions can be understood as parents' valued areas in transition preparation. The categorization of hopes and expectations into the eight wide-ranging domains aligns with previous findings suggesting that parents of autistic transition-age youth have broader considerations and priorities than the measures typically used in conceptualizing "successful outcomes" (e.g., presence of work, friendships) (Henninger & Taylor, 2014; Poon et al., 2013). Accordingly, service providers may seek to discuss and address these broader domains with families, in addition to traditional outcomes.

Parents' qualifying statements illustrated how parents oscillated among their hopes, expectations, fears, and uncertainty as they expressed their future visions. Again, the expectancy-value theory may be used to understand how parents' uncertain hopes might influence their decisions and efforts during transition planning. If parents do not expect their youth to achieve their desired outcomes, they may envision a transition plan focused on realistic expectations as opposed to their ultimate hopes. In this case – for example when crafting a "vision statement" for the youth's school transition plan – the team may encourage parents to identify both their ideal hopes and realistic expectations, as well as acknowledge associated fears, uncertainties, and support needs. Then, parents may be able to identify desirable goals that they also perceive as achievable, which can then provide guiding points for transition planning decisions and efforts.

Parents' discussions of the lack of clear guidance also has implications for decisions and efforts during the transition process. We hypothesized that the lack of a roadmap could influence parents' abilities to clearly and confidently imagine or state their hopeful visions. Relatedly, in interviewing parents and school personnel of autistic youth, Hatfield and colleagues (2017, 2018) identified the importance that participants placed on having a clear plan and process (e.g., goals, timeline) while preparing youth for adulthood. Parents and school personnel noted that a clear plan may be especially important for autistic students, as they benefit from having outlined goals to help grasp the bigger picture of transition planning and from recognizing how smaller steps indicate progress toward their larger goals (Hatfield, Ciccarelli, Falkmer, & Falkmer, 2018; Hatfield, Falkmer, Falkmer, & Ciccarelli, 2017).

Despite the benefits of clear plans, listening to families' aspirations is also needed. Researchers have examined the distinct qualities of hope and hope's role in times of uncertainty, such as life transitions. Bury, Wenzel, and Woodyatt (2016) studied individuals' expectations with respect to sports and election outcomes. Bury et al. (2016) proposed that hope arises when there is greater uncertainty about achieving the outcome, yet the outcome remains of high importance. Further, they observed that hopes are not merely idealized, unrealistic wishes; rather, both hopes and expectations are based in "reality" and an understanding of past outcomes and experiences. In the context of greater uncertainty, hope does not

necessarily signify an unrealistic expectation; instead, investment in and value of the outcome overrides uncertainty of the outcome. Applying these concepts to parents of autistic adolescents, acknowledging and incorporating parents' hopes – despite the possibility that they may seem unrealistic or uncertain at times – may be constructive, given families' investment in the outcome. Hatfield et al. (2017, 2018) also discussed the value of attending to hopes. Parents and school personnel of autistic individuals identified the importance of encouraging and supporting high aspirations; these high aspirations provide youth with opportunities to be challenged, influencing their self-perceptions of abilities and independence. Additional research to clarify the relationship among values, hopes, expectations, and uncertainty would be beneficial to understanding the experiences of families of transition-age youth with ASD.

### *Implications for Practice*

The current findings have two important implications for providers working with families of autistic transition-age youth. First, service providers can work toward establishing a comprehensive understanding of how parents envision the future. Nuances in how parents discuss the future may provide important insight into families' current situations – namely, how parents' concerns, guidance needs, and realistic expectations may influence expressions of their hopes. Given the potential significance of parents' future visions on autistic adult outcomes (e.g., Kirby, 2016), service providers may use information about valued outcomes, uncertainties, and guidance needs to help families construct visions that balance both their ultimate hopes and realistic expectations.

Second, families may benefit from interventions that offer autistic adolescents “real-life” and practical experiences and exploration to help clarify and challenge what they can expect of their son or daughter in the future. Holmes et al. (2018) recently suggested that actions during transition years may have a bidirectional relationship with parents' expectations; that is, parents' observation of their youth's performance in transition preparatory activities helps parents determine expectations for the future and subsequently engage youth in transition preparation that is congruent with their perceptions of their youth's future capabilities. Both Wigfield and Eccles (2000) and Bury and colleagues (2016) discuss how past experiences influence expectations and hopes for the future. The importance of real-life

experiences was also emphasized by Hatfield and colleagues (2017, 2018), who stated that real-life exposure in high school provides adolescents with insight into adult life, as well as the opportunity to develop skills (e.g., work skills) and certain characteristics (e.g., resilience). In addition, Carter, Austin, and Trainor (2012) suggest that work experiences in high school may enhance stakeholders' (e.g., teachers, families) expectations of students' future capabilities. Similarly, we suggest providing real-life experiences designed for families based on their current hopes and values, such as volunteering, interning, living away from home (e.g., summer camp), and engaging in new social and community-based situations. Such experiences could help families assess the likelihood of success in the future and develop or refine their future visions. As support for this notion, Hagner and colleagues (2012) studied the effectiveness of a transition planning intervention (including group training sessions, individual family interventions, and career exploration), and found the intervention to significantly improve students' and parents' expectations for the future (Hagner et al., 2012).

### *Implications for Research*

Future research can further examine the complexities of how parents think about the future of their autistic adolescents. For example, researchers may further analyze the constructs explored in the current analysis, such as parents' concerns for the future or the distinction between parents' hopes and expectations. This additional information may enhance an understanding of how families' concerns, uncertainty, perceived lack of guidance, or “qualification” of hopes and expectations may influence their transition planning decisions and outcomes. Another area for future research is an exploration of how services providers consider parents' hopes and expectations when negotiating educational transition plans. For instance, this inquiry may include service provider perspectives, family perspectives, or observation of parent-provider transition planning meetings. This research could provide a deeper understanding of the current state of parent engagement in the transition planning process, as well as potential examples of successful strategies to help families develop realistic yet desirable goals.

## Limitations

This analysis includes some limitations. First, the presented findings are the interpretations of a specific research team. We did not pilot the interview protocol or “member check” our interpretations with the study participants; this information could have further clarified our interpretations. Second, the findings are unique to the study participants. The majority of the participants were white, non-Hispanic mothers in the same state. We also did not collect data regarding youths’ support needs or behaviors; thus, we do not know how parents’ hopes and expectations reflect their student’s specific behavioral characteristics. The findings may not be generalizable to the broader population of families of autistic transition-age youth. Lastly, we included data from both focus groups and interviews in the same analysis. Focus group participants were likely prompted by other parents to discuss certain topics, whereas interview participants did not have this opportunity. Conversely, focus group participants may have been hesitant to discuss certain topics due to presence of other parents, or may have been limited in sharing their perspectives due to time constraints. Despite these limitations, the findings presented can still generate important considerations and conversations among service professionals and researchers.

## Conclusion

The current analysis provides insight into how parents of autistic high school students perceive their adolescent’s future adult life and experience the transition planning process. A close examination of how parents discussed their hopes and expectations helped to understand that their future visions may be unclear, due to conflicting fears, uncertainty, and the perceived lack of a roadmap. This understanding can help to inform the design and delivery of transition services for autistic youth, by preparing professionals and researchers to recognize potential delicacy in parents’ constant negotiation of changing ideas about their son or daughter’s abilities and future, and potentially help families envision futures that they both desire and can realistically expect.

## Acknowledgements

We thank the families who kindly dedicated their time to this study and the Dudley Allen Sargent Research Fund for funding the research.

*Accepted version, author formatted*

## Declaration of Conflicting Interest

There are no potential conflicts of interest with respect to the research, authorship, or publication of this article.

## Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research was supported by a grant from the Boston University Dudley Allen Sargent Research Fund to Gael Orsmond.

## Note

The authors’ choice to primarily use identity-first language (e.g., autistic individual) versus first-person language (e.g., person with autism) was due to this Journal’s acknowledgement of autistic persons’ preference of identity-first language (Pellicano et al., 2018).

## References

- Anderson, K. A., Shattuck, P. T., Cooper, B. P., Roux, A. M., & Wagner, M. (2014). Prevalence and correlates of postsecondary residential status among young adults with an autism spectrum disorder. *Autism, 18*(5), 562–570. <https://doi.org/10.1177/1362361313481860>
- Blacher, J., Kraemer, B., & Howell, E. (2010). Family expectations and transition experiences for young adults with severe disabilities: does syndrome matter? *Advances in Mental Health and Learning Disabilities, 4*(1), 3-16.
- Blustein, C.L., Carter, E.W., & McMillan, E. D. (2016). The voices of parents: Post-high school expectations, priorities, and concerns for children with intellectual and developmental disabilities. *The Journal of Special Education, 50*(3), 164-177. <https://doi.org/10.1177/0022466916641381>
- Brantlinger, E., Jimenez, R., Klingner, J., Pugach, M., & Richardson, V. (2005). Qualitative studies in special education. *Exceptional Children, 71*(2), 195–207. <https://doi.org/10.1177/001440290507100205>
- Bury, S. M., Wenzel, M., & Woodyatt, L. (2016). Giving hope a sporting chance: Hope as distinct from optimism when events are possible but not probable. *Motivation and Emotion, 40*(4), 588-601.

- Carter, E. W., Austin, D., & Trainor, A. A. (2012). Predictors of postschool employment outcomes for young adults with severe disabilities. *Journal of Disability Policy Studies, 23*(1), 50–63. <https://doi.org/10.1177/1044207311414680>
- Camarena, P. M., & Sarigiani, P.A. (2009). Postsecondary educational aspirations of high-functioning adolescents with autism spectrum disorders and their parents. *Focus on Autism and Other Developmental Disabilities, 24*(2), 115–128. <https://doi.org/10.1177/1088357609332675>
- Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). Sage.
- Cheak-Zamora, N., Teti, M., & First, J. (2015). ‘Transitions are scary for our kids, and they’re scary for us’: Family member and youth perspectives on the challenges of transitioning to adulthood with autism. *Journal of Applied Research in Intellectual Disabilities, 28*(6), 548–560. <https://doi.org/10.1111/jar.12150>
- Chiang, H. M., Cheung, Y. K., Hickson, L., Xiang, R., & Tsai, L. Y. (2012). Predictive factors of participation in postsecondary education for high school leavers with autism. *Journal of Autism and Developmental Disorders, 42*(5), 685–696. <https://doi.org/10.1007/s10803-011-1297-7>
- Doren, B., Gau, J. M., & Lindstrom, L. E. (2012). The relationship between parent expectations and postschool outcomes of adolescents with disabilities. *Exceptional Children, 79*(1), 7–23.
- Hagner, D., Kurtz, A., Cloutier, H., Arakelian, C., Brucker, D. L., & May, J. (2012). Outcomes of a family-centered transition process for students with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities, 27*(1), 42–50. <https://doi.org/10.1177/1088357611430841>
- Hatfield, M., Ciccarelli, M., Falkmer, T., & Falkmer, M. (2018). Factors related to successful transition planning for adolescents on the autism spectrum. *Journal of Research in Special Educational Needs, 18*(1), 3–14. <https://doi.org/10.1111/1471-3802.12388>
- Hatfield, M., Falkmer, M., Falkmer, T., & Ciccarelli, M. (2017). “Leaps of faith”: Parents' and professionals' viewpoints on preparing adolescents on the autism spectrum for leaving school. *Journal of Research in Special Educational Needs, 17*(3), 187–197. <https://doi.org/10.1111/1471-3802.12377>
- Henninger, N. A., & Taylor, J. L. (2013). Outcomes in adults with autism spectrum disorders: a historical perspective. *Autism: The International Journal of Research and Practice, 17*(1), 103–16. <https://doi.org/10.1177/1362361312441266>
- Henninger, N. A., & Taylor, J. L. (2014). Family perspectives on a successful transition to adulthood for individuals with disabilities. *Intellectual and Developmental Disabilities, 52*(2), 98–111. <https://doi.org/10.1352/1934-9556-52.2.98>
- Holmes, L.G., Kirby, A.V., Strassberg, D.S., & Himle, M. B. (2018). Parent expectations and preparatory activities as adolescents with ASD transition to adulthood. *Journal of Autism and Developmental Disorders, 48*(9), 2925–2937. <https://doi.org/10.1007/s10803-018-3545-6>
- Individuals with Disabilities Education Improvement Act, 20 U.S.C. § 1400 (2004)
- Ivey, J. K. (2004). What do parents expect? *Focus on Autism and Other Developmental Disabilities, 19*(1), 27–33. <https://doi.org/10.1177/10883576040190010401>
- Kirby, A. V. (2016). Parent expectations mediate outcomes for young adults with autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 46*(5), 1643–1655. <https://doi.org/10.1007/s10803-015-2691-3>
- Myers, E., Davis, B. E., Stobbe, G., & Bjornson, K. (2015). Community and social participation among individuals with autism spectrum disorder transitioning to adulthood. *Journal of Autism and Developmental Disorders, 45*(8). <https://doi.org/10.1007/s10803-015-2403-z>
- Orsmond, G. I., Shattuck, P. T., Cooper, B. P., Sterzing, P. R., & Anderson, K. A. (2013). Social participation among young adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*(11), 2710–2719. <https://doi.org/10.1007/s10803-013-1833-8>
- Parsons, J. E., Adler, T. F., & Kaczala, C. M. (1982). Socialization of achievement attitudes and beliefs: Parental influences. *Child Development, 53*(2), 310–321.
- Pellicano, L., Mandy, W., Bölte, S., Stahmer, A., Lounds Taylor, J., & Mandell, D. S. (2018). A new era for autism research, and for our journal. *Autism, 22*(2), 82–83. <https://doi.org/10.1177/1362361317748556>

- Poon, K. K., Koh, L., & Magiati, I. (2013). Parental perspectives on the importance and likelihood of adult outcomes for children with autism spectrum disorders, intellectual disabilities or multiple disabilities. *Research in Autism Spectrum Disorders*, 7(2), 382–390. <https://doi.org/10.1016/j.rasd.2012.10.006>
- Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Wagner, M., & Taylor, J. L. (2012). Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics*, 129(6), 1042–1049. <https://doi.org/10.1542/peds.2011-2864>
- Shogren, K. A., & Plotner, A. J. (2012). Transition planning for students with intellectual disability, autism, or other disabilities: Data from the National Longitudinal Transition Study-2. *Intellectual and Developmental Disabilities*, 50(1), 16–30. <https://doi.org/10.1352/1934-9556-50.1.16>
- Smith, L. E., & Anderson, K. A. (2014). The roles and needs of families of adolescents with ASD. *Remedial and Special Education*, 35(2), 114–122. <https://doi.org/10.1177/0741932513514616>
- Sosnowy, C., Silverman, C., & Shattuck, P. (2018). Parents' and young adults' perspectives on transition outcomes for young adults with autism. *Autism*, 22(1), 29-39.
- Wagner, M., Newman, L., Cameto, R., Javitz, H., & Valdes, K. (2012). A national picture of parent and youth participation in IEP and transition planning meetings. *Journal of Disability Policy Studies*, 23(3), 140–155. <https://doi.org/10.1177/1044207311425384>
- Wigfield, A., & Eccles, J. S. (2000). Expectancy-value theory of achievement motivation. *Contemporary Educational Psychology*, 25(1), 68–81. <https://doi.org/10.1006/ceps.1999.1015>