

PARENT REPORTED CHALLENGES FOR TEENS WITH ASD TRANSITIONING TO YOUNG ADULTHOOD

Belinda Daughrity, Ph.D., CCC-SLP Department of Speech-Language Pathology California State University, Long Beach Long Beach, CA, USA

Erica Ellis, Ph.D., CCC-SLP
Department of Communication Disorders
California State University, Los Angeles
Los Angeles, CA, USA

Ashley Wiley Johnson, Ph.D., CCC-SLP The Wiley Center for Speech and Language Development Culver City, CA, USA

- ABSTRACT -

Introduction: Teens with autism spectrum disorders (ASD) can experience challenges with transitioning out of high school and into young adulthood. Exploring diverse parent perceptions of challenges during this time is critical to best support the needs of an increasing diverse population of children receiving speech and language intervention services. Methods Participants were 13 parents of 11 culturally and/or linguistically diverse teens with an existing diagnosis of autism spectrum disorder who participated in a 90-minute focus group to explore their perceptions about perceived challenges with their child's transition to young adulthood. Results Qualitative data analysis explored parent reports of concerns throughout this critical transition period. Results revealed primary themes of employment, independence, transition support, and meaningful reciprocal relationships as parents' greatest concerns. Discussion Analysis revealed parents have significant reservations during this critical period with limited knowledge of supports to assist during this transition. Suggestions to alleviate these challenges are provided such as engaging in early and repeated intervention focused on prevocational goals for teens preparing to transition to young adulthood, promoting pipelines to employment within the community to broaden access to valuable networks of future support, and intentionally sharing positive outcomes with parents to mitigate concerns. Speech-language pathologists and other allied health professionals can use findings to inform their clinical practices to serve culturally diverse clients preparing to transition out of high school.

Keywords: autism, social skills, parent perspectives, teens, adulthood

Introduction

Transitioning to young adulthood, a period from the late teens to mid-twenties, can be a challenging process for individuals with autism spectrum disorders (ASD). Prior research asserts potential challenges following high school include employment, post-secondary education, independent living, social relationships, experiences with services, need for support, and speculation about the future (Sosnowy et al., 2018). Areas of deficit in ASD include social skills, and communication, which can create difficulty throughout the school age years that continue into college settings (Alverson et al., 2019). As primary caregivers, parents of individuals with ASD often strive to help their children meet the challenges of transitioning into young adulthood. This current study sought to explore the perceptions of parents of teens with ASD who are preparing to graduate from high school and shift into young adulthood.

ASD includes two core symptoms: social communication deficits and the presence of repetitive behaviors and/or restricted interests. Social skills deficits are prominent among this population. Deficits include, but are not limited to, issues such as: starting and maintaining conversations, coordinating eye contact, demonstrating theory of mind, and responding appropriately to an established conversation topic (Bellini, 2009). However, social skills demands change over time with age and environmental contexts. The substantial social shifts during adolescence coupled with the hormonal and neurological changes during that time period contribute to the difficulty transitioning into young adult roles (Picci & Scherf, 2015). As such, continued social skills training for individuals with ASD may be warranted throughout the lifespan as they encounter new social environments with new demands such as the transition into young adulthood.

Social skills deficits can make it difficult for teens with ASD to initiate and maintain friendships in addition to romantic relationships. Adolescents with ASD may desire to be socially involved with others, but lack the necessary skills to do so successfully, which can lead to social isolation. Adolescents with ASD report more loneliness than their neurotypical peers and demonstrate poorer friendship quality (Lasgaard et al., 2010; Locke et al., 2010). Individuals with ASD who learn and develop appropriate social interaction skills early in life often experience more optimal outcomes in language and academic achievements similar to neurotypical peers (Bauminger, 2002; Chang et al., 2014). Group-based social skills programs can provide teen clients with related examples and opportunities to practice their skills (Gates et al., 2017). In addition to direct and explicit instruction, targeted programs can help with social skills by simulating an environment for success to prepare for future situations by allowing the child to practice required skills in a safe environment. Social skills can be practiced in a structured environment, which can make it easier for the person with ASD to generalize these skills to real-life situations.

The transition from high school can be difficult for all teens, but particularly challenging for teens with ASD who may show difficulty adjusting to changes in routine. A number of factors can contribute to challenges post high school for students with ASD. One of the factors may be reduced support services. As individuals with ASD age into adulthood, many may have poor experiences during this time of transition (Anderson et al., 2018). Research suggests almost 40% of young adults were not receiving medical, mental health, case management, or speech and language services after high school (Shattuck et al., 2011). The lack of services for young adults is consistent with parent report (Anderson et al., 2018). As young adults with ASD get older, there are a scarcity of available support services compared to available services for school age children. Research on college students with ASD shows more supports are needed to promote optimal success such as increased retention and graduation (Accardo et al., 2019).

Navigating educational opportunities post high school can be particularly challenging for individuals with ASD. In the years post high-school, 50% of individuals with ASD are not enrolled in college or employed (Shattuck et al., 2012). With established laws protecting student privacy in higher education, individuals with ASD who attend college are required to navigate special education services independently without parent assistance in academics (Geller & Greenberg, 2009). Additionally, education faculty may have limited knowledge about ASD and how to assist with challenges students with ASD may have in the classroom (Alverson et al., 2019). In comparison to other disability groups, individuals with ASD have one of the lowest rates of college enrollment (Wei et al., 2014). Among students with ASD who do attend college, experiences can be bleak. Some students may report feeling overwhelmed by the experience (Cai & Richdale, 2015). Identified challenges to college success include the extent of the core features of ASD, the presence of co-morbid conditions, lack of preparation for transition, not disclosing diagnosis, and lack of services (Cai & Richdale, 2015). Research indicates individuals with ASD may benefit from targeted supports to address social interaction challenges that can be particularly manifested in common student tasks such as group projects and interactions with instructors (Vanbergeijk et al., 2008).

Young adults with ASD enter the workforce may also face particular challenges. Individuals with autism spectrum disorders are the least employed group with disabilities (Wehman et al., 2013). Some employers report positive feedback about individuals with ASD such as punctuality, a reliable work ethic, and dependability (Wei et al., 2014); however, parent report and evidence indicates many young adults with ASD are underemployed or not compensated fairly enough (Anderson et al., 2018; Burgess & Robert, 2014). Employment opportunities can make a positive impact on an individual with ASD in adulthood by helping to facilitate relationships and promote overall independence. Research indicates 80% of young adults with ASD still live at home, 21% have no higher education or employment experiences, and only 6% have competitive jobs (Shattuck et al., 2012). Social communication impairments may adversely impact the ability to understand different work environments and expectations of employers within these environments (Baker-Ericzén et al., 2018). Findings suggest impairment-focused interventions alone are not enough to achieve and maintain successful work outcomes for individuals with ASD (Scott et al., 2018). Contextual factors may be required to improve employment outcomes for individuals with ASD such as workplace accommodations with support from supervisors and co-workers trained in ASD differences (Scott et al., 2018). Overall, challenges to successful employment are evident despite many individuals with ASD having typical or minimally delayed communication skills.

In addition to higher education opportunities and employment, meaningful relationships are a critical component of success in young adulthood. Individuals with ASD are often at a higher risk for social isolation and peer victimization. A cross-sectional study conducted on children and adolescents with ASD compared to other groups such as children with ADHD and typically developing children found adolescents with ASD reported the highest levels of loneliness (Deckers et al., 2017). Individuals with ASD can report low levels of desire for social interaction due to lacking the necessary skills to do so, which can further exacerbate feelings of loneliness (Bauminger, 2002; Deckers et al., 2017; Mendelson et al., 2016). Volkmar and Wolf (2013) found less than 25% percent of adults with ASD were found to have meaningful friendships. Additionally, social interactions become more complicated with age and the awareness of social competence increases (Deckers et al., 2017). Navigating sexual relationships and close friendships independently into young adulthood may require support to experience success.

Given the noted gap of knowledge about adults with

ASD in comparison to the information known about children, more research is needed to better understand factors that can lead to success in teens with ASD transitioning into young adulthood. Landmark et al. (2007) found that parents of teens with disabilities from diverse backgrounds had varying levels of knowledge regarding transition experiences as well as various barriers impacting involvement in transition planning. Zhang and colleagues (2010) found differences among cultural groups in parent perspectives of self-determination in regards to their high schoolers with varying disabilities. Prior research suggests the need to increase our understanding of the transition to young adulthood needs of teens with ASD from diverse backgrounds.

For the purposes of this current study, perceptions of parents of diverse teens with ASD preparing to transition into young adulthood were explored to address the following research questions: (1) How do parents envision their child's future (work, living, relationships) with ASD? and (2) How do parents report the current level of support for their children with ASD as they are preparing to transition to young adulthood? As primary caregivers, parent input may help to better inform intervention needs and practices to best support individuals with ASD as they transition out of high school and into young adulthood.

Methods

Participants

Participants were parents of teens with an existing diagnosis of autism spectrum disorder. Participants were recruited via posted flyers and emails to parents of teenagers with ASD participating in a weekly teen social skills group at a private practice speech and language clinic in Los Angeles, CA. Flyers were posted on clinic entry doors and at reception desks where clients signed in for scheduled appointments. One email was sent from clinic staff regarding the voluntary option to participate in the focus group study. Parents who were interested in participating called or emailed the primary investigators to consent to participation. Fourteen parents made inquiries and thirteen parents completed the study. One parent was unable to participate due to scheduling conflicts. After giving informed consent, participants completed a brief survey with demographic information and participated in one 90-minute focus group facilitated by the second author and assisted by a student research assistant to support translation for Spanish-speaking parents. Participant recruitment, informed consent, and focus group activities adhered to standard procedures of rights of human subjects as dictated by an independent institutional review board process attained prior to initiating the investigation.

A total of 13 parents of 11 teens with ASD participated in the study including 5 fathers and 8 mothers. The parent participants reported their children were from a variety of ethnic/cultural backgrounds, reporting eight from minority racial/ethnic backgrounds. Two families reported speaking both Spanish and English at home, and one family reported speaking both Arabic and English at home. The remaining families were monolingual English-speaking (N = 8). Parent participants reported their teens with ASD were between 13-19 years old (2 female, 8 male, 1 not reported). Participants ranged in family income levels (1 family - \$10-25K, 2 families - 25-45K, 1 family -45-60K, 5 families – 60K +, 2 families – not reported). Eight mothers of teens were employed (0 unemployed and 3 not reported) and five fathers were employed (3 unemployed and 3 not reported). See Table 1 for characteristics of participants.

Table 1. Participant Reported Characteristics

Characteristic	
Participants	
Mother	8
Father	8 5
Gender of teen	
Female	2
Male	8
Not reported	1
Child background	
White/Caucasian	3
Black/African-American	3 6 2
Hispanic/Latino	2
Family Income Level	
10,000-25,000	1
25,001-45,000	2
45,001-60,000	2 1 5
60,001 +	5
Language(s) spoken at home	
English	8
Spanish/English	8 2 1
Arabic/English	1
Parent Employment Status	
Mother Employed	8
Mother Unemployed	0
Mother Not reported	3
Father Employed	5
Father Unemployed	8 0 3 5 3 3
Father Not reported	3

Parents also described their teen's educational placement and current services received on a demographic form. It was reported that seven teens were in high school, and six of those in high school were reported to be in the 12th grade. One teen was reported to be in middle school. For three teenagers, the information was not reported. All teenagers were verbally fluent, although in varied educational settings. Four parents reported their teen was in a special education placement, two indicated general education placement, and five were not reported. Only one parent indicated their teen was employed part-time through a workability program. No other teenager was reported to be employed. Seven parents reported their teen was in a social skills group, five were reported to be in speech therapy, one received occupational therapy, one received ABA, and one received recreation therapy/adapted PE services. No teenagers were reported to receive ESL services at school. See Table 2 for characteristics of teenagers.

Table 2. Teen Education Placement and Services Received

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Educational level	
College	0
High School	7
Middle School	1
Not Reported	3
Educational Placement	
General Education	2
Special Education	4
Not Reported	5
Employment	
Full-time	0
Part-time	1
Not working/Not reported	10
Services Received	
Social Skills Group	7
Speech Therapy	5
OT	1
ABA	1
Rec Tx/Adapted PE	1
ESL	0

Procedures

The use of qualitative methods provides a systematic way of gathering in-depth information and allows the commonalities and discrepancies in individual perspectives to emerge. Additionally, qualitative methodology provides the opportunity for flexibility to explore questions related to better understanding participants' perspectives. The method employed in

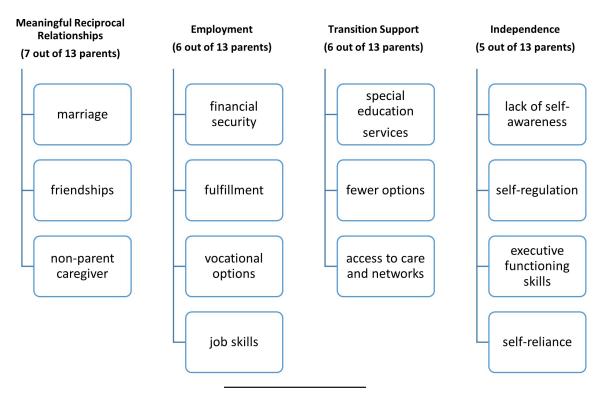
the current study aligns with phenomenological research because it emphasizes the parents' subjective experiences (Creswell, 2012) and seeks to understand their experiences from their unique point of view. The 90-minute focus group was audio recorded and transcribed by independent research assistants in its entirety for analysis. Interview questions were formed to quickly establish rapport, followed by a series of open-ended questions intended to ascertain parent experiences, opinions, feelings, and knowledge. Participants were informed about being audio recorded and prompted to not use identifying information (e.g., first and last names) during discussion in order to help maintain anonymity. A complete list of questions used to guide the focus group are provided in Appendix 1.

After the interview was transcribed, researchers developed codes, categories, and themes post data collection to form a reverse engineered hypothesis. Two independent assistants conducted initial coding, in addition to one of the primary investigators who did not attend the focus group. The first stage of analysis involved line by line coding to reveal recurring themes and ideas. All coders provided initial codes independently before discussing codes to identify the recurring themes and categories. Supporting quotations were extracted to support each category and reinforce the validity of the theme until the point coders agreed there were no additional data supporting the emergence of new codes or themes, signaling data saturation (Saunders et al., 2018). Analyst triangulation was used by employing at least two independent coders to review the collected transcripts and interpret the data. Independent coders used grounded theory methodology by allowing ideas and patterns to emerge from the transcript data, rather than first hypothesizing findings (Charmaz, 2006; Dey, 1999). As such, generalizations emerged from the collected data after collection, instead of prior to the focus group. The use of open and axial coding allowed for a systematic, two-phase approach of analyzing the data (Corbin & Strauss, 2008).

Results

Three independent raters yielded a total of eight codes reported by at least half of the participants as concerns about their teenager's impending transition to young adulthood. Codes in order of appearance by frequency included employment, independence, relationships, fading support, friendships, lack of self-awareness, discipline, and lack of life skills. These codes were analyzed and organized into four dominant themes: (1) meaningful reciprocal relationships (reported by 7 out of 13 parents – 54% of participants), (2) employment and (3) transition support (both reported by 6 out of 13 parents – 46% of participants), and (4) independence (reported by 5 out of 13 parents – 38% of participants). Table 3 reflects the development of dominant themes from initial coding.

Table 3. Initial to focused coding of themes (in order of frequency of parent report, N= 13)



Meaningful Reciprocal Relationships

Codes of romantic relationships, friendships, and care were categorized into a larger theme of meaningful reciprocal relationships. Statements from parents about friend(s), friendship, marriage, and relationships were analyzed. Parents reported concerns about who would serve as a caregiver for their child in the future, expressing fears of lack of emotional support for their young adult in their absence. Parents expressed fears about future loneliness. A parent said, "I pray to God maybe God will send him someone in any way. . . Wife, friend, or somebody to continue his life with." Nearly all parents expressed distress at the idea of dying because of fear of their child being alone and becoming socially isolated. Discerning true friends was a repeated concern expressed by parents. One parent described her teen as naïve. She reported, "The lack of self-awareness. I worry about trusting everybody. Like he trusts everybody." Many parents expressed concerns about others taking advantage of their children who may not have mastered perspective-taking skills and theory of mind to discern others' intentions. One parent described a past situation when her son spent his money buying food for his "friends" who never reciprocated the gesture. One parent explained, "I want him to be safe. If I die or something happen to me, my son in a good hand. Not only for money, money you can leave in a trust for them or a bank account, but I really would love to feel safe if I'm gone or, you know, he's alone there is someone looking after him." Overall, whether reporting the desire for friends, a parental figure, or a significant other, parents appeared significantly concerned about the need for meaningful, reciprocal intimate relationships to support their children as they transition into young adulthood. Parents expressed fears about future loneliness. For example, one parent expressed, "Cause we aren't going to be there forever, so appointing someone, finding someone that knows how to work with your child, that's scary." Emotional closeness seemed to be a primary concern as parents reported a general idea of wanting their child to have emotional safety via someone to lean on for support, encouragement, and care.

Employment

Many parents discussed the importance of working. Beyond securing a job, parents reported concerns about their children sustaining meaningful employment appropriately matched to their interests and ability levels. Parents cited the need for prevocational programs to assist with the transition to meaningful employment as a means of attaining independence and financial security. Another parent expressed a similar sentiment and said, "They want to apply for a job, but they don't know how to do anything. What

are they going to do? Picking trash or things like that? I want that they learn to do something. They can pay the bills." Parents who referenced continuing education via attending community college or a four-year institution mentioned the connection of earning a college degree to being able to obtain meaningful employment. One parent stated their child needed "More options if they can't just you know clean up or be bus boys." Overall, report indicates concern about finding employment that is both fulfilling and provides financial stability.

Transition Support

Related to the need for independence was the realization of dwindling support services as parents cited the dichotomy between the abundance of services offered for younger children compared to the limited programs for teenagers transitioning to young adulthood. One parent lamented, "It seems like elementary they give you everything you need . . . high school may be a little different." Many parents agreed funding for support services becomes increasingly scarce with increasing age. One parent simply stated, "As they become older, the support becomes less." Another parent agreed and further explained, "That's one of the biggest things we've seen. Like when he was in elementary, the support was everywhere. Then from junior high the support went down. . . and then high school the support even went lower so that's our fear is once he becomes an adult in the real world."

Independence

Parents discussed independence as a primary concern. One parent explained, "We just want him to be able to make it without us. Being independent is a big thing . . . Him just being independent is our biggest goal." Expressing similar sentiments, a parent said, "Hopefully he can be independent and doesn't need us all the time." Largely, independence encompassed both small daily tasks such as independence in completing daily chores and activities, as well as large-scale independence such as independent living and financial self-sufficiency. Another parent stated, "We want her to be mentally capable of doing whatever she wants." Overall, the idea of teens being able to appropriately assume more age-appropriate responsibility and self-sufficiency was a dominant concern.

Discussion

This current pilot study sought to explore the perceptions of culturally and/or linguistically diverse families with teens with ASD preparing to transition into young adulthood. Although this population has been under-engaged in the research literature, un-

derstanding the perspectives of diverse clients within this population is critical to help inform concerns of families during this critical transition period. Previous work examining diverse parent perspectives of transitions with teens with varying disabilities found differences among cultural groups (Landmark et al., 2007; Zhang et al., 2010). Our work adds to the existing literature by examining the parent reported challenges for diverse teens with ASD transitioning to young adulthood using focus group methodology.

Prior research on global outcomes for individuals with ASD suggests that, despite improvements and more opportunities, positive outcomes on work, friendship, and independence are still significantly challenging (Eaves & Ho, 2007). In comparison to their neuro-typical peers, individuals with ASD can face greater difficulty transitioning into independent young adulthood. This challenging transition can lead to poor outcomes such as difficulty finding and sustaining postsecondary employment, successfully completing their education, or living independently with some degree of social involvement. Aligned with other healthcare disparities, culturally and/or linguistically diverse groups of individuals with ASD can experience even more challenges (Bishop-Fitzpatrick & Kind, 2017; Magaña et al., 2012). Thus, direct report of diverse parent concerns is critical to inform clinicians who treat teenagers preparing to transition to young adulthood. Parents in the current study reported more on long-term concerns for employment, rather than post-secondary education. This finding may suggest parents are ultimately interested in outcomes for their children that will support their future livelihood, indicating parents may be more concerned about independence than higher education achievements and milestones. As such, higher education was viewed as a pathway to obtaining a more stable and financially secure job. Comments by parents suggest meaningful employment, rather than limited job prospects with repetitive tasks, is a primary concern as parents repeatedly echoed sentiments of wanting their teen to have a job related to their interests that allows them to support themselves financially. Research attests the chronic unemployment and underemployment of individuals with ASD, often citing challenges of both skills required to complete job-related tasks and the interpersonal skills that contribute to successful employment (Hendricks, 2010). Notably, research suggests the significantly high risk of unemployment for individuals with ASD after high school in comparison to other disability groups and the need for improved transition planning (Shattuck et al., 2012). Similar challenges are found in young adults with specific language impairment who demonstrate less successful outcomes than their typical peers in education and employment (Conti-Ramsden & Durkin, 2012); however, individuals with ASD appear to be one of the most adversely impacted disability groups in regards to postsecondary employment. More research on appropriate supports is needed, but preliminary studies on supported employment approaches for individuals with ASD have demonstrated positive outcomes (Wehman et al., 2012). Additionally, findings on the importance of relationships indicates parents are anticipating their child's existence without them and see the value of emotional, rather than solely financial, supports. In comparison to other disability groups, young adults with ASD demonstrate significantly less social participation, which is an important indicator of quality of life (Orsmond et al., 2013).

Results of the study will contribute to the field by offering information on ways to better assist families of children with autism spectrum disorders as their children transition out of high school and into young adulthood. Direct input from families will help speech-language pathologists and other professionals better serve families as they approach this critical milestone period from high school into college and/or employment. Parents in the current study reported significant concerns about the future for their children; however, they expressed limited optimism in spite of significantly growing opportunities for young adults on the autism spectrum to thrive as they transition out of high school and into the "real world." Speech-language pathologists and other professionals working with families during this transition period should seek to highlight cases of individuals with ASD who successfully transitioned into young adulthood. Sharing positive outcomes for families may help to alleviate some of the reservations during this timepoint. Specifically, sharing targeted anecdotes can assist caregivers who may only be viewing their child's future from a deficit, rather than strength, based approach. While all parents of teens transitioning into young adulthood are experiencing a period of uncertainty, given the known challenges for individuals with ASD, more targeted and direct encouragement to increase awareness of successful outcomes may be warranted to counteract parent apprehension. Targeted campaigns to communicate the accomplishments of individuals with autism spectrum disorder such as climate change activist Greta Thunberg, scientist Temple Grandin, and Kent State Division I basketball player Kalin Bennett, to name a few, may help parents conceive of more positive outcomes for their children focused on their children's unique strengths, rather than only their challenges. These targeted campaigns to share success stories may be even more necessary in diverse communities who can often find themselves underrepresented in mainstream media. In addition to sharing the stories of well-known individuals, parents may benefit from discussing outcomes of local students such as prior clients who are attending college or working successfully with appropriate supports. In this case, speech-language pathologists may serve as facilitators to help former students share their own outcomes with current families, which may help parents to view the transition into young adulthood more positively, despite this critical transition period often being unknown.

In the current study, parents' remarks of limited varied employment opportunities may be the result of limited networks that have the potential to provide access to pathways to independence such as higher education and/or employment. When possible, clinicians may develop community partners to best facilitate prospective job experiences for teen clients with ASD. Similar to neurotypical peers, experiences like internships and summer employment should not be overlooked for teen students with ASD. Tasks targeting executive functioning skills such as completing a job or internship application, preparing for an interview, organizing a viable work schedule, and budgeting money are tasks that would support functional goals for individuals with ASD transitioning into young adulthood. To support relationships, intervention should be delivered in a group format with age-matched peers when appropriate and clinically feasible. Efforts should be made to support genuine relationship development by assisting teens to identify mutual interests and to organize opportunities for continued social interaction. Tasks such as identifying a clear activity and planning details such as where and when to meet for social outings all target executive functioning goals such as making inferences, perspective taking, and organizing with an end goal in mind. Repeated sessions of social opportunities with fading adult support would serve to assist students to build genuine relationships with peers by repeated exposure as friendships are strengthened and maintained by ongoing interaction. Additionally, clinicians may support families by discussing topics such as estate planning and long-term care in order to better help clients and their families to prepare for the future.

In regards to direct intervention with teenagers preparing to transition to young adulthood, suggested therapy goals during this period may incorporate tasks to increase independence, self-advocacy, perspective taking, and building friendships to provide emotional support. Suggestions such as interventions utilizing antecedents, videos, and consequences in intervention, as well as incorporating preferred in-

terests in socialization activities to foster increased peer engagement have been explored as potential evidence-based practices for adolescents with ASD (de Bruin et al., 2013; Koegel et al., 2013). Further, professionals including speech-language pathologists, vocational counselors, special education teachers, may help families by targeting these essential skills long before the transition to young adulthood takes place to help readily identify areas of greatest need for families. Ideally, interventions for young adults approaching this critical transition period will take place outside of the traditional therapy setting. Rather, intervention could prove most useful in the natural environment and/or with peer involvement to best replicate the "real world" to prepare clients for the next chapter. Clinicians may consider probing students' interests during early teen years in order to consider how those interests may link to potential vocational tracks.

Overall, by considering direct concerns from parents of teenagers with ASD, this current study serves to provide direction about how clinicians may better serve clients and their families preparing to transition into young adulthood. Future directions may include firsthand accounts via direct interviews with teenagers with ASD to ascertain their own perceptions of their future as they prepare for adulthood. Comparing parent to teen perceptions may be a valuable tool to distinguish distinct patterns of congruence and divergence in views of parents and their children. Future areas of research may also explore long-term outcomes for emerging young adults to help identify precise factors that may contribute to optimal outcomes such as independence and meaningful employment for individuals with autism spectrum disorders and their families.

Limitations of the current study include the small sample size and demographics as the 13 participants were all from the Los Angeles area, which limits generalization. While the current study may be limited in scope, it can help to inform intervention practices by providing a better understanding of supports that have been helpful and the assistance that might be absent in supports needed to facilitate transition into young adulthood. Future studies may seek to collect data from additional participants and to analyze finding within cultural groups to generate a more comprehensive understanding of parent concerns across a variety of backgrounds. Additionally, future studies may seek to explore parents' knowledge of available support services during this transition period in order to assess how and where parents are accessing this critical information and if they report such supports to be effective.

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Appendix I

Focus Group Questions

INTRODUCTION

- Tell me about your child. What does he/she enjoy doing?
- What do you think are your child's strengths and weaknesses?
- Which services/groups/etc. have been helpful in your child's successes so far?
- How did you learn about these supports?
- Where do you see your child 5 years from now?
- Do you think your child will live independently?
- Has your child ever expressed a desire to live alone now or in the future?
- In 20 years, how do you see your child taking care of him/herself?/If you were not your child's primary caretaker (not able to be your child's primary caretaker), how do you think your child would take care of him/herself?
- What are your hopes for your child's future?
- What are your greatest fears for your child's future?
- What are your biggest concerns?

HIGHER EDUCATION

- What kind of career field do you see your child entering?
- What kind of career has your child expressed interest in?
- Do you think this choice matches their strengths/ talents/abilities?
- Does your child want to attend college or are they attending now?
- Do you want your child to attend college?

FAMILY/RELATIONSHIPS

- Do you have a desire for your child to be with a life partner or married?
- Do you envision your child having a family of his/ her own?
- Has your child ever expressed a desire to have a family now or in the future?

SUPPORTS

- Who has helped/is helping you navigate the transition as your child enters young adulthood?
- Who would you identify as your support network in helping you care for your child? How do these individuals assist?
- Do you feel more or less (or the same) level of support as when your child was younger? Do you think the quality of support is the same?
- How is support funded? Insurance, private, regional center, etc.

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Contact Information: Belinda Daughrity, Ph.D., CCC-SLP Email: <u>Belinda.Daughrity@csulb.edu</u>