

“Falling through the Cracks”: Challenges for High School Students with Autism Spectrum Disorder

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High school students with autism spectrum disorder (ASD) often struggle in the complex social and academic secondary environment. Current literature suggests post-secondary success is limited for adults with ASD, but little is known about the high school experiences of individuals with ASD that may be impacting their post-secondary outcomes. Focus groups with multiple stakeholders were used to examine challenges facing high school students with ASD and their service providers. Through qualitative analysis, three themes emerged that illuminate challenges posed in the high school setting for students with ASD: (1) inconsistencies, many of which

are intrinsic to the secondary environment, (2) difficulties with interpersonal connections, and (3) knowledge/process breakdowns. The findings demonstrate the misalignment or “crack” that exists between the nature of high schools and the needs of students with ASD as they prepare for success in postsecondary environments.

Keywords: autism, asd, secondary, postsecondary

High schools are large, complex environments that often lack cohesion (Rutledge, Cohen-Vogel, & Osborne-Lampkin, 2012). The average size of a high school in the United States (U.S.) is 854 students, approximately 50% larger than the average middle school (National Center for Educational Statistics, 2011). High school tends to be more impersonal, competitive, and grade-oriented than middle school (Corcoran & Silander, 2009). Middle schools are often organized in teams allowing teachers to collaborate around a cohort of students, whereas high school teachers have few opportunities to interact regarding the needs of shared students. In a single day, a high school student may have seven different classes, each with a different teacher and group of peers. Even more so than in middle school, students in high school are expected to be independent in their academic functioning with greater demands on their planning and organizational skills (Rosenthal et al., 2013). As their brains and bodies are rapidly changing, high school students may find social experiences more complicated (Crone & Dahl, 2012). For students with disabilities, including autism spectrum disorder (ASD), the high school experience may pose additional challenges. The present study explored the perspectives of stakeholders, including individuals with ASD, parents, general educators, and special education personnel through a qualitative analysis of focus group data to identify the challenges experienced by high school students with ASD and their service providers. These findings have the potential to inform improvement of services for high school students with ASD.

Secondary Students with ASD

Autism spectrum disorder is a neurodevelopmental condition characterized by deficits in social functioning and communication with restricted interests and repetitive behaviors (American Psychiatric Association [APA], 2013). Although the overall prevalence of ASD has been consistently rising in the U.S. (Center for Disease Control and Prevention, 2014), only recently has the prevalence of ASD in 14 to 17-year-olds matched that of younger ages (Blumberg et al, 2013). This increase in prevalence among adolescents has placed added strain on secondary education systems. Some authors have suggested symptoms of ASD may improve during adolescence (Schall & McDonough, 2010), but a review by Levy and Perry (2011) suggested there are varying degrees of aggression, resistance to change, unacceptable sexual behavior, and self-injurious behavior in this age group. Comorbid anxiety and depression have been noted as prevalent among adolescents with ASD (Schall & McDonough, 2010).

Within the social environment of high school, difficulties in the areas of communication and social interaction can put students with ASD at risk for social isolation and bullying (Humphrey & Symes, 2010). For some individuals with ASD, adolescence brings a growing self-awareness of social difficulties, and negative experiences with peers may exacerbate social anxiety (White, Ollendick & Bray, 2011). Positive peer relationships have been found to facilitate positive social and academic outcomes (Lynch, Lerner & Leventhal, 2013), and parents perceive social challenges as a major impediment to the educational achievement of high school students with ASD (Camarena & Sarigiani, 2009). In an era of accountability based on high stakes testing, the primary focus of educators tends to be on increasing academic achievement.

For students with ASD, the trickier aspects of social life such as entering peer groups, making friends, and developing intimate relationships may go unaddressed or overlooked by school staff as most social encounters occur outside of the classroom and in the hallways, lunchroom, and during extracurricular activities.

In addition, the chaotic and often noisy secondary environment can be at odds with the preference for routine and consistency exhibited by many individuals with ASD (Humphrey & Lewis, 2008). A hallmark characteristic of ASD is a repetitive pattern of behaviors which can manifest in overt repetitive physical behaviors (e.g., flapping or spinning), and may result in negative attention from peers and teachers alike. Restricted interests can also limit social interactions (Wilczynski, Menousek, Hunter & Mudgal, 2007). Impairment in flexibility poses challenges to successful inclusion in a wide range of everyday activities for these individuals (Rosenthal et al., 2013). Adolescents with ASD can also struggle with executive functions more than their peers, leading to greater difficulties with organization, following multiple step directions, and the ability to self-initiate (Rosenthal et al., 2013). These abilities are considered necessary for academic success in high school.

Although more than 50% of individuals with ASD are reportedly without a comorbid intellectual disability (Fombonne, 2009), only 33% of students with ASD in high school are included in the standard grade-level academic curriculum in regular education classrooms (Newman, 2007). In those classes, 67% of teachers reported they make at least some modification to the curriculum for students with ASD (Newman, 2007). Additionally, compared with their peers, students with ASD are less likely to respond orally to questions, make a presentation to the class, or work collaboratively with peers, according to their teachers (Newman, 2007). The majority of students with ASD receive some type of accommodation, the most frequent being extra time on tests or assignments. Newman reported nearly half of secondary students with ASD receive alternative assessments, meaning they will not graduate with a regular high school diploma.

There is a lack of empirical evidence on effective practices for meeting the complex and challenging needs of adolescents with ASD (Kurth & Mastergeorge, 2010). Kurth and Mastergeorge (2010) found the documentation of student progress on individualized education plan (IEP) goals declined as students increased grade levels. Another study identified that only 11% of high school teachers reported using best practices with students with ASD compared with 67% of teachers at the elementary level (Morrier, Hess & Heflin, 2011). Additionally, students may not be as engaged in the IEP process as intended for youth age 14 and above (Hagner et al., 2012). The lack of adequate supports for students with ASD at the high school level is likely contributing to their poor postsecondary outcomes.

Postsecondary Outcomes for Students with ASD

Postsecondary outcomes for individuals with ASD are variable, but generally poor (Levy & Perry, 2011). A national study on long-term outcomes for students with disabilities found the results for students with ASD to be among the poorest of any disability category (Shattuck et al., 2012). More than half of these young adults were neither engaged in work nor postsecondary education in the two years following graduation, and only a small proportion were living independently.

Researchers suggest poor outcomes for individuals with ASD may be partly due to a lack of support at the high school level (Chiang, Cheung, Hickson, Ziang, & Tsai, 2012; Gerhardt, & Lainer, 2011). Students who are served in the general education classroom in particular have few services available to help them transition to the postsecondary environment (Taylor & Seltzer, 2011; Chiang et al., 2012). These poor

outcomes have profound ramifications for adolescents, their families, and communities at large. Individuals suffer if they are unable to realize their potential, the family suffers if they become the lifetime caretaker to a child with ASD, and society loses as the cost of supporting and serving individuals with ASD across the lifespan has been estimated at \$3.2 million per person (Ganz, 2007). There is a compelling need to examine the challenges experienced by high school students with ASD to contribute to enhanced support and ultimately improved quality of life for this population.

Study Purpose

Focus groups were conducted to inform the development and implementation process of a broad school- and community-based intervention for adolescents with ASD. However, in reviewing the transcripts, we identified salient discussions about challenges of the high school experience for students with ASD that warranted closer examination. Little is known empirically about the specific challenges adolescents with ASD face when navigating the high school experience. In addition to student needs, there is a dearth of insight around the challenges faced by school staff working with these students. This information is needed to help improve, refine, and develop interventions and supports at the high school level. The purpose of this study was to analyze multiple stakeholder perspectives (i.e., individuals with ASD, parents, general educators, and special education personnel) on challenges impacting the success of students with ASD in high school. This study examined the following research question: What is challenging about high school for students with ASD and their service providers? In order to identify and describe the challenges, we used the following qualitative approaches.

Methods

Focus group methodology was used in this study as a means to access the experiences of high school students with ASD, their families, and the professionals who serve them. Focus groups are an important first step when conducting research (Vaughn, Schumm, & Sinagub, 1996) and these groups represented the initial phase of a large scale, multisite study focused on developing comprehensive programming in secondary settings for students with ASD. Our aim was to conduct an interactive discussion that would provide an in-depth understanding of the high school experience for students with ASD from the multiple perspectives identified above.

Sampling

Focus group participants were recruited through a variety of methods including emails to listservs of community organizations and university education and related departments, distribution of flyers to local businesses, and snowball sampling through targeted contacts with school autism specialists in area high schools. We conducted seven focus groups across two communities in a southeastern U.S. state that represented distinct populations. Five focus groups were conducted in Community A, a university community with a population of 55,000, and two focus groups were conducted in Community B, a mixed rural/urban community with a population of 275,000, located sixty miles from Community A.

Forty-one individuals participated across the seven groups, with a range of three to nine participants per group. The groups were organized by stakeholder category to promote positive group dynamics for productive discussions (Morgan, 1996). One group included five young adults with ASD. Individuals with ASD included two students currently in high school general education classrooms, one young adult in college, one young adult currently working and living independently, and one young adult currently unemployed and living at home. Two focus groups consisted of 10 parents of students and/or young adults with ASD. Six parents had children

Table 1: *Focus Group Participant Demographics by Role*

	Individuals with ASD (<i>n</i> =5, 1 group)	Parents (<i>n</i> =10, 2 groups)	School Personnel (<i>n</i> =26, 4 groups)
Race & Ethnicity			
White	4 (80%)	9 (90%)	22 (84.6%)
Black	1 (20%)	1 (10%)	3 (11.5%)
Asian	-	-	-
Multi-Race	-	-	1 (3.9%)
Hispanic	-	-	-
Gender			
Male	5 (100%)	-	2 (8%)
Female	-	10 (100%)	24 (92%)
Age			
≤ 18 years	2 (40%)	-	-
19–25 years	1 (20%)	-	-
26–40 years	2 (40%)	-	-
Child's Age (years)	-	Range: 13–29 M 20 (SD 5.1)	-
Experience in Education (years)	-	-	Range: 1–40 M 15 (SD 10.4)

with ASD currently attending high school, and four parents had children with ASD who were recent graduates. The parents had children who were involved in general education, occupational course of study, and self-contained programs in high school.

School personnel participants represented a diverse group of individuals who work with students with ASD in high school. One focus group consisted of five general education high school teachers. A total of 21 special education personnel participated across three focus groups and included resource specialists, transition coordinators, self-contained teachers, occupational course of study teachers, and autism-related support staff. Table 1 includes demographic information about the participants across stakeholder groups. In total, 85% of the sample was white, 12% was black, and 3% was multi-racial; 83% of the sample was female.

Focus group procedures and data collection

Focus groups were held at a university-based research office in Community A, and at a local high school in Community B. Participants signed consent/assent upon arrival and completed a demographic questionnaire before focus groups began. Each focus group was moderated by one of five university-based personnel with graduate degrees and experience working with individuals with ASD in school, home, or clinic-based settings. Moderators outlined confidentiality expectations so that participants would feel comfortable sharing openly. Moderators received training from an expert in conducting focus groups (Sharon Vaughn at University of Texas, Austin) to ensure consistency across the seven focus groups. A fixed research design was used with standardized questions (See Table 2) and procedures across groups, allowing for some flexibility for individual variation to accommodate the needs of each group (Morgan, 1996). In the focus group for individuals with ASD, the format was simplified and visual supports were provided to encourage participation.

The 90-min focus groups began with participant introductions and a brief overview of the broader research and development project, The Center on Secondary

Table 2: Focus Groups Questions

Stakeholder Group	Focus Group Questions
Parents/Teachers/ School Staff	1. What might be missing from this intervention that you think ought to be added? Why?
	2. How might this approach look similar or different depending for students all along the autism spectrum?
	3. What potential challenges might arise when trying to implement this approach consistently (i.e., with fidelity) in your school (you child’s school)? What steps should we take now to circumvent these potential challenges?
	4. To what extent are the proposed elements <i>already</i> being implemented with students (your child) in your schools?
	5. If they are being implemented: What suggests to you that these strategies are working well? What suggests that they are not working well?
	6. If they are not being implemented: Why not? What stands in the way?
	7. How would implementing this intervention align with other intervention strategies you are already implementing (being implemented) for students with autism?
	8. As we implement this national center, what resources, supports, and information ought we consider developing?
	9. How might we best share what we are learning back with you?
Individuals with ASD	1. What do you like most about high school?
	2. What do you like least about high school?
	3. How did you learn about how things worked at your high school? Who helped you?
	4. What would you like about an orientation to high school? What would you not like?
	5. What are you learning in high school about how to act and behave?
	6. What type of job would you like to have?
	7. What are the three most important things you need to learn to get it?
	8. Where would you most like to live as an adult?
	9. What are the three most important things you need to learn to be able to live there?
	10. What skills would be helpful for you to learn?
	11. What feels hard for you to learn?
	12. What helps you when you are learning new things?

Education for Students with Autism Spectrum Disorder (CSESA). Focus group questions were related to the overall high school experience for individuals with ASD from the perspectives of the different stakeholders. Moderators also provided information about high school-based interventions under development, one involving an orientation process specifically geared to students with ASD just entering high school, and the other, related to promoting independence and

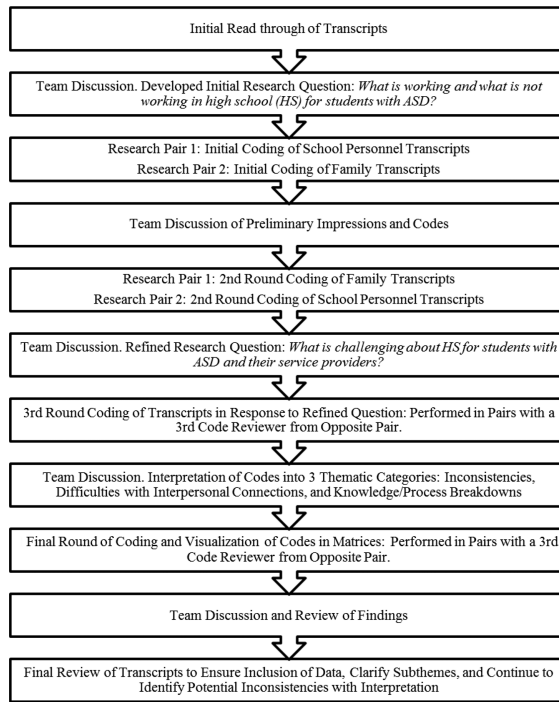
self-management in students with ASD as they prepare to transition to adulthood. Additionally, the moderators probed to discover how these interventions were similar to what was currently happening in the schools where the stakeholders were affiliated, and if not, if the participants thought the interventions would be helpful. Findings of the results of the intervention specific data will be discussed in another publication that will share findings from 21 focus groups held at four additional sites that each focused on three additional interventions being developed by the CSESA project.

Each focus group was audio recorded using two digital recorders with attached microphones to ensure the data would be audible. Additionally, sessions were video recorded to provide a visual image of the discussions to aid in transcription by providing the perspective of the body language. Audio recordings were transcribed verbatim by a trained research assistant, and checked for accuracy by another research team member. Additionally, notes were taken by a member of the research team during each focus group. Participants were encouraged to edit or clarify general themes during focus groups while the moderator made notes about group ideas on chart paper. Transcripts were read and reviewed multiple times by each author before analysis to gain familiarity with the data.

Data Analysis

Upon initial review of the transcripts, the research team identified how pervasive discussions about challenges were throughout the focus groups. Thus, although this analysis was not the primary purpose of the study, an analysis of stakeholder perspectives on challenges was warranted. The research question, which was developed inductively to capture the most salient aspects of the transcripts, was finalized as: *What is challenging about high school for students with ASD and their service providers?* A team-based process of coding, categorizing, and theme development was used to analyze data. This iterative process of analysis was purposeful and focused on asking questions and making comparisons (Corbin & Strauss, 2008). The research team engaged in a rigorous process of analysis with multiple opportunities for investigator triangulation throughout coding, questioning of emerging interpretations, and discussion of researcher bias given the roles of each researcher (Brantlinger et al., 2005; Merriam, 2009). The first four authors actively coded the data during four rounds of coding (See Figure 1); each transcript was coded by more than one team member at each phase, discussed in pairs, and then in team meetings. The remaining two authors served as auditors by reviewing, examining, and confirming or disconfirming the other authors' interpretations throughout the data analysis process (Brantlinger et al., 2005). Discrepancies between coders were discussed in pairs and then reviewed by the entire team, focusing on the coded portion of data as well as the larger surrounding discussion to fully understand the conversational context. Following thorough discussion of discrepancies, the team reached consensus on coding decisions.

During team meetings, accumulated codes and larger concepts were compared and contrasted. The emerging clusters of codes were categorized to begin to capture recurring patterns of meaning (Merriam, 2009). Matrices were used to identify further consistencies and discrepancies across the stakeholders represented by the focus groups (Miles & Huberman, 1994). After the third round of coding, a list of codes and brief descriptions were developed and codes were collapsed when the underlying ideas overlapped (e.g., 'inconsistencies over time' subtheme started as multiple codes including 'year to year changes' and 'change from middle school to high school'). Codes were then refined by the team and used in the final round

Figure 1: *Data Analysis Flow Chart*

of coding. The coding process resulted in three primary themes that represent challenges faced by high school students with ASD and their service providers.

Results

In response to our final research question, three themes emerged which illuminate ways high schools pose challenges for students with ASD: inconsistencies, difficulties with interpersonal connections, and knowledge/process breakdowns. These three themes are related to challenges that students with ASD experience in high school, and these conflict with what previous research proposed students with ASD need to be successful. One parent described her son as, “falling through the cracks,” in high school. The “crack” between what students with ASD need and what is actually happening at the high school level represents an overarching metaphor in this study.

Inconsistencies

Literature suggests students with ASD prefer consistency — or “sameness” (APA, 2013; Lam, Bodfish, & Piven, 2008) — yet our findings indicated that participants found high schools to be highly inconsistent. A salient theme identified in the focus groups was the profusion of inconsistencies in the high school experience including inconsistencies across the school day, inconsistencies over time, and inconsistencies between school and home environments. These issues, as reported by parents and school personnel, made success for these students difficult.

Inconsistencies across the school day. Participants described inconsistencies across the school day as challenging for students with ASD. One of these primary inconsistencies was differing teacher expectations. In high school, students are likely to have multiple teachers they see each day, and each teacher has different rules, expectations,

and schedules. Focus group participants said that these inconsistencies made it difficult for students with ASD to meet expectations. As one special education personnel noted, “the consistency is sometimes difficult because you’re dealing with so many different personalities with teachers: some teachers are very laid back and some teachers are very structured, and it’s really hard to get all that consistency sometimes.” Parents also mentioned the variability across teachers in their implementation of IEP goals; some even questioned if the IEP was being implemented at all.

In addition to inconsistencies across teachers, inconsistencies in schedules also posed challenges for students with ASD. When there was a change in the class schedule (e.g., school assembly or fire drill), educators reported that students with ASD had a difficult time adjusting. One general educator shared, “when we have delayed opening, they [one student with ASD] just don’t come because they can’t handle that change in schedule.” Participants described that varying teacher expectations, coupled with changes in class schedules, led to a great deal of inconsistency across the school day for students with ASD.

Inconsistencies over time. Educators and parents also mentioned inconsistencies from middle to high school and from year to year as challenging to the success of their students with ASD. For example, teachers identified the substantial decrease in support from middle to high school as a challenge to student success. Similarly, parents mentioned the lack of support from high school to college as an obstacle to post-school success. As one parent noted, “there was a lot of support in high school and there’s zero support now [in college].” Focus group participants expressed that there were drastic changes in the amounts of support available for students with ASD at different phases, and minimal assistance to ease the transitions between levels of support.

Furthermore, educators discussed a lack of communication during transitions from year to year as a significant challenge. One general educator expressed:

By the time they reach high school we should know that,... there should be something that says, ‘this works for this child’ and ‘try not to do this one’ because, you know, I mean,... there’s no reason why it has to be a new thing every single year, [no reason] the teachers have to go through this. There should be some kind of easier transition.

Parents echoed these concerns by describing the difficulties they experienced with new teachers not understanding how to implement goals and accommodations listed in the IEP. Thus, as one parent stated, “Every semester is new.”

Inconsistencies between school and home environments. Special education personnel, general educators, and parents described the challenges experienced when teachers and parents have different expectations for the student and different perspectives on the students’ needs. For example, one special education personnel shared:

We have so many families who are more upset about the child not getting the A in Algebra than the fact that they can’t brush their teeth. They don’t understand that that independence piece is going to affect their quality of life probably more than the Algebra grade.

To further add to this challenge, special education personnel stated that some parents report their children’s behaviors are worse at home than at school, making it even more difficult for parents and educators to collaborate. One participant shared, “I have parents say, ‘well you should be in my house and see what happens.’”

Additionally, parents identified that teachers seem to have differing perspectives on their child's capabilities and may disagree with their parenting styles. For example, some parents noted that teachers expect their child to do more than they are able to and believe that parents are being overly protective. One parent expressed, "The teachers — even though they knew his diagnosis — would see him as more capable than he actually was or they would see him as lazy or stubborn, or that I was too coddling." These inconsistencies were reported by educators, special education personnel, and parents as contributing to the challenges faced by high school students with ASD and those who work with them.

Difficulties with Interpersonal Connections

A second theme identified throughout the focus group discussions was the challenge to build successful relationships and make connections. Success in high school is highly dependent on forming and maintaining various relationships with multiple teachers, staff, and peers. These relationships can be challenging for students with ASD, especially considering that social-communication deficits are a core feature of the diagnosis (APA, 2013). This theme encompasses the challenges of students with ASD to make and maintain relationships as well as communication difficulties experienced by those who provide services to them.

Relationship challenges. General educators described how their students with ASD had limited social interactions with their peers. Likewise, parents explained how their children struggled to make friends, and many commented that their child did not have any friends. One parent shared, "[if you] ask him who his friend is, he'll say someone in class but he doesn't do anything with people alone." Another parent added, "He doesn't have friends. He comes to school and he's in classes, [but] he doesn't have friends". One young adult with ASD noted that learning about "engaging in social situations" was something he found particularly hard in high school.

Teachers discussed how many of the behaviors of students with ASD "annoy" their peers, are not socially acceptable, and can be offensive, which negatively impacts their ability to build peer relationships. However, as one general educator noted, "a lot of times [students with ASD] don't realize that they may be offending somebody." Forming relationships may also be challenging for students with ASD due to limited social support services at the high school level or the student with ASD not wanting extra support. One individual with ASD stated that, in high school, "sometimes being identified as different is bad." This suggests that some individuals with ASD taught in the general education classroom may not want to be singled out as needing extra supports.

In addition to difficulties making connections, participants indicated that students with ASD often experienced negative social interactions. As one parent shared, "There's always going to be a problem with how other kids view your child." Another parent expressed, "There were times that he [her son] would be in a situation and then other kids would bully him, and so there were fights," and even though the teacher knew he was being "tested" the teacher did not know what to do. Negative experiences with peers were also highlighted by participants with ASD. For example, one individual noted, "kids are not nice from my experience." Another young adult, reflecting back on his time in high school, said, "Someone said that high school ... was gonna be some of the funnest days of your life, and, and I kind,... whoever said that, really didn't, really didn't,... really [must have] got[ten] by well in high school." However, forming connections with peers was not the only relationship struggle noted; teachers also commented on the difficulty they had connecting with their students with ASD. As one general education teacher

shared, “I still have not really been able to connect with [him] and it seems like you take a couple steps forward then a step back, and so it’s really hard.”

Communication difficulties. In addition to the challenges students with ASD had making and maintaining relationships, school personnel and parents also identified challenges they experienced in collaborating with each other. According to our participants, their struggles to make connections were particularly due to inadequate communication. Participants highlighted that when limited communication existed between teachers, special education personnel, and families, challenges increased for everyone involved. For example, teachers reported a lack of communication with other teachers, which resulted in increased workload for everyone because they were repeating strategies previous teachers had tried and found unsuccessful.

Furthermore, school personnel discussed challenges surrounding issues of confidentiality related to communication. Some participants felt that being able to share a student’s diagnosis with other teachers at the school would enable a more supportive school environment; however, they were limited by school policies regarding confidentiality. Additionally, one parent shared her frustration about her child’s teachers not being aware of his IEP, and therefore not providing the necessary accommodations. This parent explained, “When I went and started talking about his IEP and what the accommodations were, they [the teachers] had not been given the IEP.” Both parents and teachers discussed becoming frustrated when there was not frequent, open communication between them. One parent expressed, “so many times they [teachers] see us as their enemy.” Parents and school personnel discussed how challenges can arise when there is limited communication within the school or between the school and the family. One participant summarized it well: “It boils down to communication, to make sure that we’re all communicating with expectations and realities.”

Knowledge/Process Breakdowns

The final theme, which was the most frequently discussed in our focus groups, was the general lack of knowledge, preparation, and adequate supports for students with ASD at the high school level. These challenges grouped into three sub-themes: roles and responsibilities, knowledge and preparation, and special education processes. These issues not only contributed to existing challenges participants faced, but also limited their beliefs about capabilities to make improvements for students with ASD in high school.

Roles and responsibilities. One challenge described by focus group participants was the multiple, and often unclear, roles and responsibilities of high school personnel. With multiple roles and responsibilities, school personnel felt they were not able to adequately provide students with ASD the specialized support they required. Some special educators expressed frustrations during the focus groups about the lack of support they received from the school at large. They described their multiple roles and responsibilities as overwhelming. One parent echoed the frustrations of these teachers by describing the pressures she had witnessed: “They only had one special [education] teacher who did all his IEPs...one person has all that responsibility.” Other participants discussed the unique challenges general educators faced when working with students with ASD. In addition to their traditional teaching roles, they often had to adapt the curriculum for students with ASD while, as one teacher explained, “keeping the rest of the class going.”

Additionally, many school staff discussed lack of available time as a significant barrier to implementing best practices for students with ASD. One participant explained, “I see that as a challenge with rolling out the Common Core Curriculum.

I see — just system wide — a lot of overwhelmed staff, overwhelmed with meetings...” Since time is already so limited, some school personnel expressed how unreasonable it seemed to try and incorporate new trainings or programs for students with ASD. For example, one special education teacher expressed:

I think a lot of teachers, we’re already so overwhelmed by paperwork and overwhelmed by expectations and what we need to do...once we get back to the classroom, forget it. I’m already working on his IEP, his re-eval., and I’m doing this and that....Who is going to help us to do it?

Knowledge and preparation. The most widely discussed theme across participant groups was a general lack of knowledge about autism as a substantial barrier to a successful high school experience for students with ASD. Although personnel in many schools have been highly educated and trained in working with students with ASD at a macro-level, participants felt there was a persistent lack of knowledge and preparation to teach these students. According to participants, this lack of knowledge and preparation limited the effectiveness of services and policies for students with ASD. Many participants spoke specifically about general educators lacking knowledge about ASD. One parent described:

I think most regular [education] teachers have a very limited knowledge of autism in general. I think it’s going to be different for the self-contained classrooms, the OCS [Occupational Course of Study] teachers, but I think that in the (pause). Anything that my kid’s teachers knew, it was because we bugged them, bugged them and bugged them, and made them.

Another parent added,

Even when they are willing, it doesn’t mean that they have had the exposure to it, necessarily. But there are some teachers who are very willing to understand but, just, they’re social studies teachers and they were drilled in that; they weren’t drilled in ‘what does percolating up to a frustration point look like?’

According to participants, since many students with ASD were in inclusion settings for at least part of their day, the knowledge and preparation of general education teachers was paramount.

Special education processes. While special education processes (i.e. IEPs) were designed to support students with special education needs, according to our participants, they were contributing to the challenges experienced by students with ASD at the high school level. In the focus groups, participants described IEPs acting as barriers. For example, participants noted experiences when IEPs were created but not implemented, written too broadly, not given to all teachers, only addressed certain aspects of functioning, and were not individualized enough. Furthermore, parents discussed how difficult it was to navigate through all the documents and address all areas of concern when the meetings were under strict time constraints. Additionally, participants identified that there were often clear expectations but not clear ways to meet the expectations. One parent described,

We are told at their 8th grade IEP that now they start coming to their IEP and they’re supposed to know about this stuff and they are responsible for advocating for themselves, but nowhere is there anybody who shows them how to do that.

General and special education personnel also discussed not always knowing *how* to address certain goals. For many of our participants, these special education processes were described as hindering, rather than supporting, students with ASD.

Discussion

In this study, we examined stakeholder perspectives on challenges faced by high school students with ASD as well as those who provide support and services for them. We identified three themes that captured ways in which high schools pose challenges for students with ASD: inconsistencies, difficulties with interpersonal connections, and knowledge/process breakdowns. We suggest these themes highlight issues illustrating a misalignment between the high school experience and the needs of students with ASD. Although it often seems blame is placed on students who do not fit with the structure of the environment, our findings suggest that the nature of the high school experience may be contributing to the challenges. Therefore, this study emphasizes the “crack” that exists between the nature of high schools, as identified by our participants, and the characteristics and needs of students with ASD. With awareness of these challenges, future work can identify more efficient and successful ways to address the needs of high school students with ASD. Based on the challenges high school students with ASD experience, as expressed by our participants, we provide suggestions for practitioners to help alleviate these challenges below. However, future research is needed to investigate the interventions and processes described below and how they impact the challenges experienced by high school students with ASD, their families, and their service providers.

Inconsistencies

The first identified theme — inconsistencies — overtly contrasts with the needs of students with ASD. Individuals with ASD tend to prefer consistency in their routines and insistence on sameness is considered to be a subtype of restricted repetitive behavior (RRB), one of the core features of the diagnosis (Lam et al., 2008). Although RRBs have been found to decrease with age, they do persist throughout the lifespan (Esbensen, Seltzer, Lam, & Bodfish, 2009). In our study, stakeholders discussed how some of the challenges students with ASD faced in high school were due to inconsistencies inherent in the typical high school experience. They suggested the lack of consistency was pervasive not only across the school day going from class to class, but over time moving from elementary to middle to high school, and in differing expectations between school and home. Stakeholders said that these inconsistencies made it difficult for students with ASD to fully participate in the functional demands of high school.

An important first step to address this challenge is for school personnel and families to recognize the inconsistencies students may be experiencing. Inconsistencies students may experience include changes in the daily schedule, different expectations across teachers, and different expectations across home to school environments. Visually presented expectations have been effective at lessening the difficulty students with ASD experience when managing expectations across settings (National Professional Development Center on Autism Spectrum Disorders, 2013). Visual applications (apps) for Apple iOS devices, such as pictello and iPrompts, can be used to visually display expectations and prepare students for different expectations across settings (see Hume, Sreckovic, Snyder, & Carnahan, 2014, for an in-depth description of visual apps to assist students with ASD). Expectations can also be visually displayed on paper in a student’s agenda or folder and reviewed by the student before transitioning to the new setting. Furthermore, providing opportunities for teachers to collaborate regarding support strategies for individual students can help improve consistency in meeting students’ needs across the school day.

However, inconsistencies are somewhat inevitable in a high school environment and will likely continue to present challenges in the postsecondary experiences

of individuals with ASD as well. Therefore, providing support for students to more effectively manage and adapt to new situations may be equally important. Cognitive self-regulation strategies where the student identifies the problem, states the reason for the problem, and suggests a solution, may be effective in helping students successfully navigate inevitable inconsistencies. Possible solutions, however, need to be explicitly taught to the student with ASD and practiced before the student is expected to perform the solution independently. Individualized Education Plan (IEP) goals can be written and support personnel may be able to provide supplemental assistance for addressing these concerns.

Difficulties with Interpersonal Connections

A second theme identified in the data was related to challenges involving interpersonal connections. Our finding that students with ASD have difficulty making connections in high school was not surprising for a few reasons. First, impairment in social interactions is considered to be a core feature of ASD (APA, 2013); therefore, we would expect students to have difficulty with such interactions in high schools. Furthermore, high school students must interact with greater numbers of individuals (e.g., teachers, staff, and peers) compared to their experiences in earlier grades, and peer relationships are often qualitatively different and more complex at the high school level (Carter et al., 2014). Carter and colleagues (2014) outlined peer-mediated and social skills group interventions that can be implemented in high school contexts to support both the social skills development of individuals with ASD and to foster relationships with their peers. Social skills interventions are designed to help students learn the skills needed to interact with their peers (e.g., join conversations, reciprocity). Peer mediated interventions, when facilitated by teachers or other support personnel, can help foster connections between students with ASD and their peers. Encouraging high school students with ASD to participate in extracurricular activities is another strategy to help students develop relationships with peers and become more connected to their schools. Social skills interventions for students with ASD, coupled with education for those whom they interact with, could help to address these social challenges (see Carter et al., 2014 for an in-depth discussion).

Interestingly, however, according to the focus group participants, making connections was not merely a challenge for students with ASD. Rather, our data suggest that making connections was difficult for school personnel and parents as well. Specifically, participants described significant challenges experienced in making connections and keeping open lines of communication between key individuals at the school, as well as between those at home and those at school. Some focus group participants also offered some suggestions as to why these challenges exist and how they may be corrected. For example, vertical planning (e.g., more explicitly sharing information about students from year to year) was suggested by one participant to help reduce the annual learning curve for teachers. Administrators can support this by building in opportunities for professional learning communities to share knowledge about students at the beginning of and throughout the school year.

The educator participants often cited a lack of time as a challenge to enhanced communication. Using technology such as email, text messaging, and chat can enhance communication and may lessen the time demands of face-to-face meetings. Additionally, creating an “IEP at a Glance” sheet that can be distributed to each teacher every semester may lessen the burden of parents having to explain the accommodations and needs of their children every semester and teachers starting over every semester. The IEP at a Glance sheet can include: strengths of the student; social,

academic, and/or behavioral strategies that work well and do not work well for the student; the student's IEP goals and suggested strategies to work on each goal; classroom accommodations; testing accommodations; key contacts (student's case manager, parents, counselor, related service providers); and the student's schedule. For teachers who have several students with IEPs in their class, having a one page sheet can easily remind the teacher of the student's needs and strategies that work well for the student. Practitioners and parents are encouraged to explicitly maintain an open line of dialogue, set goals together, and communicate clearly about strategies being implemented at school and at home. Based on the perspectives of our participants, bridging the communication gap could decrease frustrations experienced by families and school personnel which would likely result in improved services for students with ASD.

Knowledge/Process Breakdowns

The final theme of knowledge and process breakdowns highlighted some of the most frequently talked-about challenges in the focus groups. Although the number of adolescents with ASD is increasing, and these students are increasingly present in general education classrooms and other high school environments, there remains a general lack of understanding of the myriad challenges faced by these students. An overwhelming majority of participants in this study cited a lack of knowledge about ASD across the school community as a major impediment to the success of students with ASD. For example, parents spoke of general education teachers who did not know enough about ASD to be able to support students, and alternatively, school personnel shared about parents who they believed did not understand realistic expectations for these students. Participants even shared experiences in which cafeteria workers and bus drivers were involved in challenging situations due to lack of awareness of ASD in the broader school community. The lack of general knowledge about ASD may be further complicated by the nature of ASD as a 'hidden condition.' That is, it may not be immediately obvious to members of the community that a student experiences social or behavioral challenges which may contribute to challenging situations. Based on the perspectives of our stakeholders, improving awareness of autism in schools may help to ameliorate some of the challenges faced by students with ASD.

A number of recent national initiatives have been charged with identifying evidence-based practices for students with ASD across the age range, and ensuring these interventions and strategies are accessible to general education teachers (e.g., National Standards Project, <http://www.nationalautismcenter.org/nsp>; Center on Secondary Education for Students with ASD, <http://csesa.fpg.unc.edu>; Organization for Autism Research's guide for understanding ASD for secondary teachers, <http://www.researchautism.org/resources/teachersdvd.asp>; Autism Internet Modules, http://www.autisminternetmodules.org/user_mod.php). Similarly, the National Professional Development Center on ASD (<http://autismpdc.fpg.unc.edu>) has developed a number of resources and processes for professional development to promote effective implementation of evidence based practices by school and classroom teams (e.g., coaching resources, implementation checklists). Recently, the Organization for Autism Research and the Center on Secondary Education for Students with ASD created a professional development curriculum for secondary educators on foundational knowledge and evidence-based strategies to support students with ASD in their classrooms (<http://csesa.fpg.unc.edu/resources/understanding-autism-professional-development-curriculum>). These valuable resources, which are free of cost and accessible for educators, administrators, and parents, can increase knowledge about ASD and support educators in implementing empirically supported practices.

Parents of children with ASD in the focus groups additionally highlighted breakdowns in the special education process as another challenge to their children's success. Effective communication and teamwork between families and school personnel are important to IEP and transition processes (Test, Smith, & Carter, 2014), yet parents in our study felt these processes were often less than satisfactory. Parents identified the lack of school awareness about ASD and inadequacy of educational supports as limiting for their children. This may not be unique to these particular focus group participants, as there is a paucity of research on effective practices for meeting the complex and challenging needs of adolescents with ASD, leaving IEP teams to rely heavily on their personal experience and knowledge (Kurth & Mastergeorge, 2010). However, providing educators and service providers with professional development on evidence-based practices for students with ASD should enhance instructional practices and strengthen IEPs.

Limitations and Future Research

There are several limitations to discuss in this study. First, because the primary purpose of the focus groups was informing future interventions, the emphasis of the focus group questions was not entirely on challenges. Therefore, our participants may not have had the opportunity to fully elaborate on their perspectives of the challenges presented in this paper.

Second, regarding recruitment, there was limited variability in participant demographics despite recruiting from two different geographic locations. Therefore, we encourage future research teams to explore challenges adolescents with ASD face in high school with a more nationally representative sample to see if barriers and challenges vary by location or among different demographic groups. Additionally, those who agreed to participate in our focus groups may have chosen to participate because they wanted to share their particularly positive or negative experience with their students or children with ASD in high school, or because they had access to a community agency or resource that distributed the focus group information. Both of these recruitment factors may limit the diversity of opinions or ideas expressed in the groups.

Third, due to our focus on specific group perspectives using a volunteer sample, the extent to which these findings can be generalized to a broader population is unknown. As is typical with most qualitative research, the aim of this study was not generalizability of our findings to a broader population, but rather an increased understanding of a particular group (Brantlinger et al., 2005).

Fourth, although we aimed to include the perspectives of individuals with ASD themselves, the focus group consisting of five individuals with ASD did not contribute substantially to our final themes. As impairment in social interactions is a core feature of ASD, focus groups may not have been the best way to capture their perspectives. Additionally individuals with ASD can have difficulty identifying and describing their feelings (Hare, Wood, Wastell & Skirrow, 2014). These participants contributed stories about their individual experiences, but because these experiences were highly personal, it was difficult to generate themes across groups that could accurately capture their contributions. For example, when asked about what he does not like about his high school experience, one participant stated, "I'm tired of people not knowing how to spell my last name...because I don't think it's that difficult a name to spell." Another participant described, "taking two AP [Advanced Placement] classes in one year" as being one of his greatest challenges. Because of the focus group methodology, it was difficult for the facilitator to spend the necessary time to probe each participant for further details about their experiences. Therefore,

future work aiming to include the perspectives of individuals with ASD may benefit from conducting one-on-one interviews. Furthermore, having only one group consisting of individuals with ASD limited our ability to look for patterns that may have existed between different groups of individuals with ASD. However, despite the difficulty of including their perspectives, this focus group did contribute to the results, most notably in the interpersonal connections theme.

Fifth, while the focus of this study was on students with ASD, it is likely that students with other disabilities, in particular those involving executive function deficits, such as Attention Deficit Hyperactivity Disorder (ADHD), may experience similar challenges to meeting the growing demands for independence and self-management in high school. We encourage future research to examine the difficulties that students with a range of disabilities and their service providers experience at the high school level.

The results of this study illuminated some challenges that high schools may experience in meeting the needs of students with ASD. There is currently a dearth of research on secondary school interventions for students with ASD, and understanding challenges experienced at this level can contribute to development of effective interventions for this population. At this time, practitioners are encouraged to carefully track the progress of students with ASD and monitor the effectiveness of interventions being used for these students (Hume, Boyd, Hamm, & Kucharczyk, 2014). Future research is needed to investigate interventions and processes that can alleviate the challenges described for students with ASD, their families, and their service providers. We have provided several suggestions to address these challenges; however, the extent to which they reduce these challenges has not yet been systematically studied. In addition, it may be beneficial to better understand the challenges across diverse secondary settings, including alternative or charter high schools, to examine differences in environment and structure and how those may impact the secondary experience for students with ASD.

Conclusion

Echoing the findings of Taylor and Seltzer (2011), one of the parents in our study described how she felt her child was “falling through the cracks” in high school. Based on the perspectives of 41 stakeholders across seven focus groups, there exists a dramatic rift between the nature of high schools and the characteristics and needs of students with ASD. Our findings suggest that inconsistencies in the school environment, difficulties with interpersonal connections, and a general lack of awareness about autism, combined with ineffective supports, make high school a challenging experience for individuals with ASD. Although there is room for further research into these challenges, the most profound need identified is for enhanced supports to address the immediate struggles experienced by the growing number of high school students with ASD.

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References

- American Psychiatric Association. (2013). Neurodevelopmental disorders. In *Diagnostic and statistical manual of mental disorders* (5th ed.). doi: 10.1176/appi.books.9780890425596.514988
- Blumberg, S. J., Bramlett, M. D., Kogan, M. D., Schieve, L. A., Jones, J. R., & Lu, M. C. (2013). Changes in prevalence of parent-reported autism spectrum disorder in school-aged U.S. children: 2007 to 2011–2012. *National Health Statistics Report*, (65), 1–12.
- Brantlinger, E., Jimenez, R., Klingner, J., Pugach, M., & Richardson, V. (2005). Qualitative studies in special education. *Council for Exceptional Children*, 71(2), 195–207.

- 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.
- Carter, E. W., Common, E. A., Sreckovic, M. A., Huber, H. B., Bottema-Beutel, K., Gustafson, J. R., ... Hume, K. (2014). Promoting social competence and peer relationships for adolescents with autism spectrum disorders. *Remedial and Special Education, 35*(2), 91–101. doi:10.1177/0741932513514618
- Centers for Disease Control and Prevention (CDC) (2014). Prevalence of autism spectrum disorder among children aged 8 years—Autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *MMWR Surveillance Summaries, 63*(2), 1–21.
- Chiang, H., Cheung, Y., Hickson, L., Xiang, R., & Tsai, L. (2012). Predictive factors of participation in postsecondary education for high school leavers with autism. *Journal of Autism and Developmental Disorders, 42*(5), 685–696.
- Corbin, J., & Strauss, A. (2008). *Basics of qualitative research (3rd ed.): Techniques and procedures for developing grounded theory*. Thousand Oaks, CA: SAGE Publications, Inc.
- Corcoran, T., & Silander, M. (2009). Instruction in high schools: The evidence and the challenge. *The Future of Children, 19*(1), 157–183.
- Crone, E. A., & Dahl, R. E. (2012). Understanding adolescence as a period of social–affective engagement and goal flexibility. *Nature Reviews Neuroscience, 13*(9), 636–650.
- Esbensen, A. J., Seltzer, M. M., Lam, K. S. L., & Bodfish, J. W. (2009). Age-related differences in restricted repetitive behaviors in autism spectrum disorder. *Journal of Autism and Developmental Disabilities, 39*(1), 57–66.
- Fombonne, E. (2009). Epidemiology of pervasive developmental disorders. *Pediatric Research, 65*(6), 591–598.
- Ganz, M. L. (2007). The lifetime distribution of the incremental societal costs of autism. *Archives of Pediatrics & Adolescent Medicine, 161*(4), 343.
- Gerhardt, P. F., & Lainer, I. (2011). Addressing the needs of adolescents and adults with autism: A crisis on the horizon. *Journal of Contemporary Psychotherapy, 41*(1), 37–45.
- Hagner, D., Kurtz, A., Cloutier, H., Arakelian, C., Brucker, D., & 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.
- Hare, D., Wood, C., Wastell, S., & Skirrow, P. (2014). Anxiety in Asperger's syndrome: Assessment in real time. *Autism*. Advance online publication. doi:10.1177/1362361314531340
- Hume, K., Boyd, B. A., Hamm, J. V., & Kucharczyk, S. (2014). Supporting independence in adolescents on the autism spectrum. *Remedial and Special Education, 35*(2), 102–113. doi:10.1177/0741932513514617
- Hume, K., Sreckovic, M., Snyder, K., & Carnahan, C. R. (2014). Smooth transitions: Helping students with autism spectrum disorder navigate the school day. *Teaching Exceptional Children, 47*(1), 35–45.
- Humphrey, N., & Lewis, S. (2008). 'Make me normal': The views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism, 12*(1), 23–46.
- Humphrey, N., & Symes, W. (2010). Perceptions of social support and experience of bullying among pupils with autism spectrum disorders in mainstream secondary schools. *European Journal of Special Needs Education, 25*(1), 77–91.
- Kurth, J., & Mastergeorge, A. (2010). Individual education plan goals and services for adolescents with autism: Impact of age and educational setting. *The Journal of Special Education, 44*(3), 46–60.
- Lam, K. S. L., Bodfish, J. W., & Piven, J. (2008). Evidence for three subtypes of repetitive behavior in autism that differ in familiarity and association with other symptoms. *Journal of Child Psychology and Psychiatry, 49*, 1193–1200.
- Levy, A., & Perry, A. (2011). Outcomes in adolescents and adults with autism: A review of the literature. *Research in Autism Spectrum Disorders, 5*(4), 1271–1282.
- Lynch, A. D., Lerner, R. M., & Leventhal, T. (2013). Adolescent academic achievement and school engagement: An examination of the role of school-wide peer culture. *Journal of Youth and Adolescence, 42*(1), 6–19.
- Merriam, S. B. (2009). *Qualitative research: A guide to design and implementation*. San Francisco: Jossey Bass.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook*. Thousand Oaks, CA: SAGE Publications, Inc.
- Morgan, D. L. (1996). Focus groups. *Annual Review of Sociology, 22*, 129–152.
- Morrier, M. J., Hess, K. L., & Heflin, L. (2011). Teacher training for implementation of teaching strategies for students with autism spectrum disorders. *Teacher Education And Special Education, 34*(2), 119–132.
- National Center for Educational Statistics. (2011). Numbers and types of public elementary and secondary schools from the common core of data: School year 2010–11. Retrieved from http://nces.ed.gov/pubs2011/pesschools09/tables/table_05.asp
- National Professional Development Center on ASD. (2013). Evidence-based practice briefs. Retrieved December 11, 2013, from <http://autismpdc.fpg.unc.edu/>
- Newman, L. (2007). *Secondary school experiences of students with autism*. Menlo Park, CA. SRI International. Retrieved from <http://ies.ed.gov/ncser/pdf/20073005.pdf>
- Rosenthal, M., Lawson, R., Dixon, E., Wallace, G., Wills, M., Yerys, B., & Kenworthy, L. (2013). Impairments in real-world executive function increase from childhood to adolescence in autism spectrum disorders. *Neuropsychology, 27*(1), 13–18.
- Rutledge, S., Cohen-Vogel, L., & Osborne-Lampkin, L. (2012). Identifying the characteristics of effective high schools: Report from year one of the National Center on Scaling up Effective Schools. Research Report. *National Center on Scaling Up Effective Schools*.

- Schall, C., & McDonough, J. (2010). Autism spectrum disorders in adolescence and early adulthood: Characteristics and issues. *Journal of Vocational Rehabilitation, 32*(2), 81–88.
- Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Wagner, M., & Taylor, J. L. (2012). Post-secondary education and employment among youth with an autism spectrum disorder. *Pediatrics, 129*(6), 1042–1049.
- Taylor, J. L., & Seltzer, M. M. (2011). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism and Developmental Disorders, 41*(5), 566–574.
- Test, D., Smith, L. & Carter, E. (2014). Equipping youth with autism spectrum disorders for adulthood: Promoting rigor, relevance, and relationships. *Remedial and Special Education.*
- Vaughn, S., Schumm, J. S., & Sinagub, J. (1996). *Focus group interviews in education and psychology.* Thousand Oaks, CA: Sage.
- White, S., Ollendick, T., & Bray, B. (2011). College students on the autism spectrum: Prevalence and associated problems. *Autism, 15*(6), 683–701.
- Wilczynski, S., Menousek, K., Hunter, M. & Mudgal, D. (2007). Individualized education programs for youth with autism spectrum disorders. *Psychology in the Schools, 44*(7), 653–666.

