“Falling through the Cracks”
Challenges for Students with ASD In High School

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OUTLINE

- Background
- Methods
- Results
- Strategies
HIGH SCHOOLS

- Very different from elementary and middle school
- Present opportunities for increased independence
- High stakes testing is prominent; thus, the primary focus of educators tends to be on academic achievement
- Highly social contexts
AUTISM SPECTRUM DISORDER

(APA, 2013; CDC, 2014)

- **Prevalence:** 1 in 68 children
- **Male to female ratio:** 4.5 to 1
- **Core features:**
  - Social communication & social interaction deficits
  - Restricted, repetitive patterns of behavior, interests, or activities
- **69%** have average or above-average IQ scores
- **Impacts daily functioning throughout the lifespan**
- **Different levels of severity and presentation of symptoms**
WHAT DO WE KNOW ABOUT HIGH SCHOOL STUDENTS WITH ASD?

- Only recently has the prevalence of ASD in 14 to 17-year-old cohorts matched that of younger cohorts (Blumberg et al., 2013)

- 33% of students with ASD in high school are included in the standard grade-level academic curriculum in regular education classrooms (Newman, 2007)

- 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 (Newman, 2007)

- High school teachers are often not provided with professional development specifically about best practices for use with students with ASD (Morrier, Hess & Heflin, 2011)
PROBLEMATIC CHARACTERISTICS

(Humphrey & Symes, 2010; Levy & Perry, 2011)

- Aggression
- Resistance to Change
- Depression
- Self-Injurious Behavior
- Anxiety
- Unacceptable Sexual Behavior
HS transition services focus on improving academic and functional achievement (IDEA reauthorization, 2004)

- start at age 14
- student and parent involvement
- plan for adult outcomes
- coordination with adult services

National research data suggests that students with ASD

- rarely take an active role in the HS transition planning process
- make less progress on transition goals vs. comparison groups

(Shogren & Plotner, 2012)
Studies suggest that individuals with ASD:

- **Have low rates of employment** (Holwerda et al., 2012)
  - work in segregated settings (Carter et al., 2012)
  - work menial jobs (Taylor & Seltzer, 2011)
  - switch jobs frequently (Hendricks & Wehman, 2009)
  - low wages & hours (Taylor & Seltzer, 2011)
  - even when compared to individuals w/ other dxs (Cimera & Cowan, 2009)
  - especially in the first 2 years after HS (Shattuck et al., 2012)

- **Live with their parents** (Farley et al., 2009; Taylor & Seltzer, 2011)

- **Are socially isolated** (Liptak et al., 2011)
  - many have no friendships (Billstedt et al., 2011; Liptak et al., 2011)
  - participate in segregated groups (Shattuck et al., 2011)
RESEARCH PURPOSE

- **Purpose**: To better understand the challenges impacting the success of students with ASD in high school through stakeholder perspectives in order to inform interventions and supports in high school.

- **Research question**: What is challenging about high school for students with ASD and their service providers?
METHODS
RECRUITMENT

- Emails to mailing lists
- Flyers to local business
- Snowball sampling
FOCUS GROUPS

Community A
- 5 Individuals with ASD
- 7 Parents
- 5 General Educators
- 4 Special Education Personnel
- 8 Special Education Personnel

Community B
- 3 Parents
- 9 Special Education Personnel
### Participant Demographics

<table>
<thead>
<tr>
<th></th>
<th>Youth with ASD (n=5, 1 group)</th>
<th>Parents (n=10, 2 groups)</th>
<th>School Personnel (n=26, 4 groups)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Race &amp; Ethnicity</strong></td>
<td>White = 4 Black = 1</td>
<td>White = 9 Black = 1</td>
<td>White = 22 Black = 3 Multi-Race = 1</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>5 Male / 0 Female</td>
<td>0 Male / 10 Female</td>
<td>2 Male / 24 Female</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>≤ 18 yrs = 2 19 - 25 yrs = 1 26 - 40 yrs = 2</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>Child’s Age</strong></td>
<td>-</td>
<td>13 – 29 years (M = 20)</td>
<td>-</td>
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<tr>
<td><strong>Experience in Education</strong></td>
<td>-</td>
<td>-</td>
<td>1 - 40 years (M=15)</td>
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Questions about the HS experiences of students with ASD

5 trained moderators

~90 minutes in length
  - Audio & video recorded
  - Transcribed verbatim

Member checking
  - Opportunities to edit/clarify themes throughout
What is working and what isn’t working in HS for students with ASD?

Team Discussion

Initial Coding of School Personnel Transcripts

Initial Coding of Family Transcripts

2nd Round Coding of Family Transcripts

2nd Round Coding of School Personnel Transcripts

Team Discussion. Refined research question:
What is challenging about HS for students with ASD and those who provide services for them?

Re-Coding

Clarification of Themes

Final Reading
RESULTS
MAIN FINDING

HIGH SCHOOLS
- Highly inconsistent
- Highly social
- Lack knowledge and supports for ASD

STUDENTS with ASD
- Prefer consistency
- Challenged by relationships
- Need specialized supports
THEME 1: INCONSISTENCIES

Across the school day

Over time

Between school & home
INCONSISTENCIES ACROSS THE SCHOOL DAY

- Teachers have different classroom structures, teaching styles, and hold different expectations for their students

“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” (Administrator)
Changes in the daily schedule impact students with ASD

“When we have delayed opening, they just don’t come because they can’t handle that change in schedule.” (Special educator)

Variability across teachers in their implementation of IEP goals
INCONSISTENCIES OVER TIME

- Inconsistencies between middle and high school
- Inconsistencies from year to year in high school

“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, the teachers have to go through this. There should be some kind of easier transition.” (General education teacher)

- Inconsistencies during transition out of high school
  - “There was a lot of support in high school and there’s zero support now [in college].” (Parent)
Different expectations for students

“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.” (Special education personnel)

“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.” (Parent)
THEME 2: INTERPERSONAL CONNECTIONS

Students with ASD making and maintaining relationships

Communication challenges experienced by service providers
MAKING AND MAINTAINING RELATIONSHIPS

- Behaviors of students with ASD “annoy” peers (Teacher)
- Learning about “engaging in social situations” was hard in high school (Individual with ASD)
- Negative experiences with peers

“Sometimes being identified as different is bad.” (Individual with ASD)

“Kids are not nice from my experience.” (Individual with ASD)
“He doesn’t have friends. He comes to school and he’s in classes, [but] he doesn’t have friends”.
(Parent)

“[If you] ask him who his friend is, he’ll say someone in class but he doesn’t do anything with people alone.”
(Parent)
COMMUNICATION DIFFICULTIES

- Lack of communication with other teachers
- Issues of confidentiality related to communication
- Communication is difficult between parents and teachers
  - “So many times [teachers] see us as their enemy.” (Parent)
- Teachers unaware of IEPs

“When I went and started talking about his IEP and what the accommodations were, [the teachers] had not been given the IEP.” (Parent)
THEME 3: KNOWLEDGE / PROCESS BREAKDOWNS

- Knowledge and preparation
- Roles and responsibilities
- Special education processes
Lack of general knowledge about ASD

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?’ (Parent)

Anything that my kid’s teachers knew, it was because we bugged them, bugged them and bugged them, and made them. (Parent)
MULTIPLE, AND OFTEN UNCLEAR, ROLES AND RESPONSIBILITIES OF HIGH SCHOOL PERSONNEL

LACK OF SUPPORT FROM THE SCHOOL

“They only had one special [education] teacher who did all his IEPs...one person has all that responsibility.” (Parent)

EDUCATORS ARE OVERWHELMED

“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?” (Special educator)
Clear expectations, but not clear ways to meet them

“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.” (Parent)
Participants described multiple problems with IEPs:

- created but not implemented
- written too broadly
- only addressed certain aspects of functioning
- not given to all teachers
- were not individualized enough
IMPLICATIONS FOR PRACTITIONERS
Nature of high school experience may be contributing to the challenges individuals with ASD encounter in HS

- Inconsistencies across the school day, over time, and between environments
- Difficulties making and maintaining relationships in a highly social context and communication difficulties among stakeholders
- Lack of knowledge and preparation of school personnel
School personnel and families are encouraged to recognize inconsistencies students may be experiencing:

- Changes in daily schedule
- Expectations from teacher to teacher
- Expectations from home to school
- Variability in accommodations and modifications
STRATEGIES: INCONSISTENCIES

- Visual Supports

Pictello
STRATEGIES: INCONSISTENCIES

- Provide support to students so they can effectively manage new situations
  - self-awareness strategies
  - self-regulation strategies

**Self-Regulation Script Example**

1. *Identify/label the issue* (e.g., “I am going to miss 4th block.”)
2. *State the reason* (e.g., “It is starting to snow so school is getting out early.”)
3. *Offer a strategy* (e.g., “I can get through this by...”)
4. *General reassurance* (e.g., “There is always a solution to a problem.”)
Parent and/or teacher creates quick reference sheet of accommodations and modifications based on student's IEP and distributes to all teachers.

STRATEGIES: INCONSISTENCIES

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**IEP At a Glance**

Student:
Student Strengths:

<table>
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<tr>
<th>IEP Goals</th>
<th>Suggested Strategies to work on goals</th>
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<td>1.</td>
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<td>3.</td>
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Classroom Accommodations:

Testing Accommodations:

Key Contacts:
- Case Manager
- Parents
- Counselor
- Related Services

Class Schedule:
STRATEGIES: CHALLENGING RELATIONSHIPS

- Social skills interventions
  - Social Competence Intervention (Stichter et al., 2010)

- Peer mediated interventions
  - Peer Supports (Carter, Sisco, & Chung, 2012)
  - Peer Networks (Haring & Breen, 1992)

- Interventions aimed at reducing challenging behaviors that may impact peer relationships (e.g., calling out in class)
  - Self-management strategies and differential reinforcement of other behaviors (Odom et al., 2010)
STRATEGIES: COMMUNICATION

- Vertical planning
- Prearranged communication
- IEP at a Glance
- Quick Tip Sheets

Quick Tip Sheet Ideas:
- Strengths of the student
- Social, academic, and/or behavioral strategies that work well and don’t work well for the student
- Strategies that work well if the student displays undesirable behavior
RESOURCES

- **Center on Secondary Education for Students with ASD**
  [http://csesa.fpg.unc.edu](http://csesa.fpg.unc.edu)

- **Autism at a Glance Series**
  [http://csesa.fpg.unc.edu/resources/autism-glance-supporting-communication-high-school](http://csesa.fpg.unc.edu/resources/autism-glance-supporting-communication-high-school)

- **Understanding Autism Professional Development Kit**
  [http://csesa.fpg.unc.edu/resources/understanding-autism-professional-development-curriculum](http://csesa.fpg.unc.edu/resources/understanding-autism-professional-development-curriculum)

- **Autism Internet Modules**
  [http://www.autisminternetmodules.org/user_mod.php](http://www.autisminternetmodules.org/user_mod.php)

- **National Professional Development Center on ASD**
  [http://autismpdc.fpg.unc.edu](http://autismpdc.fpg.unc.edu)
NEED INFORMATION ON ASD AND HIGH SCHOOL?

Special Issue in RASE: Autism, Adolescence, and High School
• Addressing academic needs
• Preparing youth with ASD for adulthood
• Promoting social competence and peer relationships
• Supporting independence
• Roles and needs for families of individuals with ASD
• Applying an implementation science framework for adopting a comprehensive program
More information is needed about the challenges of high school from the perspectives of individuals with ASD.

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.
QUESTIONS

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