Post School Outcomes and Follow-up for Young Adults on the Autism Spectrum Following Participation in the Center on Secondary Education for Students with ASD (CSESA)

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Co-Presenters
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Sara McDaniel, San Diego State University, CA
Samuel Odom, University of North Carolina, Chapel Hill
Leann Smith-DaWalt, University of Wisconsin, Madison
About

A randomized control trial (RCT) to evaluate a comprehensive intervention model for high school students with ASD

Sixty high schools across three states (California, Wisconsin, North Carolina) participated

30 schools randomly assigned to the intervention (TX) and 30 to the services as usual (SAU) group. 8-12 target students per school. Total sample = 546

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Today we present data on the first group (n = 57) of young adults who exited the school system across the 60 participating schools; 31 in the TX group and 26 in SAU.
Identify post-school outcomes and key findings in the first exited group of CSESA participants, as described by young adult and parent participants.
Exited Sample Demographics (N=57)

Mean Age of 17 at Time 1 (range =15-20)
82% Male
Race: 65% White, 18% Black, 17% Other
Mean Leiter Score of 85.55 (range = 31-135) **assessed by school psychologist
Mean Vineland Score of 75.49 (range = 31-104) **assessed by teacher
Diploma type: 58% standard, 42% modified
Measures for Exited Data Collection

Parent/Caregiver Check-In:

Developed by CSESA team

29 item questionnaire examining adult domain areas (postsecondary education, employment, daily living, adult services, social/community activities)

21 parents responded
### Parent/Caregiver Check-In

Thank you for allowing your son/daughter to participate in the CESA project. We will use this questionnaire to learn more about what happens as students leave high school. Most of the questions will ask about the time since your son/daughter exited their high school or transition program. NOTE: As part of this study, we are working with young adults across the whole autism spectrum, so some of these questions may be more or less relevant to your son/daughter and family. Please answer each question even if it is less relevant for your family.

### General Information

1) Describe your son/daughter's current living situation. Choose one answer:

- [ ] 1. Living in the family home
- [ ] 2. Living in another home (e.g., extended family, foster home, etc.)
- [ ] 3. Living independently by him/herself in apartment, dorm, house, etc.
- [ ] 4. Living independently with others in apartment, dorm, house, etc.
- [ ] 5. Living in a partially supported/semi-independent setting outside the home
- [ ] 6. Living in a fully supported/group home setting outside the home with fewer than 8 residents
- [ ] 7. Living in a fully supported/residential placement (e.g., psychiatric facility, long-term care facility) outside the home with 8 residents or more
- [ ] 8. Other Specify: ________________

2) Please check what best describes your current situation regarding guardianship of your son/daughter. Choose one answer:

- [ ] 1. Full guardianship
- [ ] 2. Limited guardianship
- [ ] 3. Power(s) of attorney

### Work/Vocation and Related Activities

23) Indicate which of the following work/vocational activities your son/daughter has participated in the past 6 months.

<table>
<thead>
<tr>
<th>Work/Vocational Activities</th>
<th>Participate in last 6 months?</th>
<th>IF YES: How many hours per week?</th>
<th>Is it a paid position?</th>
<th>Are they in the position now?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Independent, competitive employment in community (at least minimum wage)</td>
<td></td>
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<td></td>
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<tr>
<td>2. Supported, employment in community (e.g., job coach at work setting)</td>
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<td></td>
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<tr>
<td>3. Microenterprise (e.g., self-owned business)</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>4. Internship or apprenticeship</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>5. Military service</td>
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<tr>
<td>6. Contract/sheltered work (e.g., paid by the piece, paid less than min. wage in group setting)</td>
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<tr>
<td>7. Adult day program or day rehabilitation program</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>8. Volunteer work</td>
<td></td>
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<td></td>
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<tr>
<td>9. Other Specify: ________________</td>
<td></td>
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</tbody>
</table>
Parent/Caregiver Interview:

Developed by CSESA team
34 question structured interview
Conducted in-person by CSESA researchers
Gathered qualitative information pertaining to adult domains (postsecondary education, employment, daily living, adult services, social/community activities)
25 parents participated in interview
Interviews audio taped and transcribed
Parent/Caregiver Interview

Introduction

Time began: ___ : ___ AM / PM (Circle one.)

Thank you so much for allowing your son/daughter to participate in the CSESA study and for speaking with us today. This interview will focus on your son/daughter (Name of Child). The purpose of this interview is to learn more about your son/daughter as well as your experiences and your son’s/daughter’s experiences since leaving high school. We are working with young adults across the whole autism spectrum so some of these questions may be more or less relevant for your son/daughter or your family. This will likely take between 30 and 60 minutes. You can say as much or as little as you want about each question or skip any question.

I would like to be focused on listening to you, and sometimes it is difficult to write down all of the information you give me so I would like to audio record the interview so I don’t miss anything. The recording is kept in a locked office and also in a locked file cabinet, or on a secured computer network. If you choose not to be recorded, you can still do the interview. Do you have any questions before we start the interview? May I record the interview?

No ☐ If the parent indicates to NOT be recorded, proceed without doing so, but take thorough notes.
Yes ☐ I will begin recording now. First, I will record today’s date, then I will say your ID number. [Check the recording device to make sure the interview is recording. Proceed with interview.]

Social/Community Activities

Now, we’ll talk about social and community activities. This can include more structured activities such as sports teams, religious services or groups, clubs, or meet-up groups or unstructured activities like hanging out with friends or going out to movies.

21) Tell me more about your son’s/daughter’s experiences participating in social or community activities:

22) Tell me about your son’s/daughter’s relationships and interactions with family, friends, or significant others.

23) For the next question, please look at Response Card Option #1. How helpful was high school in preparing your son/daughter for these social and community activities and why? On a scale of 1-5, 1 being “Very Unhelpful” to 5 being “Very Helpful”.

<table>
<thead>
<tr>
<th>Very Unhelpful</th>
<th>Unhelpful</th>
<th>Neither unhelpful nor helpful</th>
<th>Helpful</th>
<th>Very Helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

24) What are some things that have gone well related to participation in social and community activities? OR In addition to what you have already talked about, are there other things that have gone well related to participation in social and community activities?

25) What are some barriers to your son/daughter related to participation in social or community activities? OR In addition to what you have already talked about, are there other things that have been barriers to your son/daughter related to participation in social or community activities?
Young Adult Check-In:

Developed by CSESA team

35 item interview protocol examining adult domains (postsecondary education, employment, daily living, adult services, social/community activities)

Conducted in-person as structured interview with CSESA researchers

24 young adults participated in interview

Interviews audio taped and transcribed
Young Adult Check-In

Thank you for participating in the CSESA project! We are using these questions to learn more about life after high school. Your participation is voluntary and you can choose to skip any question you do not want to answer. As part of this check-in, we are going to ask you questions about four areas: (1) Overall life after high school, (2) Educational experiences, (3) Work and work-related activities, and (4) Social and community activities.

Overall, how do you feel about your life after high school? On a scale of 1-5, 1 being “Very Unsatisfied” to 5 being “Very Satisfied”.

<table>
<thead>
<tr>
<th>Very Unsatisfied</th>
<th>Unsatisfied</th>
<th>In the middle</th>
<th>Satisfied</th>
<th>Very Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

How helpful was high school in getting you ready for adulthood? On a scale of 1-5, 1 being “Very Unhelpful” to 5 being “Very Helpful”.

<table>
<thead>
<tr>
<th>Very Unhelpful</th>
<th>Unhelpful</th>
<th>In the middle</th>
<th>Helpful</th>
<th>Very Helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Have you had any educational experiences in the past 6 months?

- No
- Yes

If NO, What are some things that stop you from being a part of educational experiences?

If YES, Tell us about your educational experiences after high school.

What are some things that have gone well in your educational experiences?

What are some things that have been hard in your educational experiences?
**Procedures**

Participants involved in CSESA RCT

- Graduation/Age Out of K-22 services

- Participants must have been exited from CSESA 1 year prior to follow-up

- Parent/Caregiver Check-In distributed and collected via mail (N=21)

- Eligible families from Cohort 1 were contacted for participation (N = 57)

- Interviews with parents and young adults conducted (N = 25/24)
Findings

1. Parent Reports of Post-School Life for Young Adults with ASD

2. Young Adult Views of Life After High School

3. Differences in Perception of Post-School Life for Young Adults with ASD and their parents.
Parent Reports of Post-School Life for YA with ASD

Satisfaction

with High School

<table>
<thead>
<tr>
<th>Percentage of Ratings of High School as Helpful or Very Helpful for Experiences after High School</th>
<th>Parent/Caregiver Interview (n=25)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educational Experiences</td>
<td>58.3</td>
</tr>
<tr>
<td>Work/Vocational Experiences</td>
<td>52.0</td>
</tr>
<tr>
<td>Social and Community Experiences</td>
<td>52.0</td>
</tr>
<tr>
<td>Community Living</td>
<td>48.0</td>
</tr>
<tr>
<td>Adult Services</td>
<td>38.1</td>
</tr>
<tr>
<td>General</td>
<td>70.8</td>
</tr>
</tbody>
</table>
Overall, 42% indicate that their child participates in some type of work:

*In the past 6 months, these CSESA exited young adults participated in:*

<table>
<thead>
<tr>
<th>Type of Work</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Competitive Employment</td>
<td>33%</td>
</tr>
<tr>
<td>Supported Employment</td>
<td>0%</td>
</tr>
<tr>
<td>Self Employed</td>
<td>10%</td>
</tr>
<tr>
<td>Internship</td>
<td>5%</td>
</tr>
<tr>
<td>Sheltered/Contract Work</td>
<td>5%</td>
</tr>
<tr>
<td>Adult Day Program</td>
<td>10%</td>
</tr>
<tr>
<td>Volunteer Work</td>
<td>15%</td>
</tr>
<tr>
<td>Military</td>
<td>0%</td>
</tr>
</tbody>
</table>
Parent Reports of Post-School Life for YA with ASD

**Vocational**

Most Frequent:
Completed Job Applications (38%)

Least Frequent:
Interviewed for Jobs (19%)
Parent Reports of Post-School Life for YA with ASD

**Education**

“He graduated late, but is taking classes at [community college]. He started with just 1-2 classes at a time, but he’s enjoying them and taking responsibility for his schooling.”

47% of parents reported that their child participates in some sort of educational activity:

*In the past 6 months, exited CSESA students have been involved in:*

- Taken classes at a Community College/Vocational School- 38%
- Taken classes at a 4-year university- 14%
- Taken classes at an educational program designed for individuals w/ disabilities- 0%
Parents’ reported difficulty in finding, getting and using various adult support services:

- Very Difficult - 0%
- Difficult - 33%
- Neither Difficult nor Easy - 52%
- Easy - 11%
- Very Easy - 5%
Parent Reports of Post-School Life for YA with ASD

Adult Services

Most Frequent:
Mental Health Service (52%)
SSI (33%)
Developmental Disability Services (33%)
Transportation (33%)
Parent Reports of Post-School Life for TA with ASD

Social & Community

“He needs a peer. Someone to help him open doors to activities/possibilities.”

100% of parents report that their child participates in at least 1 social activity at least 1x per month

Sports/Athletic Teams - 19%
Exercise - 62%
Hanging out with Friends - 57%
Online Gaming - 76%
Social Networking (online) - 72%
Meet-Up Groups Related to Hobbies - 33%

Religious Groups - 67%
Support Groups - 33%
Social Skills Groups - 29%
Social Groups w/ others w/ disabilities - 34%
Visual/Performing Arts - 43%
Parent Reports of Post-School Life for YA with ASD

Social & Community

“He lives in a group home with other boys, and gets more and more independent and mature each year. I don’t see him ever living on his own, but I hope that he can find peace and do more day-to-day.”

Young Adult’s Current Living Situation:

- 77% living at home
- 12% living independently (alone)
- 11% Other
### Young Adult Views of Life After High School

#### Satisfaction

<table>
<thead>
<tr>
<th>Area</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>General</td>
<td>50.0</td>
</tr>
<tr>
<td>Educational experiences</td>
<td>50.0</td>
</tr>
<tr>
<td>Job activities</td>
<td>54.2</td>
</tr>
<tr>
<td><strong>Social life</strong></td>
<td><strong>75.0</strong></td>
</tr>
<tr>
<td>Community activities</td>
<td>37.5</td>
</tr>
</tbody>
</table>

*“I’m not a very social person, so that hasn’t changed.”*

*“I started online dating!”*
### Young Adult Views of Life After High School Helpfulness

Percentage of Young Adults Rating High School as “Helpful” or “Very Helpful” in Terms of Preparing for Experiences after High School

<table>
<thead>
<tr>
<th>Experience</th>
<th>Rating</th>
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<tbody>
<tr>
<td>Educational Experiences</td>
<td>70.8</td>
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<tr>
<td>Social and Community Experiences</td>
<td>75.0</td>
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<tr>
<td>General</td>
<td>62.5</td>
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*Based on a scale of 1-5, 1 being “Very Unhelpful” to 5 being “Very Helpful.*
52% of exited young adults reported a job experience in the past 6 months. Of those
- 82% reported having a job related to things they are good at
- 64% reported having a job related to their interests
- 36% reported having the support of a job coach

“Last year I had a job coach, but this year I haven’t done anything like that. No job yet, since high school.”
Differences in Perception of Post-School Life for Young Adults with ASD and their Parents

Involvement

Average Rating of Involvement in Life Experiences after High School

<table>
<thead>
<tr>
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<th>Parent/Caregiver Interview (n=25)</th>
<th>Young Adult Check-In (n=24)</th>
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<tbody>
<tr>
<td>% involved in educational experiences in past 6 months</td>
<td>75.0</td>
<td>60.9</td>
</tr>
<tr>
<td>% involved in work or vocational experiences in past 6 months</td>
<td>52.0</td>
<td>52.2</td>
</tr>
</tbody>
</table>
### Differences in Perception of Post-School Life for Young Adults with ASD and their Parents

**Helpfulness**

<table>
<thead>
<tr>
<th>Percentage of Ratings of High School as Helpful or Very Helpful for Experiences after High School</th>
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<td>62.5</td>
</tr>
</tbody>
</table>
Discussion

Based on the findings from this CSESA sample of exited young adults on the autism spectrum what is most surprising?

Are these findings similar to what you are experiencing in your schools and districts?
Thank You!