Post School Outcomes and Follow-up for Young Adults on the Autism Spectrum

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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**
Today we present data on young adults who were part of Cohort 1 and exited the school system across the 60 participating schools (n= 74)
Session Objectives

1. The session will present post-school outcome data for a cohort of 74 young adults with Autism Spectrum Disorder (ASD) after exiting high school.

2. Resources to support high-school and transition programming for individuals with ASD will be shard from the CSESA website.
Exited Sample Demographics (n=74)

- **Mean age** of 20 (range = 18-24)
- **Gender**: 78% Male, 21% Female, 1% Non-Binary
- **Race**: 72% White, 7% African American, 11% Multi/Biracial, 10% Other
- **Mean Leiter Score** of 90 (range = 33-135) **assessed by CSESA Research Team**
- **Mean Vineland Score** of 77.21 (range = 34-116) **assessed by teacher**
- **Diploma type**: 72% standard, 28% modified
Measures for Data Collection for Exited Young Adults

Parent/Caregiver Online Survey:

- Developed by CSESA team
- 21 item questionnaire examining adult domain areas (postsecondary education, employment, daily living, adult services, social/community activities)
- 74 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.
   - [x] Living in the family home
   - [ ] Living in another home (e.g., extended family, foster home, etc.)
   - [x] Living independently (no paid staff) by himself/herself in apartment, dorm, house, etc.
   - [x] Living independently (no paid staff) with others in apartment, dorm, house, etc.
   - [ ] Living in a partially supported/semi-independent setting outside the home
   - [ ] Living in a fully supported/group home setting outside the home with fewer than 8 residents
   - [ ] Living in a fully supported/residential placement (e.g., psychiatric facility, long-term care facility) outside the home with 8 residents or more
   - [x] Other Specify:

2. Please check what best describes your current situation regarding guardianship/conservatorship of your son/daughter. Choose one answer.
   - [x] Full guardianship/conservatorship
   - [ ] Limited guardianship/conservatorship
   - [x] No (zero) involvement

#### Daily Living Activities
1. The following questions refer to your son/daughter’s recent social activities. If you do not currently see them regularly, please ask your son/daughter or others who are familiar with their recent activities.

<table>
<thead>
<tr>
<th>Activity Description</th>
<th>Never</th>
<th>1-2 times this month</th>
<th>A few times this month</th>
<th>About once a week</th>
<th>A few times a week</th>
<th>Several days a week</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Get together with friends/peers as part of an organized group or activity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Get together with friends/peers other than organized group or activity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) Call or send a text message to his/her friends/peers</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>d) Interact with others using the internet (e.g., e-mail, chat rooms, gaming, Facebook)</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

#### High School Services and Supports
6. Please indicate if your son/daughter uses each service or support during high school.

<table>
<thead>
<tr>
<th>Service or Support</th>
<th>During high school</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Social security (SSI or SSDI)</td>
<td>No</td>
</tr>
<tr>
<td>b) Medicaid</td>
<td>No</td>
</tr>
<tr>
<td>c) Vocational rehabilitation services</td>
<td>No</td>
</tr>
<tr>
<td>d) Developmental disabilities services (e.g., Regional Center)</td>
<td>No</td>
</tr>
<tr>
<td>e) Nursing or personal care assistant</td>
<td>No</td>
</tr>
<tr>
<td>f) Speech-language pathology</td>
<td>No</td>
</tr>
<tr>
<td>g) Occupational therapy, or life skills therapy or training</td>
<td>No</td>
</tr>
<tr>
<td>h) Physical therapy</td>
<td>No</td>
</tr>
<tr>
<td>i) Mental health or psychological services</td>
<td>No</td>
</tr>
<tr>
<td>j) Social work</td>
<td>No</td>
</tr>
<tr>
<td>k) Assistive technology</td>
<td>No</td>
</tr>
<tr>
<td>l) Respite care</td>
<td>No</td>
</tr>
<tr>
<td>m) Living services (e.g., supported apartment, group home)</td>
<td>No</td>
</tr>
<tr>
<td>n) Private or public transportation</td>
<td>No</td>
</tr>
</tbody>
</table>
Measures Continued

**Parent/Caregiver Interview:**

- Developed by CSESA team
- 17 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)
- 65 parents participated in interview
Parent/Caregiver Interview

Introduction

Date: ________________________

Introductions and friendly small talk to establish a comfortable atmosphere.

Thank you so much for allowing your son/daughter to participate in the CESA study and for speaking with us today. This interview will focus on your son/daughter (insert NAME) The purpose of this Interview is to learn more about your son/daughter and the types of activities he/she has been involved in 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 the information you give me, so I would like to audio record the interview so that I don’t miss anything. The recording is kept in a locked file cabinet within a locked office, or on a secured computer network. If you choose not to be recorded, you can still do the interview.

May I record the interview?

No x □ If the parent indicates to NOT be recorded, proceed without going 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.)

Do you have any questions before we start the interview?

What date (month & year) did he/she exit high school? ________________

Education and Related Activities:

1. Initial Education Question:

First, I would like to ask you about educational experiences that [NAME] has participated in. Has [NAME] been engaged in any experiences in educational settings since leaving high school? This includes post-high school programs, 2-year or 4-year college programs, postsecondary programs specifically for students with disabilities, and online courses.

☐ NO [IF NO, STOP education questions and GO to Initial Work/Vocation Question]

☐ YES [IF YES, proceed with follow-up education questions below]

Follow-up education questions:

2. After [NAME] left high school, what type of educational settings did they attend or take classes in? Ask about each of the following and record answers below.

<table>
<thead>
<tr>
<th>Educational Settings</th>
<th>School/Program Name</th>
<th>Average # hours per week in class</th>
<th>Currently Enrolled?</th>
<th>Number of months attended</th>
<th>This coursework will lead to:</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>Technical Vocational High School</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>None</td>
</tr>
<tr>
<td>Yes</td>
<td>2-year or 4-year college</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>None</td>
</tr>
</tbody>
</table>

If they are between semesters, ask directional for the term or explained how they are currently enrolled in college.

11. Can you tell me about the type of activities your son/daughter currently performs or performed at the day program/sheltered workshop? *Important for Voc. Index

12. How does this program fit with [NAME’s] interests or strengths?

13. How satisfied is/are [NAME] with this program?

14. [NAME] paid for any of these work-related activities?

☐ NO

☐ YES Weekly, or other, rates?

Ask Q. 15 if son/daughter has/had a supported or competitive job or military or self-employment/ microenterprise following high school exit.

15. Can you tell me more about the job(s) [NAME] had after he/she left high school?
Measures Continued

**Young Adult Check-In:**

- Developed by CSESA team
- Conducted in-person as structured interview with young adult
- 25 item interview protocol examining adult domains (education, employment, daily living, adult services, social/community activities)
- 54 young adults participated in interview
## Young Adult Check-In

Thank you for participating in the CESA 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.

Please place a ✔ in the box that best describes how you feel about each statement below.

### High School Experiences

<table>
<thead>
<tr>
<th>Statement</th>
<th>No</th>
<th>In the Middle</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) I liked my high school.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2) My high school prepared me for my life now.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3) My high school prepared me for going to work.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4) My high school prepared me to do activities with other people.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5) My high school prepared me for taking classes after high school.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Work After High School:

<table>
<thead>
<tr>
<th>Question</th>
<th>No</th>
<th>In the Middle</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>7) I have, or had, a job after high school.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7a) If &quot;yes&quot;, I liked the job I have/had after high school.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7b) If &quot;no&quot;, why not?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Social Activities After High School:

<table>
<thead>
<tr>
<th>Activity</th>
<th>No</th>
<th>In the Middle</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>8) I have friends.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9) I like my friends.</td>
<td></td>
<td></td>
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<tr>
<td>10) I call or text my friends.</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>11) I like calling and texting my friends.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12) I go out to restaurants.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13) I like going out to restaurants.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14) I go grocery shopping.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15) I like going grocery shopping.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16) I meet new people.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17) I like meeting new people.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18) Other things I do.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Life Now and in the Future:

<table>
<thead>
<tr>
<th>Question</th>
<th>No</th>
<th>In the Middle</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>19) I like my life right now.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20) I would like a different job in the future.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>21) If &quot;yes&quot;, what job would you like?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Life Now and in the Future (cont.):

<table>
<thead>
<tr>
<th>Question</th>
<th>No</th>
<th>In the Middle</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>21a) If &quot;yes&quot;, what classes would you take?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22) I would like some things to be different about my social life.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22a) If &quot;yes&quot;, what would you like to be different about your social life?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

23) What are the things you're interested in now? Do you get to do the things you like?
Procedures

Participants involved in CSESA RCT

Participants exited from high school between 2016 and 2018

Eligible families from Cohort 1 were contacted for participation

Interviews with parents and young adults conducted
Findings

1. Parent Reports of Post-School Life for Young Adults with ASD
2. Young Adult Views of Life After High School
3. Case Studies – Where are they now?
## Vocational Employment-Related Activity % Participating Average Hrs. Per Week

<table>
<thead>
<tr>
<th>Employment-Related Activity</th>
<th>% Participating</th>
<th>Average Hrs. Per Week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Volunteering</td>
<td>13%</td>
<td>4.5 hrs</td>
</tr>
<tr>
<td>Adult Day Program</td>
<td>12%</td>
<td>19 hrs</td>
</tr>
<tr>
<td>Sheltered/Contract Work</td>
<td>8%</td>
<td>17 hrs</td>
</tr>
<tr>
<td>Supported Employment</td>
<td>42%</td>
<td>14 hrs</td>
</tr>
<tr>
<td>Competitive Employment</td>
<td>58%</td>
<td>20 hrs</td>
</tr>
<tr>
<td>Military</td>
<td>0%</td>
<td>N/A</td>
</tr>
<tr>
<td>Self-Employed</td>
<td>9%</td>
<td>2 hrs</td>
</tr>
<tr>
<td>Internship</td>
<td>13%</td>
<td>18 hrs</td>
</tr>
</tbody>
</table>
Parent Reports of Post-School Life for YA with ASD

Vocational

- 70% have completed a job application
- Median reported wage = $9.63/hr.
- 65% have participated in a job interview
Education

Since exiting high school, **74%** of CSESA students have:

- Taken classes at a community college- **49%**
- Taken online classes- **25%**
- Taken classes at a vocational school- **27%**
- Taken classes at a 4-year university- **14%**
- Taken classes at an educational program designed for individuals w/ disabilities- **23%**
Parents’ reported YA Living Situation:

- Living in Family Home
- Fully Supported Group Home
- Partially Supported Independent Living
- Living Independently
- Living in Another Home
- Other

% Of YA’s
**Parent Reports of Post-School Life for YA with ASD**

**Guardianship**

Parents’ reported status of guardianship of young adults:
- Full guardianship- 34%
- Limited guardianship- 14%
- Power of Attorney- 4%
- No current guardianship, but plans to get it- 12%
- No current guardianship, and no plans to get it- 34%
- Other- 2%
Use of Adult Services since High School

% of Participants Who Have Used Adult Services Service Since Exiting H.S.

- Mental Health
- SSI
- Dev. Disability Services
- Transportation
- Nursing Assistance
- Medicaid
- Vocational Rehabilitation
- Social Work
- Respite Care
- Assistive Technology

% of Participants Who Have Used Service Since Exiting H.S.
Parent Reports of Post-School Life for YA with ASD

**Adult Services**

Participants reported waiting lists for:

- Supported Housing
- SSI
- Vocational Programming/Rehab
- Mental Health Services

Are you on a waiting list for any services?

24% reported YES!
Parent Reports of Post-School Life for YA with ASD

Social & Community

Reported Social Activities

- Organized Group Activity
- Hang out with Friends/Peers
- Calls/Sends texts to Friends/Peers
- Interacts with Others Online

- Never
- Sometimes
- Often
**Young Adult Views of Life After High School**

*Helpfulness of High School*

Percentage of Young Adults rating high school as having prepared them for various experiences after high school

“*My High School prepared me for…*”

<table>
<thead>
<tr>
<th>Activity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life Now</td>
<td>44%</td>
</tr>
<tr>
<td>Going to Work</td>
<td>45%</td>
</tr>
<tr>
<td>Doing Activities with Other People</td>
<td>50%</td>
</tr>
<tr>
<td>Taking Classes</td>
<td>43%</td>
</tr>
</tbody>
</table>

*Based on having responded to the item “Yes” (out of “No,” “In the Middle,” and “Yes”)
Young Adult Life Satisfaction

“I like my life right now.”

60% said “Yes”
Young Adult Views of Life After High School

“Do I...”

- Have Friends
- Call/Text Friends
- Go to Restaurants
- Go Grocery Shopping
- Meeting New People

- “No”
- “Yes”
Young Adult Views of Life After High School

Satisfaction with Life Activities

"Do I Like…"

- My Friends
- Calling/Texting Friends
- Going to Restaurants
- Going Grocery Shopping
- Meeting New People

- "No"
- "In the Middle"
- "Yes"
“Any other hopes for the future?”

Transfer to a 4 yr. university to learn about animation and eventually get a job in a major studio. Someday I see myself living on my own close to my family.

“Live a stable life. Secure income, good size paycheck, not having to worry about debts and loans. Would love to have someone to help, like a wife or husband. A person willing to help and care.”

“Not much except win the lottery so I can fix my dads back.”

“Have my own independent life; have a job that makes me satisfied. Lots of people have jobs they don't like, and I don't want to be one of those people.”

“Travel, see other countries - I have a natural curiosity for that.”
“What would you like to be different about your social life?”

“I would like to meet someone special and have a relationship. I'm lonely.”

- “Be more engaged in my friend group; go more places and spend more time with them as not as much time interacting with them online; I'd like to be more physically connected to my friends.”
- “Being more open with people and being able to talk more and not be awkward.”
- “I have had issues responding to friends on time, due to juggling my homework assignments.”
What are things you’re interested in now? Do you get to do the things you like?

- “Animation, art, movies. I get to do these things but would like to do them with friends.”
- “I am interested in driving with Uber or Lift so I can meet other new people.”
- “Trying to mature better; I need to grow. I’m looking for more volunteer opportunities to get a better job; handling responsibilities; not being as lazy and be more proactive. I am trying a little bit to do all these things”
“Is there anything else you feel it is important to share with us?”

“I feel, like, fortunate, to be a part of this organization. You have been very helpful the way you’ve observed me over the years.”

“I’ve been going to college for 2 years. Culinary track.”

“A note related to my work after high school – I don’t like being paid $5 below national average.”

“I prefer to be at home and be on my own. I’m not good with authority figures.”

“I stopped taking my medications.”

I have concerns and anxiety about going out, how to get out in the world, but I want to learn how to cope with it.”
Case Studies

Where are they now?
Case Studies

Meet some of the young adults who were involved with the CSESA project, and see what they’re up to now!

“Jon”

Age: 22 years old
Graduated w/ Standard Diploma June 2017

- Works independently as a cook at Buffalo Wild Wings and at a local pizza restaurant
- Living in the family home
- Gets together with friends weekly & interacts with peers by phone or internet several times weekly

“The transition from high school continues to be a struggle with little to no support, but Jon has been persistent in his work ethic.”
Case Studies

Meet some of the young adults who were involved with the CSESA project, and see what they’re up to now!

“Mara”

- Currently taking classes to one day becoming a music therapist.
- Works 10 hours/week as an eyewear specialist.
- Enjoys volunteering at her church and at the animal shelter.

Age: 20 years old
Graduated w/ Standard Diploma June 2018

“I like my job because I enjoy working with the customers.”
Case Studies

Meet some of the young adults who were involved with the CSESA project, and see what they’re up to now!

“José”

Age: 22 years old
Graduated w/ Modified Diploma June 2016

- Member of California Conservation Corps
- Has held 3 food service jobs
- Receiving on-the-job training to become chef
- Has a girlfriend and spends time on many hobbies

“I feel that José has really transformed in the last couple of months, both in his attitude and abilities. CCC has really helped our relationship. He’s happier, more independent, motivated, healthier. He’s lost 45 lbs.!”
Discussion

• Based on the findings from this CSESA sample of exited young adults with ASD, what is most surprising?

• Are these findings similar to what you are experiencing in your schools, districts and communities?

• Questions?
Free Resources!

The CSESA Website (link via QR Code) has dozens of free resources available for researchers, practitioners, and families!
Thank You!

Contact Information

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