

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

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## **Co-Presenters**

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# About



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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**

# About



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 shared 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 Online Survey



SESA Proximal Measure: PARENT (Out-School)

ID LABEL HERE

## Parent/Caregiver Check-In

Thank you for allowing your son/daughter to participate in the CSESA 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's/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 (no paid staff) by him/herself in apartment, dorm, house, etc.
- ☐ 4 Living independently (no paid staff) 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/conservatorship of your son/daughter. *Choose one answer.*

- ☐ 1 Full guardianship/conservatorship
- ☐ 2 Limited guardianship/conservatorship
- ☐ 3 *Deputy of attorney*

4) The following questions refer to your son's/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.*

	Never	1-2 times this month	A few times this month	About once a week	Several days a week
<b>During the past 1 month about how often did your son or daughter:</b>					
a) Get together with friends/peers as part of an organized group or activity	①	②	③	④	⑤
b) Get together with friends/peers other than organized group or activity	①	②	③	④	⑤
c) Call or send a text message to his/her friends/peers	①	②	③	④	⑤
d) Interact with others using the internet (e.g. e-mail, chat rooms, gaming, Facebook)	①	②	③	④	⑤

### Daily Living Activities

5) Please check the box that best describes your son's/daughter's involvement in daily living activities over the **past 6 months**. *Select one box per activity.*

Daily Living Activities	My son's/daughter's involvement:		
	Not at all	With support	Independently
a) Hygiene (e.g., bathing, grooming)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Cleaning (e.g., laundry, dishes, cleaning rooms)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Cooking or food preparation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Shopping (e.g., grocery, clothing, household goods)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Lawn work or property care (e.g., mowing lawn, landscaping, shoveling)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Household repairs (e.g., fixing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



SESA Proximal Measure: PARENT (Out-School)

ID LABEL HERE

### High School Services and Supports

6) Please indicate if your son/daughter uses each service or support **during high school**.

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

## 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



CSESA Follow-Up Study

Interviewer: \_\_\_\_\_

Interviewee: \_\_\_\_\_

## 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 CSESA 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 <input type="checkbox"/>	If the parent indicates to NOT be recorded, proceed without doing so, but take thorough notes.
Yes <input type="checkbox"/>	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 technical/vocational 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 enroll or take classes in? Ask about each of the following and record answers below.*

*If they are between semesters: ask if enrolled for this term or registered for classes next term - counts as YES.*

Educational Settings	School/Program Name	Average # hours per week in class	Currently Enrolled?	Number of months attended	This coursework will lead to a:
<input type="checkbox"/> No <input type="checkbox"/> Yes	Technical/Vocational/trade school	• • • •	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No	_____ _____ _____ _____	<input type="checkbox"/> Certificate <input type="checkbox"/> License <input type="checkbox"/> 2-year degree <input type="checkbox"/> 4-year degree <input type="checkbox"/> None
<input type="checkbox"/> No <input type="checkbox"/> Yes	2-year or community college	• • • •	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No	_____ _____ _____ _____	<input type="checkbox"/> Certificate <input type="checkbox"/> License <input type="checkbox"/> 2-year degree <input type="checkbox"/> 4-year degree <input type="checkbox"/> None



CSESA Follow-Up Study

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/did the program fit with [NAME]'s interests or strengths?*

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

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

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

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

☐ NO  
☐ YES Hourly, or other, rate? \_\_\_\_\_

**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?*

100 1

## 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



CSESA Proximal Measure: YA (Out-School)

ID LABEL HERE

## 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.

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

### High School Experiences

First, we would like to know your feelings about high school:	1 No	2 In the Middle	3 Yes
1) I liked my high school.	①	②	③
2) My high school prepared me for my life now.	①	②	③
3) My high school prepared me for going to work.	①	②	③
4) My high school prepared me to do activities with other people.	①	②	③
5) My high school prepared me for taking classes after high school.	①	②	③

### Life After High School

In this section, we are going to ask you about activities after high school.

	②	
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CSESA Proximal Measure: YA (Out-School)

ID LABEL HERE

### Work After High School:

	1 No	2 In the Middle	3 Yes
7) I have, or had, a job after high school.	①		③
7a) If "Yes", I liked the job I have/had after high school	①	②	③
7b) If "No", why not?			

### Social Activities After High School:

	1 No	2 In the Middle	3 Yes
8) I have friends.	①		③
9) I like my friends.	①	②	③
10) I call or text my friends.	①		③
11) I like calling and texting my friends	①	②	③
12) I go out to restaurants.	①		③
13) I like going out to restaurants	①	②	③
14) I go grocery shopping	①		③
15) I like going grocery shopping	①	②	③
16) I meet new people	①		③
17) I like meeting new people.	①	②	③
18) Other things I do:			



CSESA Proximal Measure: YA (Out-School)

ID LABEL HERE

### Life Now and in the Future:

	1 No	2 In the Middle	3 Yes
19) I like my life right now.	①	②	③
20) I would like a different job in the future.	①		③
20a) If "Yes", what job would you like?			
21) I would like to take classes in the future.	①		③
21a) If "Yes", what classes would you take?			
22) I would like some things to be different about my social life in the future	①		③
22a) If "Yes", what would you like to be different about your social life?			

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

Parent/Caregiver  
Online Questionnaire  
distributed and  
collected via  
REDCap

2 year Intervention Period

Exited Cohort 1 Follow-Up

Graduation/Age  
Out of K-22  
services

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
Volunteering	13%	4.5 hrs
Adult Day Program	12%	19 hrs
Sheltered/Contract Work	8%	17 hrs
Supported Employment	42%	14 hrs
Competitive Employment	58%	20 hrs
Military	0%	N/A
Self-Employed	9%	2 hrs
Internship	13%	18 hrs

# 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



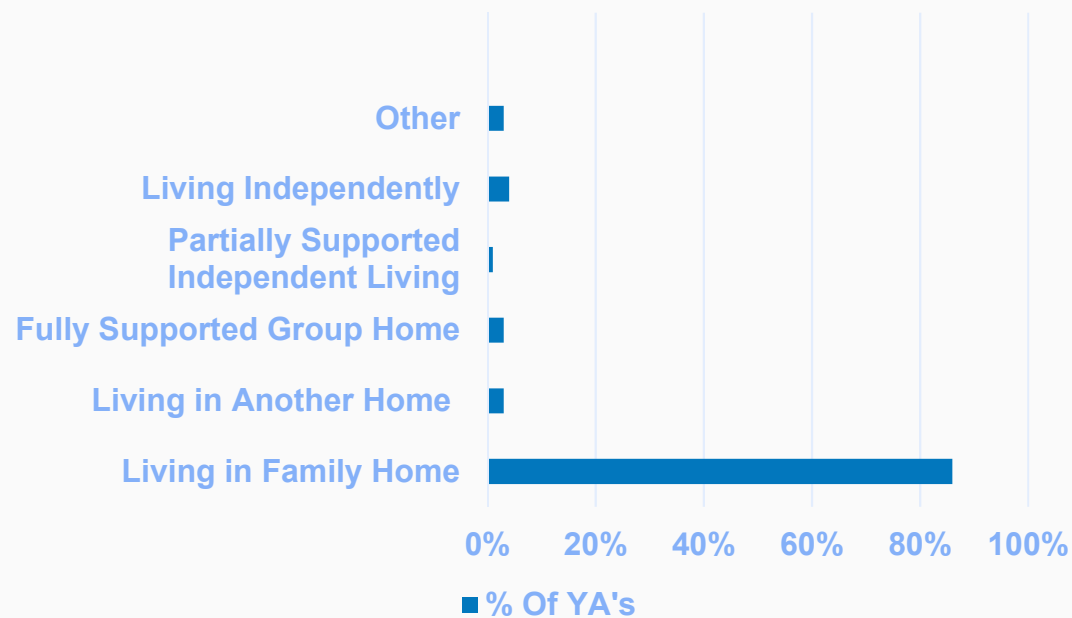
Since exiting high school, 74% of CSESA students have:

- 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%**



# Community Living

## Parents' reported YA Living Situation:



## **Parent** Reports of Post-School Life for YA with ASD

### *Guardianship*

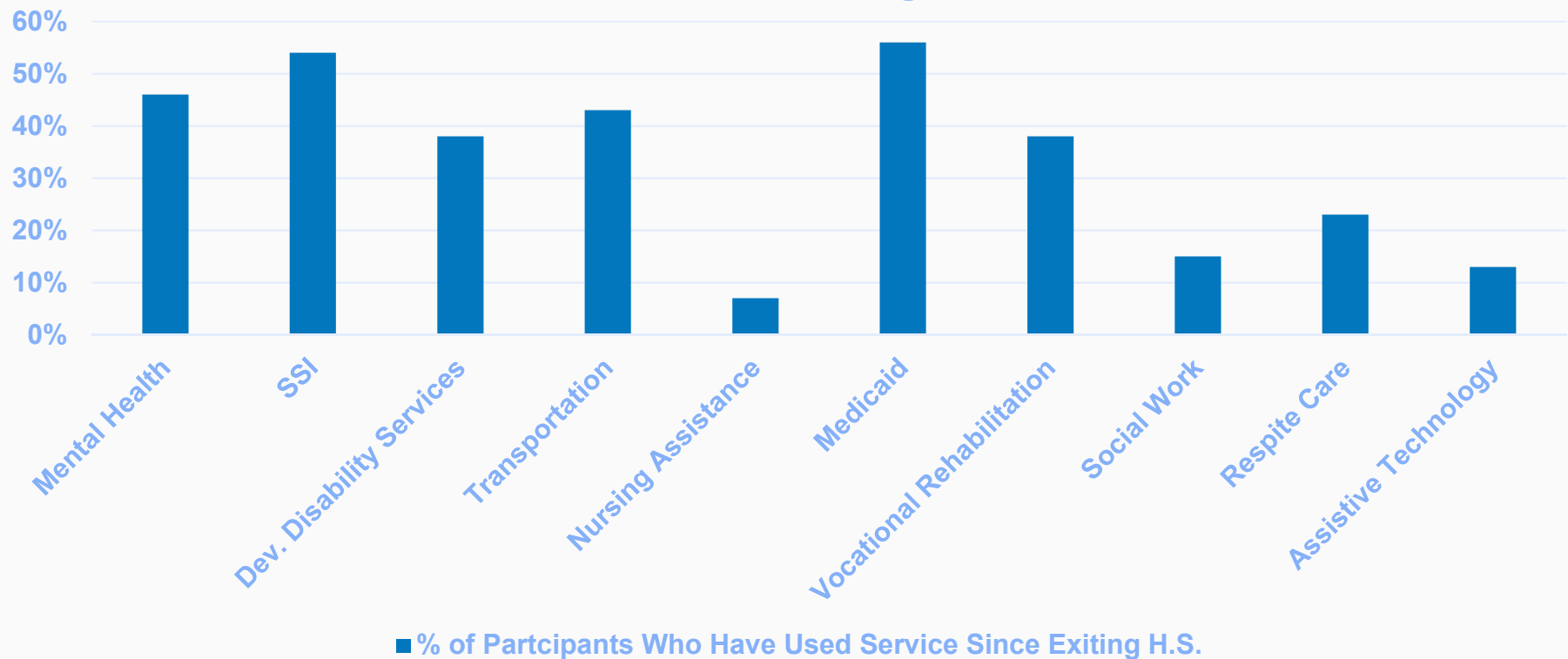


#### **Parents' reported status of guardianship of young adults:**

- 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.



## Parent Reports of Post-School Life for YA with ASD

### *Adult Services*

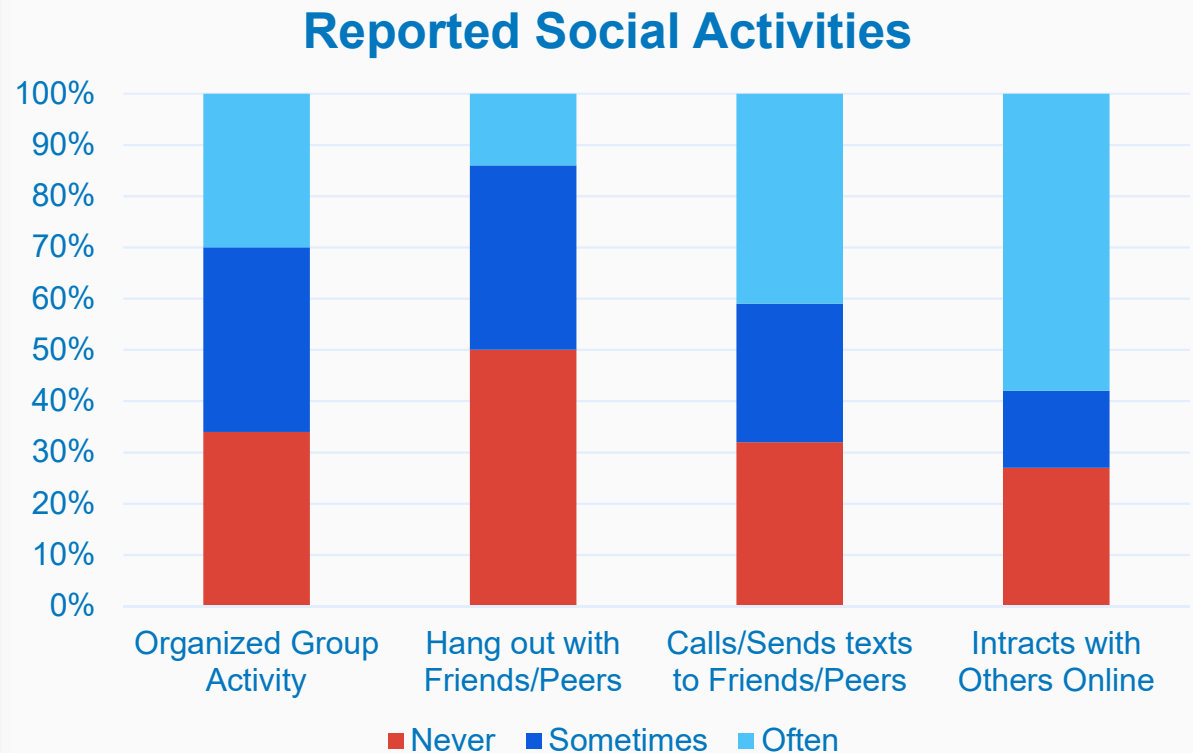
Are you on a waiting list for any services?

24% reported YES!

Participants reported waiting lists for:

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

## Parent Reports of Post-School Life for YA with ASD *Social & Community*



## 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**

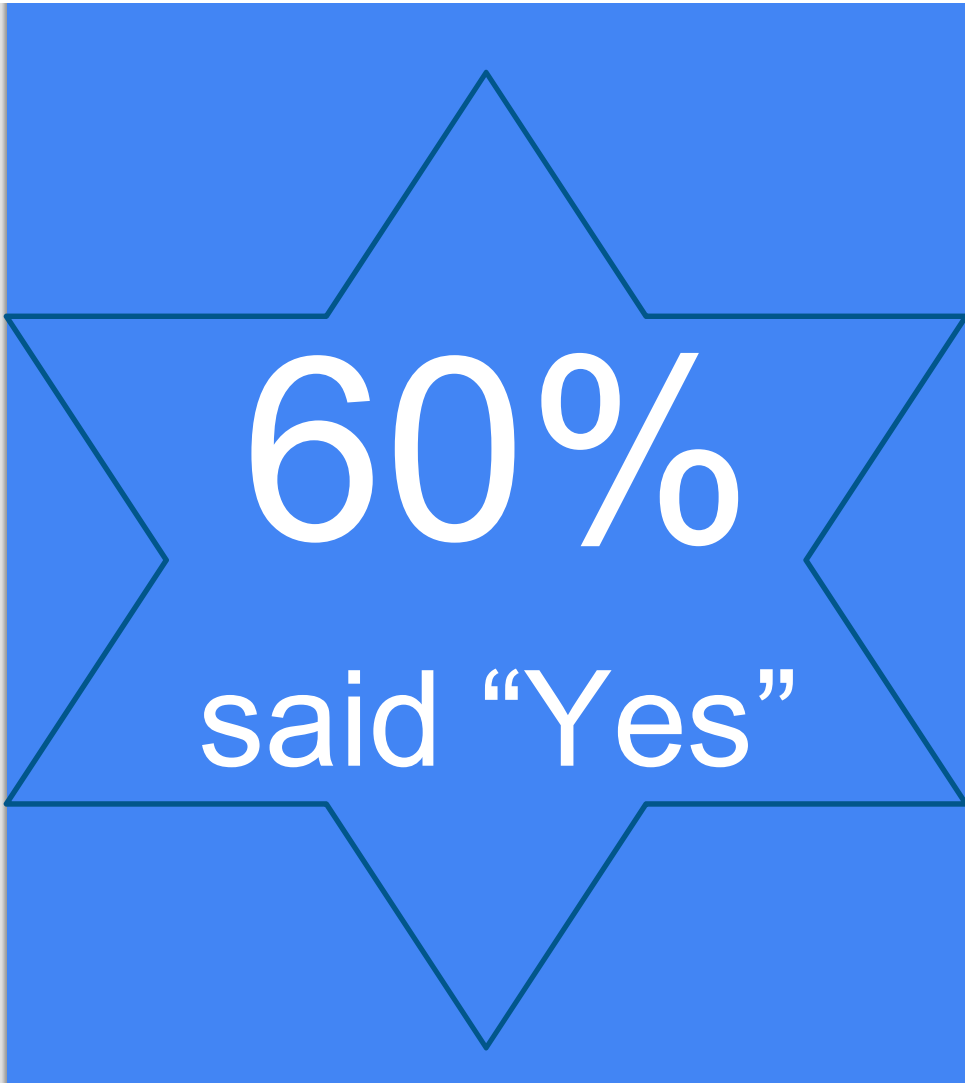
“My High School prepared me for...”

Life Now	44%
Going to Work	45%
Doing Activities with Other People	50%
Taking Classes	43%

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

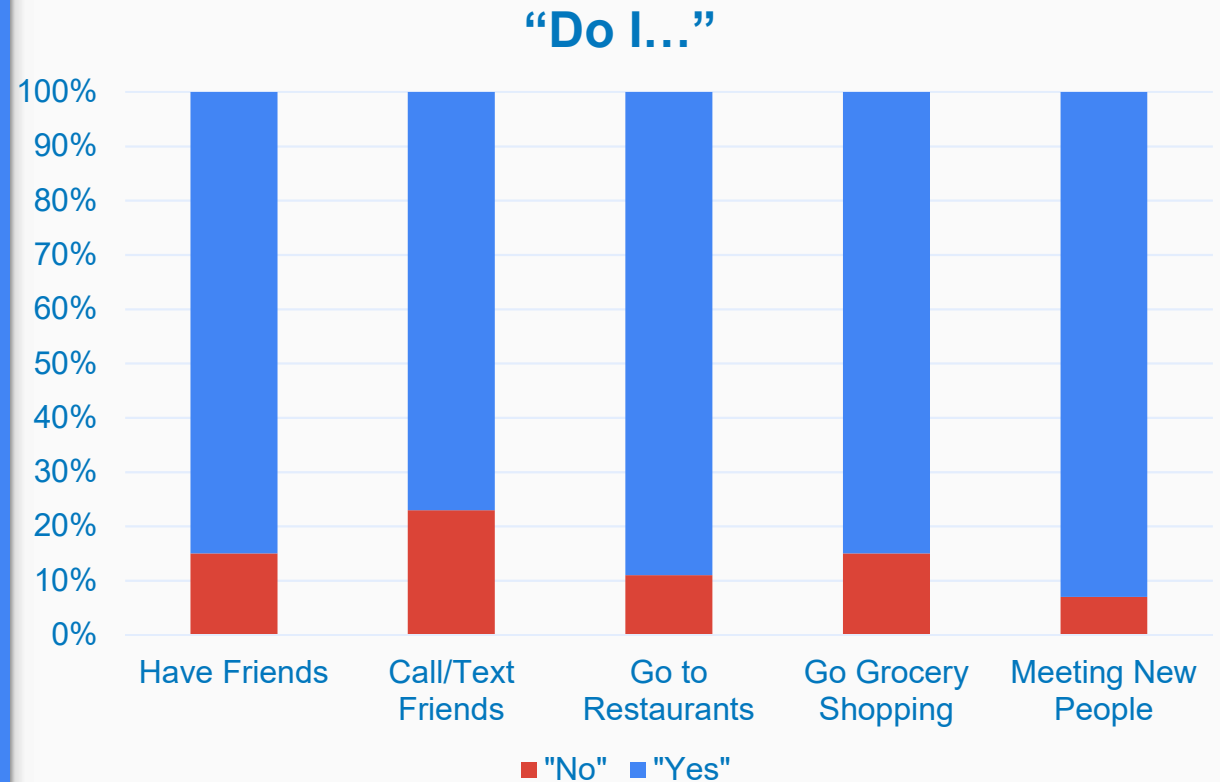
*Young Adult Life Satisfaction*

**“I like my life  
right now.”**



**60%**  
**said “Yes”**

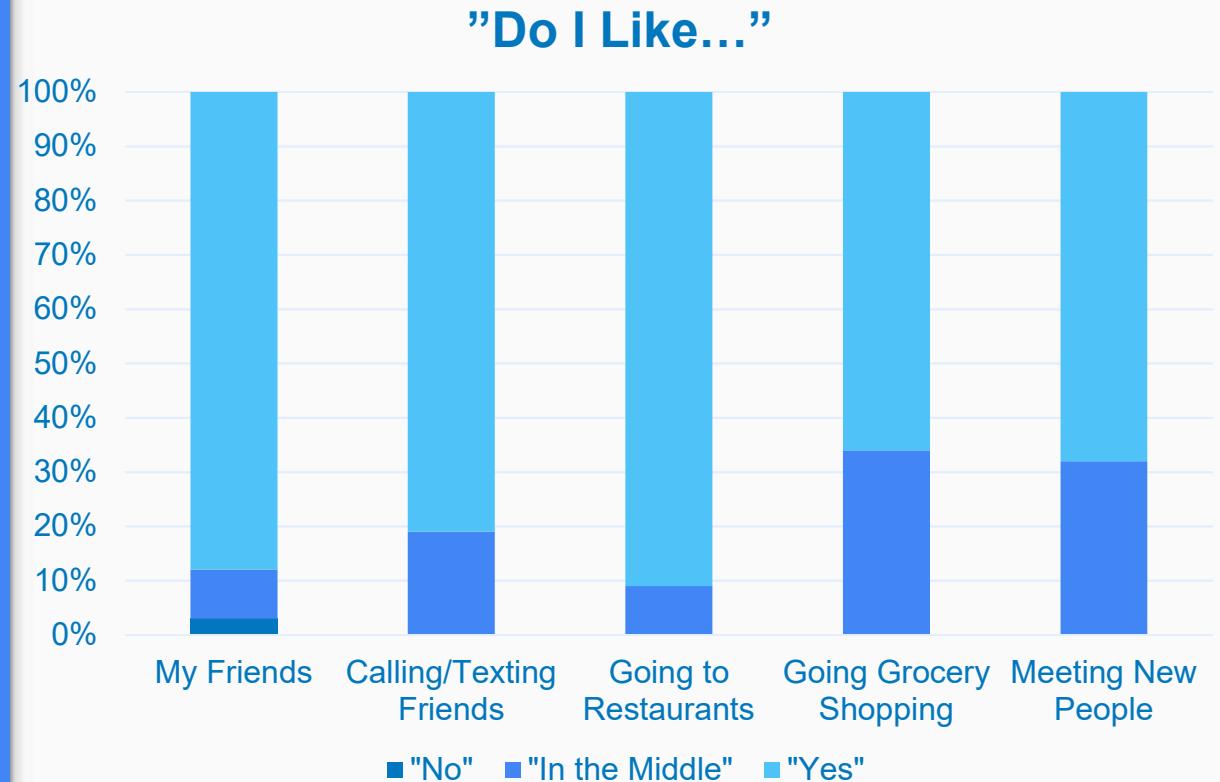
## Young Adult Views of Life After High School





# Young Adult Views of Life After High School

## *Satisfaction with Life Activities*



# “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.

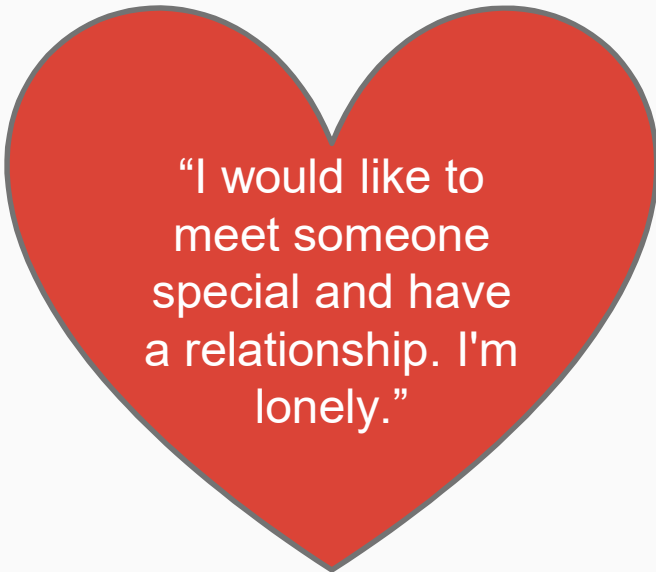
“Not much except win the lottery so I can fix my dads back.”

“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.”

“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.”

“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”



“Dragons - I have a corner cabinet in my room filled with dragons.”

“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”

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

- 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.

“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?

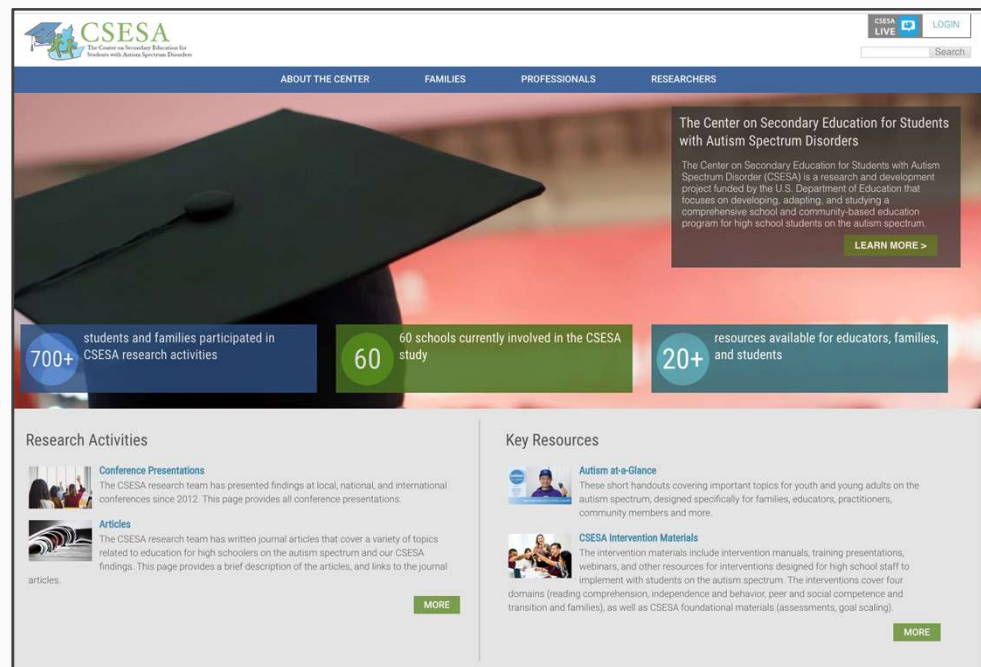


Free Resources!



SCAN ME

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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