PA AUTISM NEEDS ASSESSMENT

Thank you for completing this survey. The term autism is used throughout to refer to Autism Spectrum Disorder (ASD). Mark only one answer choice per question unless otherwise specified. Please contact the ASERT Collaborative at info@paautism.org or 1-877-231-4244 if you have questions.

Section 1

Which category best fits your gender?

◯ Male ◯ Female ◯ Other _____

What is your race / ethnicity? *Choose all that apply*.

☐ American Indian or Alaska Native
☐ Asian Indian
☐ Caucasian / European American
☐ Black or African American
☐ Chinese
☐ Filipino
☐ Hispanic or Latino
☐ Japanese
☐ Korean
☐ Native Hawaiian
☐ Vietnamese
☐ Other _____
☐ Prefer not to answer

What is your 5-digit zip code?

What year and month were you born?

Month of Birth (MM) _____ Year of Birth (YYYY) _____

Which of the following best describes your current marital status?

◯ Married
◯ Never Married
◯ Prefer not to answer
◯ Widowed
◯ Separated / Divorced

Do you have any children?

◯ Yes
◯ No, but planning to have
◯ No, undecided about having children
◯ No, I do not want to have children
◯ Prefer not to answer

Which of the following is closest to your annual income from employment?

☐ $0-$10,000
☐ $10,001-$20,000
☐ $20,001-$30,000
☐ $30,001-$40,000
☐ $40,001-$50,000
☐ $50,001-$60,000
☐ $60,001-$70,000
☐ $70,001-$80,000
☐ $80,001-$90,000
☐ $90,001-$100,000
☐ $100,000 +

Do you have any pets (including service animals)?

◯ Yes ◯ No

Do you have any relatives with autism?

◯ Yes ◯ No ◯ Not sure

If yes, which relatives are diagnosed with autism? *Choose all that apply*.

☐ Parent
☐ Brother / Sister
☐ Grandparent
☐ Aunt / Uncle
☐ Cousin
☐ Niece / Nephew
☐ Son / Daughter
☐ Other _____

Section 2

Compared to 12 months ago, would you say that your overall health is:

◯ Better ◯ Worse ◯ The same

Please explain your choice:

About how long has it been since you last saw a dentist? *(Include all types of dental professionals / specialists, such as orthodontists, oral surgeons, and dental hygienists.)*

◯ Less than 6 months ago ◯ 6 months to 1 year ago ◯ More than 1 year ago

About how long has it been since you last visited a doctor for a routine checkup? *(A routine checkup is a general physical examination, not an examination for a specific injury, illness, or condition.)*

◯ Less than 6 months ago ◯ 6 months to 1 year ago ◯ More than 1 year ago

Are you currently prescribed medication, other than vitamins?

◯ Yes ◯ No ◯ Not Sure

If yes, please list medications currently prescribed to you:

Section 3

Have you ever been diagnosed with any of the following? *Choose all that apply*.

- ☐ Anxiety Disorder
- ☐ Attention Deficit / Hyperactivity Disorder (ADHD)
- ☐ Bipolar Disorder
- ☐ Central Auditory Processing Discorder (CAPD)
- ☐ Conduct Disorder (CD)
- ☐ Depression
- ☐ Developmental Delay
- ☐ Hearing Impairment
- ☐ Hoarding Disorder
- ☐ Learning Disability
- ☐ Intellectual Disability (formerly known as Mental Retardation)
- ☐ Obsessive Compulsive Disorder (OCD)
- ☐ Oppositional Defiant Disorder (ODD)
- ☐ Schizophrenia or other psychotic disorder
- ☐ Seizures / Seizure Disorder / Epilepsy
- ☐ Sensory Integration Disorder
- ☐ Post Traumatic Stress Disorder (PTSD)
- ☐ Substance Use Disorder
- ☐ None
- ☐ Other _____

How old were you when you received an autism diagnosis?

◯ Years Old _____ ◯ Not Sure

Section 4

Are you covered by any of the following kinds of health insurance? *Choose all that apply*.

- ☐ Private health insurance that you or a family member receive through employment
- ☐ Private health insurance that you or a family member purchases (not through employment)
- ☐ Medicaid (Medical Assistance), CHIP, or Medicare
- ☐ Veteran's benefits or TRICARE
- ☐ Dental insurance
- ☐ Vision insurance
- ☐ Insurance that covers prescription medications
- ☐ Other _____

Are you currently on the Waiting List or Interest List?

- ◯ Waiting List for programs for individuals with intellectual disability (P/FDS or Consolidated waivers)
- ◯ Interest List for programs through the Bureau of Autism Services (BAS - Adult Autism Waiver or ACAP)
- ◯ Both
- ◯ Neither
- ◯ Not sure

Are you currently on any Medical Assistance Waivers / Programs? *Please make sure to fill out both columns.*

	I am enrolled in this waiver		I would like more information about this waiver	
	Yes	No	Yes	No
Adult Autism Waiver	◯	◯	◯	◯
Adult Community Autism Program (ACAP)	◯	◯	◯	◯
Consolidated Waiver	◯	◯	◯	◯
P/FDS Waiver	◯	◯	◯	◯
OBRA Waiver	◯	◯	◯	◯
Other _____	◯	◯	◯	◯

Section 5

Have you ever used drugs other than those required for medical reasons (excluding vitamins)?

◯ Yes ◯ No ◯ Prefer not to answer

Have you ever overdosed on drugs (prescription or illegal)?

◯ Yes ◯ No ◯ Prefer not to answer

Section 6

In the past year, have you been to the emergency room for behavioral or psychiatric reasons?

◯ Yes, _____ time(s) ◯ No ◯ Prefer not to answer

In the past year, were you admitted to a hospital or hospital-like setting for behavioral or psychiatric reasons?

◯ Yes, _____ time(s) ◯ No ◯ Prefer not to answer

IF YOU ANSWERED YES TO BEING ADMITTED TO A HOSPITAL OR HOSPITAL-LIKE SETTING, PLEASE ANSWER THE FOLLOWING QUESTIONS BASED ON YOUR MOST RECENT ADMISSION. OTHERWISE, PLEASE SKIP TO SECTION 7.

What was / were the reasons you were admitted to a hospital or hospital-like setting? *Choose all that apply.*

- ☐ Aggression
- ☐ Anxiety
- ☐ Defiant / Oppositional behaviors
- ☐ Depression
- ☐ Running away from home / school
- ☐ Self-injurious behaviors
- ☐ Significant increase in obsessions
- ☐ Other _____
- ☐ Not sure
- ☐ Prefer not to answer

How satisfied or dissatisfied were you with the following aspects of your hospital stay?

	Very satisfied	Satisfied	Dissatisfied	Very dissatisfied
Quality of treatment	◯	◯	◯	◯
Discharge planning	◯	◯	◯	◯

How were you admitted?

- ◯ I admitted myself (201, voluntary treatment)
- ◯ I was admitted against my will (302, involuntary treatment)
- ◯ Prefer not to answer

How long was your stay at the hospital or hospital-like setting?

- ◯ Less than 24 hours
- ◯ 24-48 hours
- ◯ 2+ days, please tell us how long _____

Was this your first admission to a hospital or hospital-like setting for behavioral or psychiatric reasons?

- ◯ Yes
- ◯ No
- ◯ Not sure

Please write any additional detail about your most recent hospital stay for behavioral or psychiatric reasons.

Section 7

Have you ever had any of the following interactions with the police / justice system? *Choose all that apply*.

- ☐ Police Called
- ☐ Stopped and questioned by the police for something other than a traffic violation
- ☐ Police Warning Issued (other than traffic violation)
- ☐ Citation Issued
- ☐ Arrested by police
- ☐ Served time in jail
- ☐ Charged with misdemeanor or felony
- ☐ Been on probation or parole
- ☐ Other _____
- ☐ None
- ☐ Prefer not to answer

Have you ever been a victim of a crime?

- ◯ Yes
- ◯ No
- ◯ Prefer not to answer

If you feel comfortable, please share more information on your experience with police or other justice system personnel or as a victim of a crime.

Section 8

Are you currently employed? Please only include paid positions.

- ◯ Yes, employed full time *(35 hours per week or more)*
- ◯ Yes, employed part time *(fewer than 35 hours per week)*
- ◯ No, but currently looking for employment
- ◯ No, I am retired
- ◯ No, I am not retired nor looking for work

If yes, what type of job do you have?

- ◯ Office / Administrative support
- ◯ Sales position (including retail)
- ◯ Food preparation / serving
- ◯ Transportation / materials handling
- ◯ Production / manufacturing
- ◯ Other _____

If no, have you ever held a job?

◯ Yes ◯ No ◯ Not Sure ◯ Prefer not to answer

At what age did you start working?

Which of the following have you used to search for employment. *Choose all that apply.*

- ☐ School Counselor
- ☐ Internet Search
- ☐ Job Fair
- ☐ Newspaper
- ☐ Parent / Relative Connection
- ☐ Word of Mouth
- ☐ Office of Vocational Rehabilitation (OVR) Counselor
- ☐ Employment support from a waiver or other program
- ☐ Other _____
- ☐ N/A (Not seeking employment)

Please complete the following statements about the job search process.

	Very Difficult	Difficult	Easy	Very Easy
Finding employment opportunities is…	◯	◯	◯	◯
Filling out job applications is…	◯	◯	◯	◯
Creating a resume is…	◯	◯	◯	◯
Getting potential employers to interview me is…	◯	◯	◯	◯
Interviewing is…	◯	◯	◯	◯
Finding transportation to and from interviews is…	◯	◯	◯	◯
Following up after interviews is…	◯	◯	◯	◯

Please indicate your level of agreement with the following statements about your employment.

	Strongly Agree	Agree	Disagree	Strongly Disagree	N/A
I feel comfortable working in a group environment.	◯	◯	◯	◯	◯
I feel comfortable asking my peers for information or help.	◯	◯	◯	◯	◯
I feel comfortable asking an authority figure for information or help.	◯	◯	◯	◯	◯
I feel comfortable asking an authority figure for time off from work.	◯	◯	◯	◯	◯
I feel comfortable asking for accommodations.	◯	◯	◯	◯	◯

Please tell us how much you agree or disagree with the following statements about your current or most recent workplace.

	Strongly Agree	Agree	Disagree	Strongly Disagree	N/A
My skills are underused.	○	○	○	○	○
My pay is fair.	○	○	○	○	○
I receive accommodation / support for autism.	○	○	○	○	○

Do people in your workplace know that you have autism?

- ○ Yes, everyone knows
- ○ Yes, but only my supervisor knows
- ○ Yes, but only my peers / coworkers know
- ○ No
- ○ N/A (I am not currently employed)

If no, why not? *Choose all that apply.*

- ☐ I don't know how to tell them
- ☐ I don't want to be treated differently
- ☐ I don't feel it is necessary
- ☐ I am afraid of being judged
- ☐ Other _____
- ☐ Prefer not to answer

Section 9

What is your current living situation?

- ○ Alone without support (rent or own)
- ○ Alone with support (rent or own)
- ○ With a roommate / spouse (rent or own)
- ○ With parents or other relatives
- ○ In a residential facility (including state hospital or state center)
- ○ In a group home
- ○ Homeless
- ○ Other _____

How long have you been living in this situation?

- ○ All of my life
- ○ Less than 1 year
- ○ 1-2 years
- ○ 3-5 years
- ○ More than 5 years

How happy are you with your current living arrangement?

- ○ Very happy
- ○ Happy
- ○ Unhappy
- ○ Very unhappy

How difficult is it for you to throw things away even if you don't use them?

- ○ Very difficult
- ○ Somewhat difficult
- ○ Not difficult at all

How often does clutter in your home get in the way of your daily activities? *(For example, can't find materials or other belongings, or problems getting around in your space.)*

- ○ Always
- ○ Most of the time
- ○ Sometimes
- ○ Never

Section 10

Are you currently in school?

- ◯ Yes, High School
- ◯ Yes, two-year college
- ◯ Yes, four-year college
- ◯ Yes, graduate school
- ◯ Yes, vocational / technical school
- ◯ No, but I would like to be
- ◯ No
- ◯ Other _____

If not, what is the highest level of education you have completed?

- ◯ Some schooling, but did not complete high school
- ◯ High School graduate / GED
- ◯ Vocational / Technical school
- ◯ Some college
- ◯ Associate's Degree
- ◯ Bachelor's Degree
- ◯ Master's Degree
- ◯ Professional or doctoral degree beyond a Master's degree (e.g. MD, DDS, DVM, PhD)

IF YOU ARE CURRENTLY IN SCHOOL, PLEASE ANSWER THE FOLLOWING QUESTIONS. OTHERWISE, PLEASE SKIP TO SECTION 11.

What is the status of your school enrollment?

- ◯ Full-time
- ◯ Part-time
- ◯ Not Sure

Do you attend classes in person or online?

- ◯ In-person classes
- ◯ Online classes
- ◯ Both in-person and online classes

Please indicate how the following activities have helped you develop friendships.

	Very strong friendships	Casual friendships	No friendships	Have not participated
Peer mentoring	◯	◯	◯	◯
Student groups or clubs	◯	◯	◯	◯
Meeting people in class	◯	◯	◯	◯
Meeting people in your dorm or housing	◯	◯	◯	◯
Social media	◯	◯	◯	◯
Intramural and club sports	◯	◯	◯	◯
Other social events	◯	◯	◯	◯

Are you aware of assistance and / or resources for students with disabilities at your school?

- ◯ Yes, but I don't use them
- ◯ Yes, and I use them
- ◯ No
- ◯ Not sure

Have you been identified by your school as needing accommodations (e.g. tutoring, special housing, counseling)?

- ◯ Yes
- ◯ No
- ◯ Not sure

Please tell us about your education needs. *Please make sure to fill out both columns.*

	Are you receiving this service?		Do you need more of this service?	
	Yes	No	Yes	No
Special housing	○	○	○	○
Test-taking assistance	○	○	○	○
Academic counseling	○	○	○	○
Note-taking assistance	○	○	○	○
Tutoring	○	○	○	○
Peer mentoring / social supports	○	○	○	○
Other _____	○	○	○	○

What are your plans after graduation? *Choose all that apply.*

- ☐ Continue education (towards a degree)
- ☐ Look for a job
- ☐ Take time off (for travel or otherwise)
- ☐ Volunteer
- ☐ I don't know
- ☐ Other _____

Section 11

Please check the following services that you are either aware of, involved with, or need more information about. *Choose all that apply*.

	Aware of	Involved With	Need More Information About	N/A
Office of Vocational Rehabilitation	☐	☐	☐	☐
Social Security benefits	☐	☐	☐	☐
Other government assistance (food stamps, subsidized housing, etc.)	☐	☐	☐	☐

Section 12

During the last month, about how many days a week on average have you spent time with friends outside of school or work?

◯ 0 ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ Prefer not to answer

During the last 12 months, have you taken part in any group activities, outside of school, like a youth group or a community sports team?

◯ Yes ◯ No ◯ Not Sure

If yes, how many of the groups that you take part in include only people with disabilities?

◯ 0 ◯ 1 ◯ 2 ◯ 3 ◯ 4+

Please indicate if the following challenges interfere with or prevent you from participating in activities in the community, such as sports, clubs, hobbies, or other organized activities.

	Yes	No	Not Sure
Emotional challenges (anxiety, depression, fear, etc.)	◯	◯	◯
Behavioral challenges (aggression, self-injurious behaviors, etc.)	◯	◯	◯
Physical challenges (access, mobility, etc.)	◯	◯	◯

Please describe your satisfaction with the following relationships.

	I do not have, but would like…	I have, but would like more / better…	I am satisfied with my…	N/A	Prefer Not to Answer
Friends to confide in	◯	◯	◯	◯	◯
Friends to socialize with	◯	◯	◯	◯	◯
Relationships with parents	◯	◯	◯	◯	◯
Relationships with siblings	◯	◯	◯	◯	◯
Relationships with your children	◯	◯	◯	◯	◯
Relationship with significant other (e.g. spouse, partner)	◯	◯	◯	◯	◯
Acquaintances	◯	◯	◯	◯	◯
Other relationships _____	◯	◯	◯	◯	◯

Tell us how often each of the following statements describes how you feel.

	Often	Sometimes	Rarely	Never	Prefer not to answer
I have nobody to talk to	◯	◯	◯	◯	◯
My interests and ideas are not shared by those around me	◯	◯	◯	◯	◯
It is difficult for me to make friends	◯	◯	◯	◯	◯

Do you participate in the following activities? *Please make sure to fill out both columns.*

	I participate in this activity		If yes, please indicate how many hours per week you participate.
	Yes	No	Hours
Volunteer Work	○	○	
Groups, clubs or organizations	○	○	
Spiritual or religious activities	○	○	
Exercise	○	○	
Organized or recreational sports	○	○	
Hobbies or special interestes	○	○	
Household chores / duties	○	○	
Social activities with friends	○	○	
Other activities _____	○	○	

Please tell us if you participated in the following activities as much as you would like in the last 30 days, and if these activities are important to you. *Please make sure to fill out both columns.*

	Do you do this activity?			Is this activity important to you?	
	Enough	Not Enough	Too Much	This is important to me	This is not important to me
Go to a library	○	○	○	○	○
Go to a gym, health or exercise club, including pool, or participate in a sports event (including bowling, tennis, miniature golf, etc.)	○	○	○	○	○
Go to a self advocate run organization or advocacy group / organization	○	○	○	○	○
Go to a social group in the community (for example a book club, hobby group, other group of people with similar interests)	○	○	○	○	○
Go to or participate in civic or political activities or organizations	○	○	○	○	○

Section 13

Please tell us about your specialty health and education service needs. Please select whether you are receiving the service, and whether you need more of the service listed. *Please make sure to fill out both columns.*

	Are you receiving this service?		Do you need more of this service?	
	Yes	No	Yes	No
Mental Health Counseling	○	○	○	○
Speech / Language Therapy	○	○	○	○
Occupational Therapy	○	○	○	○
Physical Therapy	○	○	○	○
Social Skills Training	○	○	○	○
Behavioral Support	○	○	○	○
One-to-One Support (e.g. support coordinators, community inclusion staff, community support professional, personal care worker)	○	○	○	○
Supports Coordination	○	○	○	○
Case Management	○	○	○	○
Neurology Services	○	○	○	○
Medication Management	○	○	○	○
Sexual Health Education	○	○	○	○
Relationship Counseling	○	○	○	○
Drug and Alcohol Counseling	○	○	○	○
Vocational Training	○	○	○	○
Transition Planning	○	○	○	○
Supported Employment	○	○	○	○
Career Counseling	○	○	○	○
Primary Health Care	○	○	○	○
Dental Care	○	○	○	○
Benefits Counseling	○	○	○	○

Please tell us if you agree with the following statement regarding the following services: "The professionals providing this service have the necessary skills to work with me."

	Strongly Agree	Agree	Disagree	Strongly Disagree	N/A
Mental Health Counseling	○	○	○	○	○
Speech / Language Therapy	○	○	○	○	○
Occupational Therapy	○	○	○	○	○
Physical Therapy	○	○	○	○	○
Social Skills Training	○	○	○	○	○
Behavioral Support	○	○	○	○	○
One-to-One Support (e.g. support coordinators, community inclusion staff, community support professional, personal care worker)	○	○	○	○	○
Supports Coordination	○	○	○	○	○
Case Management	○	○	○	○	○
Neurology Services	○	○	○	○	○
Medication Management	○	○	○	○	○
Sexual Health Education	○	○	○	○	○
Relationship Counseling	○	○	○	○	○
Drug and Alcohol Counseling	○	○	○	○	○
Vocational Training	○	○	○	○	○
Transition Planning	○	○	○	○	○
Supported Employment	○	○	○	○	○
Career Counseling	○	○	○	○	○
Primary Health Care	○	○	○	○	○
Dental Care	○	○	○	○	○
Benefits Counseling	○	○	○	○	○

Have you experienced any barriers to getting specialty health and education services?

○ Yes ○ No

If yes, which of these choices make it harder for you to get those services? *Choose all that apply*.

- ☐ Transportation
- ☐ Scheduling Issues
- ☐ No service providers in the area
- ☐ Not enough service providers in the area
- ☐ Cost of services / My insurance does not cover available services
- ☐ Providers do not have enough staff
- ☐ Providers in the area will not see people with autism
- ☐ Providers in the area will not see people with mental health diagnosis
- ☐ Other _____

Do you have a formal communication system in place? *(For example, Picture Exchange Communication System (PECS), tablet, speech generating device, or other augmentive communication system.)*

◯ Yes ◯ No ◯ Other _____

If yes, please select where you use this communication system. *Choose all that can apply.*

☐ Home ☐ School ☐ Other _____
☐ Work ☐ In the Community

Section 14

Do you feel comfortable answering some questions regarding your gender identity?

◯ Yes ◯ No

IF YES, PLEASE ANSWER THE QUESTIONS BELOW. OTHERWISE, PLEASE SKIP TO SECTION 15.

What sex were you assigned at birth?

◯ Male ◯ Female ◯ Intersex ◯ Prefer not to answer

Do you identify as transgender and / or gender non-conforming?

◯ Yes ◯ No ◯ Prefer not to answer

Section 15

In terms of transportation, how do you typically get where you need to go? *Choose all that apply*.

☐ Drive yourself in a private car
☐ Passenger in a private car with parents or family
☐ Passenger in a private car with friends
☐ Bus / van operated by a county, municipality, or non-profit
☐ Taxi or other for-hire vehicle
☐ Walk
☐ Bicycle
☐ Passenger in a private car with volunteer driver
☐ Public transit
☐ Transportation is provided by a day program
☐ Transportation is provided by a group home
☐ Transportation is provided by school / educational institution
☐ Ride Sharing (Uber / Lyft)
☐ Car Share (E.g. ZipCar, Enterprise Car Share)
☐ Other _____

For what purpose do you use transportation? *Choose all that apply.*

☐ Work / employment
☐ Education, vocational, or job training
☐ Social or recreational activities
☐ Medical and health-care appointments
☐ Religious activities
☐ Visiting families and friends
☐ Shopping / daily errands
☐ Gym or health club
☐ To get to bus stop or train station
☐ Other _____

When walking around, which of the following situations do you have trouble with? *Choose all that apply.*

☐ Crossing a street
☐ Judging the distance and/or speed of cars
☐ Walking in areas without sidewalks (on grass or in streets)
☐ Dealing with distractions while walking
☐ Too many people on the sidewalk
☐ Too many cars or too much traffic
☐ Difficulty determining directions / route
☐ Other _____
☐ No difficulties walking

Which of the following make it difficult for you to ride public transportation? *Choose all that apply*.

- ☐ Not available in my area
- ☐ Difficulty getting to the bus stop / train station without help
- ☐ Difficulty getting on / off trains or buses
- ☐ Public transportation service is not available when needed
- ☐ Public transportation does not go where I need it to
- ☐ Too many trip transfers needed
- ☐ Public transportation costs too much
- ☐ Parents / guardians do not want me to use public transportation
- ☐ Difficulty with planning a public transportation trip
- ☐ Public transportation service is not reliable
- ☐ Worried about crime on public transportation
- ☐ Worried about finding a seat on a bus / train
- ☐ Worried about public transportation driver friendliness / helpfulness
- ☐ Worried about how other public transportation passengers will treat you
- ☐ Other _____
- ☐ No difficulties with public transportation

Section 16

The following question is about some parts of your relationships. How often do you have trouble getting along with…

	Always	Sometimes	Never	N/A
Your parent(s) or other caregiver(s)	○	○	○	○
Your brothers and sisters	○	○	○	○
Your extended family members (grandparents, aunts, uncles, etc.)	○	○	○	○
Others who visit your home	○	○	○	○

Section 17

Are you a part of a support group or advocacy group?

○ Yes ○ No, but used to be ○ No, but would like to be ○ No

If yes, was it online or in person?

○ Online ○ In person ○ Both

If yes, why are you a part of this group? *Choose all that apply*.

- ☐ Friendships / Socialization
- ☐ To find information
- ☐ Similar Interests / Experience
- ☐ Raising awareness
- ☐ Someone recommended it to me
- ☐ Advocate / Make a difference
- ☐ Other _____

If not, why not? *Choose all that apply*.

- ☐ Transportation
- ☐ None in my area / too far away
- ☐ Not interested
- ☐ Not enough time
- ☐ Not age/interest appropriate
- ☐ Feel excluded / Don't fit in
- ☐ Costs money/membership fee
- ☐ Other _____

Thank you for completing the PA Autism Needs Assessment!