PA AUTISM NEEDS ASSESSMENT

Thank you for completing this survey. Since most respondents will be parents / guardians, we refer to the person with autism as "your child." The term autism is used to refer to Autism Spectrum Disorder (ASD). Please complete this survey for your oldest child with autism. 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

Please identify yourself.

◯ Mother ◯ Father ◯ Foster Parent ◯ Other _____

Are you the legal guardian of your child with autism?

◯ Yes ◯ No ◯ Not Sure

Which of the following best describes your current marital status?

◯ Married to/living with child's other parent
◯ Married to/living with person other than child's other parent
◯ Widowed
◯ Never been married
◯ Separated / divorced
◯ Prefer not to answer

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 the race / ethnicity of your child? *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 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)

What year and month was your child born?

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

What is the sex of your child?

◯ Male ◯ Female ◯ Other _____

Is your child adopted?

◯ No
◯ Yes. How old was your child when you adopted them? _____

How many siblings does your child with autism have? *(Include step-siblings, half-siblings, etc.)*

How many of those siblings have also been diagnosed with autism?

Which of the following is closest to your annual household income?

☐ $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 +

Section 2

Compared to 12 months ago, would you say the overall health of your child with autism is:

◯ Better ◯ Worse ◯ The same

Please explain your choice:

About how long has it been since your child 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 your child 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

Is your child with autism currently prescribed medication, other than vitamins?

◯ Yes ◯ No ◯ Not Sure

If yes, please list medications currently prescribed to your child.

Section 3

Getting an autism diagnostic evaluation for your child was…

◯ Very easy ◯ Somewhat easy ◯ Somewhat difficult ◯ Very difficult ◯ Not applicable

If "Somewhat difficult" or "Very difficult," what made getting an evaluation difficult?
Choose all that apply.

☐ Finding a doctor / professional
☐ Transportation
☐ Getting a referral
☐ Guardianship
☐ Health insurance coverage
☐ Scheduling issues
☐ Cost / copay
☐ Long wait time
☐ Lack of child care
☐ Language barrier / lack of translator
☐ Other _____

Did your child receive any of the following diagnoses prior to receiving their autism diagnoses? *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 _____

Does your child with autism currently have any of the following diagnoses? *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 _____

What type of professional first diagnosed your child with autism? *Choose all that apply*.

- ☐ Developmental Pediatrician
- ☐ Neurologist
- ☐ Psychiatrist
- ☐ Primary Care Physician (family doctor / pediatrician)
- ☐ Psychologist
- ☐ Not sure
- ☐ Other _____

How old was your child when they received an autism diagnosis?

- ◯ Years Old _____
- ◯ Not Sure

After receiving an autism diagnosis, what sort of follow-up and resources / services did you receive? *Choose all that apply*.

- ☐ Follow-up appointment
- ☐ Referral to a specialist for further assessment
- ☐ Referral to a specialist for treatment
- ☐ Referral to Early Intervention services
- ☐ Referral to support groups
- ☐ Referral to website, literature (e.g handouts, information booklets)
- ☐ None
- ☐ Other _____

Did your child receive Early Intervention services?

- ◯ Yes. What age did services start? _____
- ◯ No
- ◯ Not Sure

Does your child have any of the following plans? *Choose all that apply*.

- ☐ Individualized Family Service Plan (IFSP)
- ☐ Individualized Education Plan (IEP)
- ☐ 504 Plan
- ☐ Individual Support Plan (ISP)
- ☐ None
- ☐ Not sure

If your child has an Individualized Family Service Plan (IFSP), please answer the following question.
Please make sure to fill out all three columns.

	Are you satisfied that this plan meets all of your child's needs?		Did you attend the latest IFSP meeting?		Is your input included in this plan?	
	Yes	No	Yes	No	Yes	No
Individualized Family Service Plan (IFSP)	○	○	○	○	○	○

If your child has an Individualized Education Plan (IEP), please answer the following question.
Please make sure to fill out all three columns.

	Are you satisfied that this plan meets all of your child's needs?		Did you attend the latest IEP meeting?		Is your input included in this plan?	
	Yes	No	Yes	No	Yes	No
Individualized Education Plan (IEP)	○	○	○	○	○	○

If your child has a 504 plan, please answer the following question.
Please make sure to fill out all three columns.

	Are you satisfied that this plan meets all of your child's needs?		Did you attend the latest 504 plan meeting?		Is your input included in this plan?	
	Yes	No	Yes	No	Yes	No
504 Plan	○	○	○	○	○	○

If your child has an Individual Support Plan (ISP), please answer the following question.
Please make sure to fill out all three columns.

	Are you satisfied that this plan meets all of your child's needs?		Did you attend the latest ISP meeting?		Is your input included in this plan?	
	Yes	No	Yes	No	Yes	No
Individual Support Plan (ISP)	○	○	○	○	○	○

Section 4

Is your child now 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 _____

Is your child currently enrolled in Medical Assistance or Medicaid?

◯ Yes ◯ No ◯ Not Sure

Is your child currently enrolled in any of the following Medical Assistance or Medicaid Programs?

◯ Adult Autism Waiver
◯ Adult Community Autism Program (ACAP)
◯ Consolidated Waiver
◯ P/FDS Waiver
◯ OBRA Waiver
◯ Other _____
◯ None of the above

Is your child 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

Section 5

Has your child ever used drugs other than those required for medical reasons (excluding vitamins)?

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

Has your child ever overdosed on drugs (prescription or illegal)?

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

Section 6

In the past year, <u>have you taken your child to</u> the emergency room for behavioral or psychiatric reasons?

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

In the past year, <u>has your child been admitted to</u> a hospital or hospital-like setting for behavioral or psychiatric reasons?

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

PLEASE ANSWER THE FOLLOWING QUESTIONS BASED ON YOUR CHILD'S MOST RECENT STAY IN A HOSPITAL OR HOSPITAL-LIKE SETTING.

What was / were the reasons your child was admitted to a hospital or hospital-like setting? *<u>Choose all that apply</u>*.

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

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

	Very satisfied	Satisfied	Dissatisfied	Very dissatisfied
Quality of treatment	◯	◯	◯	◯
Discharge planning	◯	◯	◯	◯
Staff's inclusion of parent(s) in treatment planning	◯	◯	◯	◯

How was your child admitted?

- ◯ My child (under 14) was admitted by his/her parent(s)
- ◯ My adolescent child (14 to 18) was admitted by his/her parent(s) and agreed to admission
- ◯ My adolescent child (14 to 18) was admitted by his/her parent(s) but did not agree to admission
- ◯ My adult child (18 or older) admitted him/herself (201, voluntary treatment)
- ◯ My adult child (18 or older) was admitted against his/her will (302, involuntary treatment)
- ◯ Prefer not to answer

How long was your child's 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 child's first admission to a hospital or hospital-like setting for behavioral or psychiatric reasons?

◯ Yes ◯ No ◯ Not sure

Please add any additional detail about your child's most recent hospital stay for behavioral or psychiatric reasons.

Section 7

Has your child's behavior ever resulted in 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

Has your child ever been victim of a crime?

◯ Yes ◯ No ◯ Prefer not to answer

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

Section 8

IF YOU ARE A FOSTER PARENT TO AN INDIVIDUAL WITH AUTISM, PLEASE ANSWER THE FOLLOWING QUESTIONS. OTHERWISE, PLEASE SKIP TO SECTION 9.

In the past year, did you receive support, training or resources for your role and responsibilities as a foster parent?

◯ Yes ◯ No

If yes, please specify who provided the support, training, or resources, and whether you thought the training prepared you for your roles and responsibilities. *Please make sure to fill out all three columns.*

	Did you receive training, support, or resources from this agency?		Did you feel prepared after this training?			Was this training autism specific?		
	Yes	No	Yes	No	N/A	Yes	No	N/A
County Children and youth agency	◯	◯	◯	◯	◯	◯	◯	◯
From the child's school	◯	◯	◯	◯	◯	◯	◯	◯
Private foster care agency, please specify _____	◯	◯	◯	◯	◯	◯	◯	◯
Other _____	◯	◯	◯	◯	◯	◯	◯	◯

Please answer the following questions about your foster care experience.

	Almost never / never	Sometimes	Usually	Always / almost always
Are you included as part of the treatment team for your child?	◯	◯	◯	◯
Are you included in other meetings about the care for your child?	◯	◯	◯	◯
Do you get help when you ask for it?	◯	◯	◯	◯

Section 9

In the past year, has your child been placed in a residential facility?

◯ Yes ◯ No, but currently on a waiting list ◯ No, and not on a waiting list ◯ Prefer not to answer

IF YOUR CHILD HAS BEEN PLACED IN A RESIDENTIAL FACILITY, PLEASE ANSWER THE FOLLOWING QUESTIONS. OTHERWISE, PLEASE SKIP TO SECTION 10.

About how many miles is this residential facility away from your home?

◯ 0-20 miles ◯ 21-40 miles ◯ 41-60 miles ◯ 61-80 miles ◯ 81-100 miles ◯ Over 100 miles ◯ Not sure

Why was your child placed in a residential facility? *Choose all that apply*.

- ☐ Aggression
- ☐ Anxiety
- ☐ Defiant / Oppositional behaviors
- ☐ Depression
- ☐ Running away from home / school
- ☐ Self-injurious behaviors
- ☐ Significant increase in obsessions
- ☐ Other _____

How long is / was your child's stay at the residential treatment facility?

◯ Less than a week ◯ 1-4 weeks ◯ More than 4 weeks

How satisfied or dissatisfied were you with the following aspects of your child's stay in the residential facility?

	Very satisfied	Satisfied	Dissatisfied	Very Dissatisfied
Quality of treatment	◯	◯	◯	◯
Discharge planning	◯	◯	◯	◯
Staff's inclusion of parent(s) in treatment planning	◯	◯	◯	◯

Was information about community-based services (recreational, sports, volunteer opportunities, or others) included in your discharge plan?

◯ Yes ◯ No ◯ Not sure

Was the treatment / discharge plan written in a way that was easily understood?

◯ Yes ◯ No

Section 10

Is your child capable of the following activities?

	Independently	With Help	Not Capable	N/A
Toileting	◯	◯	◯	◯
Feeding self	◯	◯	◯	◯
Dressing self	◯	◯	◯	◯
Requesting things they need	◯	◯	◯	◯
Requesting things they want	◯	◯	◯	◯
Indicating when they are sick/hurt	◯	◯	◯	◯
Cooking/preparing meals	◯	◯	◯	◯
Managing money	◯	◯	◯	◯
Getting around via driving / public transportation / biking / walking	◯	◯	◯	◯

Is your child currently receiving services or other support for any of the following? *Choose all that apply*.

- ☐ Self-injurious behaviors
- ☐ Sleep problems
- ☐ Anxiety
- ☐ Aggressive behaviors
- ☐ Running away
- ☐ Toileting
- ☐ None

Does you child currently receive Behavioral Health Rehabilitation Services (BHRS or 'wraparound')?

- ◯ Yes, in school
- ◯ Yes, at home / community
- ◯ Yes, both in school and at home / community
- ◯ No, but waiting for an evaluation
- ◯ No, but evaluation complete, plan in development
- ◯ No
- ◯ Not sure

If yes, how happy are you with the support you received from the treatment team?

- ◯ Very Happy
- ◯ Happy
- ◯ Unhappy
- ◯ Very Unhappy

Section 11

Is your child 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, they are retired
- ◯ Not retired and not seeking employment

If yes, what type of job does your child have?

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

Is your child currently or did they previously receive services through the Office of Vocational Rehabilitation (OVR)?

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

What types of supports do you think your child needs to find and keep a job? *Choose all that apply*.

- ☐ Help finding job opportunities
- ☐ Support with application and interview
- ☐ Support when problems or new situations arise
- ☐ Short-term support
- ☐ Ongoing support
- ☐ Will not need any support
- ☐ Other _____

Section 12

What is your child's current living situation?

- ◯ With parent(s) or other relatives in a family home
- ◯ In a residential facility (including state hospital or state center)
- ◯ In a group home
- ◯ With a roommate / spouse (rent or own)
- ◯ Lives on own with support (rent or own)
- ◯ Lives on own without support (rent or own)
- ◯ Homeless
- ◯ Other _____

How long has your child been in this current living situation?

- ◯ All of child's life
- ◯ Less than 1 year
- ◯ 1-2 years
- ◯ 3-5 years
- ◯ More than 5 years

How happy are you with your child's current living arrangement?

◯ Very happy ◯ Happy ◯ Unhappy ◯ Very unhappy

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

◯ Very difficult ◯ Somewhat difficult ◯ Not difficult at all

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

◯ Always ◯ Most of the time ◯ Sometimes ◯ Never

Section 13

Is your child currently in school?

◯ Yes ◯ No

If yes, where are they currently in school?

◯ Pre-k
◯ Kindergarten
◯ Elementary School
◯ Middle School
◯ High School
◯ Two year college
◯ Four year college
◯ Graduate school
◯ Vocational Training
◯ Other _____

If not, what is your child's highest level of education?

◯ No schooling completed
◯ Some schooling, but did not complete high school
◯ High School graduate / GED or alternative credential
◯ Vocational / Technical school
◯ Some college
◯ Associates Degree
◯ Bachelor's Degree
◯ Master's Degree
◯ Professional or doctoral degree beyond a Master's degree (e.g. MD, DDS, DVM, PhD)

IF YOUR CHILD IS CURRENTLY IN SCHOOL, PLEASE ANSWER THE FOLLOWING QUESTIONS. OTHERWISE, PLEASE SKIP TO SECTION 14.

In the last year, has your child been disciplined at school in any of the following ways? *Choose all that apply*.

☐ Time-out / De-escalation room
☐ Sent out of classroom
☐ Detention
☐ In-school suspension
☐ Out-of-school suspension
☐ Expulsion
☐ None of the above

In what category of special education is your child currently placed? *Choose all that apply*.

☐ Autistic Support
☐ Emotional Support
☐ Learning Disabilities
☐ Intellectual Disability (formerly Mental Retardation)
☐ Multiple Disabilities
☐ None (My child is not receiving special education services)
☐ Not sure
☐ Other _____

Section 14

What long term plans do you have for your child when you are no longer able to care for them? *Choose all that apply*.

- ☐ Arrange housing plans
- ☐ Set up financial trust
- ☐ Designated guardianship
- ☐ Designated power of attorney
- ☐ Currently developing plans
- ☐ None at this time

How concerned are you about making and maintaining these plans?

	Very concerned	Concerned	Somewhat concerned	Not concerned	N/A
Arrange housing plans	○	○	○	○	○
Set up financial trust	○	○	○	○	○
Designated guardianship	○	○	○	○	○
Designated power of attorney	○	○	○	○	○
Currently developing plans	○	○	○	○	○

Do you feel you have the resources to appropriately prepare for these plans?

	Yes	No	N/A
Arrange housing plans	○	○	○
Set up financial trust	○	○	○
Designated guardianship	○	○	○
Designated power of attorney	○	○	○
Currently developing plans	○	○	○

Section 15

Please check the following services that you are either aware of, involved with, or need more information about for your child:

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

Section 16

Please indicate if the following challenges interfere with or prevent your child 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.)	○	○	○

Does your child participate in the following activities? *Please make sure to fill out both columns.*

	Do they participate?		**If yes, please indicate how many hours per week they 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 _____	○	○	

Section 17

Please select the response that reflects your experiences getting services for your child.

	Strongly Agree	Agree	Disagree	Strongly Disagree	N/A
In general, I have experienced barriers in getting services for my child	○	○	○	○	○
My child's doctors and other health care providers spend enough time with them	○	○	○	○	○
My child's doctors and other health care providers listen carefully to me	○	○	○	○	○
My child's doctors and other health care providers are sensitive to my family's values and customs	○	○	○	○	○
My child's doctors or other health care providers explain things in a way that is easy to understand	○	○	○	○	○

Please tell us about your child's health and education service needs. *Please make sure to fill out both columns.*

	My child is receiving this service		Does your child 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. TSS, BSC, Behavioral Specialist)	○	○	○	○
Supports Coordination	○	○	○	○
Mobile Therapy	○	○	○	○
Case Management	○	○	○	○
Benefits Counseling	○	○	○	○
Neurology Services	○	○	○	○
Medication Management	○	○	○	○
Sexual Health Education	○	○	○	○
Relationship Counseling	○	○	○	○
Summer Camp	○	○	○	○
Summer School (ESY)	○	○	○	○
Vocational Training	○	○	○	○
Transition Planning	○	○	○	○
Supported Employment	○	○	○	○
Career Counseling	○	○	○	○
Primary Health Care	○	○	○	○
Dental Care	○	○	○	○

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 my child."

	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. TSS, BSC, and Behavioral Specialist)	○	○	○	○	○
Supports Coordination	○	○	○	○	○
Mobile Therapy	○	○	○	○	○
Case Management	○	○	○	○	○
Benefits Counseling	○	○	○	○	○
Neurology Services	○	○	○	○	○
Medication Management	○	○	○	○	○
Sexual Health Education	○	○	○	○	○
Relationship Counseling	○	○	○	○	○
Summer Camp	○	○	○	○	○
Summer School (ESY)	○	○	○	○	○
Vocational Training	○	○	○	○	○
Transition Planning	○	○	○	○	○
Supported Employment	○	○	○	○	○
Career Counseling	○	○	○	○	○
Primary Health Care	○	○	○	○	○
Dental Care	○	○	○	○	○

Which of the following barriers do you experience when trying to get services for your child? *Choose all that apply*.

- ☐ Transportation
- ☐ Scheduling Issues
- ☐ Not enough service providers in area
- ☐ Cost of services / My insurance does not cover available services
- ☐ No service providers in the area
- ☐ Providers do not have enough staff
- ☐ Providers in the area will not see people with autism
- ☐ None
- ☐ Other _____

Does your child have a formal communication system in place? (*For example, Picture Exchange Communication System (PECS), tablet, speech generating device, or other augmentative communication system.)*

◯ Yes ◯ No ◯ Other _____

If yes, please select the settings where your child uses his / her communication system. *Choose all that apply*.

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

Section 18

In terms of transportation, how does your child typically get where they need to go? *Choose all that apply*.

- ☐ Drives himself / herself in a private car
- ☐ Passenger in a private car with parents or other family members
- ☐ Passenger in a private car with friends
- ☐ Bus / van operated by a country, municipality or nonprofit
- ☐ 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 _____

Section 19

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 you have been or currently are part of a support or advocacy group, was it online or in person?

◯ Online ◯ In person ◯ Both

If you are currently or have been in a support or advocacy group, why are you a part of this group? *Choose all that apply*.

- ☐ Friendships / Socialization
- ☐ Resource Sharing
- ☐ Similar Interests / Experience
- ☐ Raising Awareness
- ☐ It was recommended
- ☐ Make change
- ☐ Other _____

If you are not or have not been in a support or advocacy group, please select the reasons why you are not participating in a support or advocacy group. *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 _____

Section 20

Does your child have trouble getting along with…

	Always	Sometimes	Never	N/A
Parent(s) or other caregiver(s)	○	○	○	○
Brothers and sisters	○	○	○	○
Extended family members (grandparents, aunts, uncles, etc.)	○	○	○	○
With others that come into the home, and using socially appropriate behaviors	○	○	○	○

Please tell us about your family support service needs. *Please make sure to fill out both columns.*

	Is your family receiving?		My family needs more of this service	
	Yes	No	Yes	No
Respite Care	○	○	○	○
Adult Daycare	○	○	○	○
Family Counseling	○	○	○	○
Sibling Support Groups	○	○	○	○
Sibling Mental Health Counseling	○	○	○	○
Parent Support Groups	○	○	○	○
Parent Mental Health Counseling	○	○	○	○

How strongly do you agree or disagree with the following statement: "The professionals providing this service have the necessary skills to work with my family."

	Strongly Agree	Agree	Disagree	Strongly disagree	N/A
Respite Care	○	○	○	○	○
Adult Daycare	○	○	○	○	○
Family Counseling	○	○	○	○	○
Sibling Support Groups	○	○	○	○	○
Sibling Mental Health Counseling	○	○	○	○	○
Parent Support Groups	○	○	○	○	○
Parent Mental Health Counseling	○	○	○	○	○

How strongly do you agree or disagree with the following statement: "This services is effective in meeting my family's needs."

	Strongly Agree	Agree	Disagree	Strongly disagree	N/A
Respite Care	○	○	○	○	○
Adult Daycare	○	○	○	○	○
Family Counseling	○	○	○	○	○
Sibling Support Groups	○	○	○	○	○
Sibling Mental Health Counseling	○	○	○	○	○
Parent Support Groups	○	○	○	○	○
Parent Mental Health Counseling	○	○	○	○	○

What limitations or barriers do you face accessing family support services? *Choose all that apply.*

- ☐ Transportation
- ☐ Scheduling Issues
- ☐ Not enough service providers in area
- ☐ No service providers in the area
- ☐ Cost of services / My insurance does not cover available services
- ☐ None
- ☐ Other _____

In what ways (if any) has your child's autism affected your family's workforce participation? *Choose all that apply*.

	Me	My partner
Stopped working outside the home	☐	☐
Decreased work hours	☐	☐
Increased work hours	☐	☐
Changed employer	☐	☐
Changed type of work	☐	☐
Changed work schedule	☐	☐
Changed position with same employer	☐	☐
Used Family Medical Leave Act (FMLA)	☐	☐
Lost promotion / advancement opportunities	☐	☐
Terminated from employement	☐	☐
Disciplined / Suspended	☐	☐
None	☐	☐
Other _____	☐	☐

We would like to ask about your participation in your community.

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

	Do you participate?		If yes, please indicate how many hours per week you participate.
	Yes	No	Hours
Volunteer Work	○	○	
Community groups/organizations	○	○	
Spiritual or religious activities	○	○	
Exercise	○	○	
Hobbies or special interests	○	○	
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?			This activity is important to me	
	Enough	Not Enough	Too Much	Yes	No
Go to a Library	○	○	○	○	○
Go to a gym, health or exercise club, including pool, or participate in a sport event (including bowling, tennis, miniature golf, etc.)	○	○	○	○	○
Go to an 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	○	○	○	○	○

Thank you for completing the PA Autism Needs Assessment!