AUTISM NEEDS ASSESSMENT

Please note that you must be at least 18 years of age to complete this survey

Thank you for agreeing to complete 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 all Autism Spectrum Disorders (ASD). Please complete this survey for your oldest child with autism. Mark only one answer choice per question unless otherwise specified.

1. Please identify yourself:

- ☐ Mother
- ☐ Father
- ☐ Foster parent
- ☐ Legal guardian
- ☐ Other *(Please specify)* _____

2. 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 parent
- ☐ Widowed
- ☐ Never been married
- ☐ Separated/Divorced

3. What is your race/ethnicity? *(Check all that apply)*

- ☐ African American
- ☐ Asian/Pacific Islander
- ☐ Caucasian/European American
- ☐ Latino, Hispanic, or Chicano
- ☐ Native American
- ☐ Other *(Please specify)* _____

4. What is the race/ethnicity of your spouse or significant other? *(Check all that apply)*

- ☐ African American
- ☐ Asian/Pacific Islander
- ☐ Caucasian/European American
- ☐ Latino, Hispanic, or Chicano
- ☐ Native American
- ☐ N/A
- ☐ Other *(Please specify)* _____

5. What is your zip code (e.g. 19104)? ☐☐☐☐☐

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

- ☐ Under $20,000
- ☐ $20,000-$39,999
- ☐ $40,000-$59,999
- ☐ $60,000-$79,999
- ☐ $80,000-$99,999
- ☐ $100,000 or above

7. What is your highest level of completed education?

- ☐ No high school
- ☐ Some high school
- ☐ High school graduate/GED
- ☐ Vocational/Technical school
- ☐ Some college
- ☐ College degree
- ☐ Some graduate studies
- ☐ Graduate degree

8. What is the sex of your child?

☐ Male
☐ Female

9. How old is your child? _____ years _____ months

10. Is your child adopted?

☐ Yes
☐ No

11. What is his/her race/ethnicity? *(Check all that apply)*

☐ African American
☐ Asian/Pacific Islander
☐ Caucasian/European American
☐ Latino/Hispanic/Chicano
☐ Native American

☐ Other *(Please specify)* _____

12. How many siblings does he/she have? _____

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

14. What is your child's primary diagnosis?

☐ Asperger's Disorder
☐ Autistic Disorder/Autism
☐ Childhood Disintegrative Disorder
☐ Pervasive Developmental Disorder (PDD/NOS)
☐ Rett Syndrome

☐ Other *(Please specify)* _____

15. Does your child **currently** have any of the following diagnoses? *(Check all that apply)*

☐ Anxiety Disorder
☐ Attention Deficit/Hyperactivity Disorder
☐ Bipolar Disorder
☐ Central Auditory Processing Disorder
☐ Conduct Disorder (CD)
☐ Depression
☐ Developmental Delays
☐ Hearing Impairment
☐ Learning Disability
☐ Mental Retardation/ Intellectual Disability
☐ Obsessive Compulsive Disorder (OCD)
☐ Oppositional Defiant Disorder (ODD)
☐ Seizures/ Seizure Disorder/Epilepsy
☐ None

☐ Other *(Please specify)* _____

16. Did your child receive any of the following diagnoses **prior** to receiving his/her autism diagnosis? (*Check all that apply*)

☐ Anxiety Disorder
☐ Attention Deficit/Hyperactivity Disorder
☐ Bipolar Disorder
☐ Central Auditory Processing Disorder
☐ Conduct Disorder (CD)
☐ Depression
☐ Developmental Delays
☐ Hearing Impairment
☐ Learning Disability
☐ Mental Retardation/ Intellectual Disability
☐ Obsessive Compulsive Disorder (OCD)
☐ Oppositional Defiant Disorder (ODD)
☐ Seizures/ Seizure Disorder/Epilepsy
☐ None

☐ Other *(Please specify)* _____

17. How old was your child when you first became concerned about his/her development?

_____ years _____ months

18. What type of professional first diagnosed your child with autism?

- ☐ Developmental Pediatrician
- ☐ Educational team (IEP or EI)
- ☐ Neurologist
- ☐ Primary Care Physician (Family doctor/Pediatrician)
- ☐ Psychiatrist
- ☐ Psychologist

☐ Other *(Please specify)* _____

19. About how many miles did you travel for the initial autism diagnosis (roundtrip)?

- ☐ 0-20 miles
- ☐ 21-40 miles
- ☐ 41-60 miles
- ☐ 61-80 miles
- ☐ 81-100 miles
- ☐ More than 100 miles

20. How old was your child when he/she received this diagnosis? _____ years _____ months

21. How many professionals (e.g. psychologist, developmental pediatrician) did you visit before your child received an autism diagnosis? _____

22. After receiving a diagnosis, what sort of follow-up and resources/services did you receive? (*Check 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 websites, literature (e.g. handouts, information booklets)
- ☐ None

☐ Other *(Please specify)* _____

23. How do you pay for your child's health care services? (*Check all that apply*)

- ☐ Private health insurance
- ☐ Medicaid (Medical Access)
- ☐ Out-of-pocket
- ☐ I don't know

☐ Other *(Please specify)* _____

24. In the past year, have you taken your child to the emergency room for behavioral or psychiatric reasons?

☐ Yes
On how many occasions? _____

☐ No

25. In the past year, has your child been admitted to a hospital or hospital-like setting for behavioral or psychiatric reasons?

☐ Yes
On how many occasions? _____

☐ No

If you answered "No" to question 25, please SKIP to question 26

25a. What was/were the reason(s) your child was admitted to a hospital or hospital-like setting? *(Check all that apply)*

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

☐ Other *(Please specify)* _____

25b-d. How satisfied or dissatisfied were you with the following aspects of your child's hospital stay?

	Very Satisfied	Satisfied	Dissatisfied	Very Dissatisfied
b. Discharge Planning	☐	☐	☐	☐
c. Staff's Inclusion of Parent(s) in Treatment Planning	☐	☐	☐	☐
d. Quality of Treatment	☐	☐	☐	☐

25e. 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 the admission
- ☐ My adolescent child (14 to 18) was admitted by his/her parent(s) but did not agree to the 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)

Please continue answering the questions

26. 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

If your child has not been placed in a residential facility or is not currently on a waiting list, please SKIP to question 27

26a. 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
- ☐ More than 100 miles

Please continue answering the questions

27. What is your child's current living situation?

- ☐ With parent(s) in a family home
- ☐ With other relative(s) in a family home
- ☐ Residential facility
- ☐ Group home
- ☐ Lives on own with support
- ☐ Lives on own without support

28. How satisfied or dissatisfied are you with your child's current living arrangement?

☐ Very Satisfied ☐ Satisfied ☐ Dissatisfied ☐ Very Dissatisfied

29. Is your child receiving therapy or intervention for any of the following issues?

	Yes, and needs it	Yes, but does not need	No, but needs	No, and does not need it
a. **Self-injurious behaviors**	☐	☐	☐	☐
b. **Sleep Problems**	☐	☐	☐	☐
c. **Anxiety**	☐	☐	☐	☐
d. **Aggressive Behaviors**	☐	☐	☐	☐
e. **Running Away**	☐	☐	☐	☐
f. **Toileting**	☐	☐	☐	☐

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

☐ Time-out/De-escalation room
☐ Sent out of classroom
☐ Detention
☐ In-school suspension
☐ Out-of-school suspension
☐ Expulsion
☐ None
☐ N/A (My child is not in school)

☐ Other *(Please specify)* _____

31. Has your child's behavior resulted in any of the following interactions with the police? *(Check all that apply)*

☐ Police called
☐ Police warning issued
☐ Child adjudicated
☐ Served time in jail
☐ Served time in a juvenile detention facility
☐ None

☐ Other *(Please specify)* _____

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

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

☐ Other *(Please specify)* _____

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

	Me	My Partner
a. **Stopped working outside the home**	☐	☐
b. **Decreased work hours**	☐	☐
c. **Increased work hours**	☐	☐
d. **Changed employer**	☐	☐
e. **Changed type of work**	☐	☐
f. **Changed work schedule**	☐	☐
g. **Changed position with same employer**	☐	☐
h. **Used Family Medical Leave Act**	☐	☐
i. **Lost promotion/advancement opportunities**	☐	☐
j. **Terminated from employment**	☐	☐
k. **Disciplined/Suspended**	☐	☐
l. **None**	☐	☐
m. **Other** *(Please specify)* _____	☐	☐

34. Does your child have an IEP *(Individualized Education Plan)?*

☐ Yes
☐ No, but evaluation complete, waiting for results
☐ No, but waiting for an evaluation
☐ No
☐ I don't know

If your child DOES NOT have an IEP, please SKIP to question 35

34a. How strongly do you agree or disagree with the following statement?
"My child's IEP addresses all of my concerns for my child's development and education."

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

34b. Did you or another family member attend your child's last IEP meeting?

☐ Yes ☐ No

34c. What is the most recent transition your child has made?

☐ Elementary School to Middle School
☐ Middle School to High School

☐ Other *(Please specify)*_____

34d. How satisfied are you with the support you received from the IEP team during this transition?

☐ Very Satisfied
☐ Somewhat Satisfied
☐ Somewhat Dissatisfied
☐ Very Dissatisfied
☐ N/A

Please continue answering the questions...

35. In what category of special education is your child currently placed? *(Check all that apply)*

☐ Autism
☐ Emotional Support
☐ Learning Disabilities
☐ Mental Retardation
☐ Multiple Disabilities
☐ None (My child is not receiving special education services)

☐ Other *(Please specify)*_____

36. What are your plans for your child's future?

☐ Four-year college
☐ Two-year college
☐ Vocational/Technical school
☐ Seek employment
☐ Undecided
☐ I don't know

☐ Other *(Please specify)*_____

37. Is your child capable of the following activities?

	Independently	With Help	Not Capable
a. **Toileting**	☐	☐	☐
b. **Feeding self**	☐	☐	☐
c. **Dressing self**	☐	☐	☐
d. **Requesting things he/she needs**	☐	☐	☐
e. **Requesting things he/she wants**	☐	☐	☐
f. **Indicating when he/she is sick/hurt**	☐	☐	☐
g. **Cooking/Preparing meals**	☐	☐	☐
h. **Managing money**	☐	☐	☐
i. **Getting around via driving/public transportation/biking/walking**	☐	☐	☐

38. Does your child have any siblings?

☐ Yes
☐ No

Please answer questions 38 a-m in regard to the sibling closest in age to your child with autism, even if this sibling does not have autism. If your child does not have any siblings, please SKIP to question 39.

38a. How old is this sibling? _____ years _____ months

38b. What is his/her sex?

☐ Male ☐ Female

38c. Does this sibling currently live in the same home as your child with autism?

☐ Yes ☐ No

38d. What is his/her relationship to your child with autism?

☐ Biological siblings ☐ Half-siblings
☐ Adoptive siblings ☐ Stepsiblings

☐ Other *(please specify)*_____

38e. Does this sibling have any of the following diagnoses? *(Check all that apply)*

☐ Anxiety Disorder
☐ Attention Deficit/Hyperactivity Disorder
☐ Autistic Disorder/Autism
☐ Bipolar Disorder
☐ Central Auditory Processing Disorder
☐ Conduct Disorder (CD)
☐ Depression
☐ Developmental Delays
☐ Hearing Impairment
☐ Learning Disability
☐ Mental Retardation/ Intellectual Disability
☐ Obsessive Compulsive Disorder (OCD)
☐ Oppositional Defiant Disorder (ODD)
☐ Seizures/ Seizure Disorder/Epilepsy
☐ None of these

38f-q. Based on this sibling's behavior in the past six months, how often has he/she demonstrated the following behaviors compared to his/her peers? ***"This child …"***

	Never	Sometimes	Often	Almost Always
f. **Was physically aggressive**	☐	☐	☐	☐
g. **Was verbally aggressive**	☐	☐	☐	☐
h. **Seemed anxious**	☐	☐	☐	☐
i. **Seemed depressed**	☐	☐	☐	☐
j. **Made suicidal threats/comments**	☐	☐	☐	☐
k. **Exhibited suicidal/self-harming behaviors**	☐	☐	☐	☐
l. **Complained that no one loves/cares about him/her**	☐	☐	☐	☐
m. **Complained about his/her sibling with autism**	☐	☐	☐	☐
n. **Had conflicts with parents**	☐	☐	☐	☐
o. **Had conflicts with his/her sibling with autism**	☐	☐	☐	☐
p. **Had conflicts with peers**	☐	☐	☐	☐
q. **Had conflicts with authority figures (e.g. principal, teacher)**	☐	☐	☐	☐

39. How strongly do you agree or disagree with the following statements?

"My child is receiving all the regular care he/she needs for…"

	Strongly Agree	Agree	Disagree	Strongly Disagree
a. **Primary Health Care**	☐	☐	☐	☐
b. **Dental Services**	☐	☐	☐	☐

"The individuals providing these services are able to meet my child's needs."

	Strongly Agree	Agree	Disagree	Strongly Disagree
c. **Primary Health Care**	☐	☐	☐	☐
d. **Dental Services**	☐	☐	☐	☐

40. What limitations do you face accessing primary health care? *(Check all that apply)*

☐ Transportation
☐ Scheduling issues
☐ Child's behavior problems
☐ Shortage of service providers in the area
☐ No service providers in the area
☐ Providers in the area won't see children with autism
☐ Cost of services/My insurance does not cover available services
☐ None

☐ Other *(Please specify)* _____

☐ Other *(Please specify)* _____

41. What limitations do you face accessing dental services? *(Check all that apply)*

☐ Transportation
☐ Scheduling issues
☐ Child's behavior problems
☐ Shortage of service providers in the area
☐ No service providers in the area
☐ Providers in the area won't see children with autism
☐ Cost of services/My insurance does not cover available services
☐ None

☐ Other *(Please specify)* _____

☐ Other *(Please specify)* _____

42. Please tell us about your child's service needs:

	My child is receiving	My child is receiving, but needs more	My child is receiving, but does not need	My child is not receiving, but needs	My child is not receiving
a. **Mental Health Counseling**	☐	☐	☐	☐	☐
b. **Speech/Language Therapy**	☐	☐	☐	☐	☐
c. **Occupational Therapy**	☐	☐	☐	☐	☐
d. **Physical Therapy**	☐	☐	☐	☐	☐
e. **Social Skills Training**	☐	☐	☐	☐	☐
f. **One-to-one Support (e.g. TSS)**	☐	☐	☐	☐	☐
g. **Mobile Therapy**	☐	☐	☐	☐	☐
h. **Case Management**	☐	☐	☐	☐	☐
i. **Neurology Services**	☐	☐	☐	☐	☐
j. **Medication Management**	☐	☐	☐	☐	☐
k. **Summer Camp**	☐	☐	☐	☐	☐
l. **Summer School (ESY)**	☐	☐	☐	☐	☐
m. **Sexual Health Education**	☐	☐	☐	☐	☐
n. **Transitional Planning**	☐	☐	☐	☐	☐
o. **Vocational Training**	☐	☐	☐	☐	☐
p. **Support Groups**	☐	☐	☐	☐	☐
q. **Career Counseling**	☐	☐	☐	☐	☐
r. **Academic Tutoring**	☐	☐	☐	☐	☐
s. **Drug & Alcohol Counseling**	☐	☐	☐	☐	☐
t. **Relationship Counseling**	☐	☐	☐	☐	☐
u. **Supported Employment**	☐	☐	☐	☐	☐

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

	Strongly Agree	Agree	Disagree	Strongly Disagree	N/A
a. **Mental Health Counseling**	☐	☐	☐	☐	☐
b. **Speech/Language Therapy**	☐	☐	☐	☐	☐
c. **Occupational Therapy**	☐	☐	☐	☐	☐
d. **Physical Therapy**	☐	☐	☐	☐	☐
e. **Social Skills Training**	☐	☐	☐	☐	☐
f. **One-to-one Support (e.g. TSS)**	☐	☐	☐	☐	☐
g. **Mobile Therapy**	☐	☐	☐	☐	☐
h. **Case Management**	☐	☐	☐	☐	☐
i. **Neurology Services**	☐	☐	☐	☐	☐
j. **Medication Management**	☐	☐	☐	☐	☐
k. **Summer Camp**	☐	☐	☐	☐	☐
l. **Summer School (ESY)**	☐	☐	☐	☐	☐
m. **Sexual Health Education**	☐	☐	☐	☐	☐
n. **Transitional Planning**	☐	☐	☐	☐	☐
o. **Vocational Training**	☐	☐	☐	☐	☐
p. **Support Groups**	☐	☐	☐	☐	☐
q. **Career Counseling**	☐	☐	☐	☐	☐
r. **Academic Tutoring**	☐	☐	☐	☐	☐
s. **Drug & Alcohol Counseling**	☐	☐	☐	☐	☐
t. **Relationship Counseling**	☐	☐	☐	☐	☐
u. **Supported Employment**	☐	☐	☐	☐	☐

44. How strongly do you agree or disagree with the following statement?
"This service is effective in meeting my child's needs."

	Strongly Agree	Agree	Disagree	Strongly Disagree	N/A
a. **Mental Health Counseling**	☐	☐	☐	☐	☐
b. **Speech/Language Therapy**	☐	☐	☐	☐	☐
c. **Occupational Therapy**	☐	☐	☐	☐	☐
d. **Physical Therapy**	☐	☐	☐	☐	☐
e. **Social Skills Training**	☐	☐	☐	☐	☐
f. **One-to-one Support (e.g. TSS)**	☐	☐	☐	☐	☐
g. **Mobile Therapy**	☐	☐	☐	☐	☐
h. **Case Management**	☐	☐	☐	☐	☐
i. **Neurology Services**	☐	☐	☐	☐	☐
j. **Medication Management**	☐	☐	☐	☐	☐
k. **Summer Camp**	☐	☐	☐	☐	☐
l. **Summer School (ESY)**	☐	☐	☐	☐	☐
m. **Sexual Health Education**	☐	☐	☐	☐	☐
n. **Transitional Planning**	☐	☐	☐	☐	☐
o. **Vocational Training**	☐	☐	☐	☐	☐
p. **Support Groups**	☐	☐	☐	☐	☐
q. **Career Counseling**	☐	☐	☐	☐	☐
r. **Academic Tutoring**	☐	☐	☐	☐	☐
s. **Drug & Alcohol Counseling**	☐	☐	☐	☐	☐
t. **Relationship Counseling**	☐	☐	☐	☐	☐
u. **Supported Employment**	☐	☐	☐	☐	☐

45. What limitations do you face accessing the specialty health and education services mentioned? *(Check all that apply)*

- ☐ Transportation
- ☐ Scheduling issues
- ☐ Child's behavior problems
- ☐ Shortage of service providers in the area
- ☐ No service providers in the area
- ☐ Providers in the area won't see children with autism
- ☐ Cost of services/My insurance does not cover available services
- ☐ None

☐ Other *(Please specify)* _____

☐ Other *(Please specify)* _____

46. Please tell us about your family support service needs:

	My family is receiving	My family is receiving, but needs more	My family is receiving, but does not need	My family is not receiving, but needs	My family is not receiving
a. **Respite Care**	☐	☐	☐	☐	☐
b. **Babysitting**	☐	☐	☐	☐	☐
c. **Afterschool Care**	☐	☐	☐	☐	☐
d. **Weekend Childcare**	☐	☐	☐	☐	☐
e. **Family Counseling**	☐	☐	☐	☐	☐
f. **Sibling Support Groups**	☐	☐	☐	☐	☐
g. **Sibling Mental Health Counseling**	☐	☐	☐	☐	☐
h. **Parent Support Groups**	☐	☐	☐	☐	☐
i. **Parent Mental Health Counseling**	☐	☐	☐	☐	☐

47. 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
a. **Respite Care**	☐	☐	☐	☐	☐
b. **Babysitting**	☐	☐	☐	☐	☐
c. **Afterschool Care**	☐	☐	☐	☐	☐
d. **Weekend Childcare**	☐	☐	☐	☐	☐
e. **Family Counseling**	☐	☐	☐	☐	☐
f. **Sibling Support Groups**	☐	☐	☐	☐	☐
g. **Sibling Mental Health Counseling**	☐	☐	☐	☐	☐
h. **Parent Support Groups**	☐	☐	☐	☐	☐
i. **Parent Mental Health Counseling**	☐	☐	☐	☐	☐

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

	Strongly Agree	Agree	Disagree	Strongly Disagree	N/A
a. **Respite Care**	☐	☐	☐	☐	☐
b. **Babysitting**	☐	☐	☐	☐	☐
c. **Afterschool Care**	☐	☐	☐	☐	☐
d. **Weekend Childcare**	☐	☐	☐	☐	☐
e. **Family Counseling**	☐	☐	☐	☐	☐
f. **Sibling Support Groups**	☐	☐	☐	☐	☐
g. **Sibling Mental Health Counseling**	☐	☐	☐	☐	☐
h. **Parent Support Groups**	☐	☐	☐	☐	☐
i. **Parent Mental Health Counseling**	☐	☐	☐	☐	☐

49. What limitations do you face accessing the family support services mentioned? *(Check all that apply)*

☐ Transportation
☐ Scheduling issues
☐ Shortage of service providers in the area
☐ No service providers in the area
☐ Cost of services/My insurance does not cover available services
☐ None

☐ Other *(Please specify)* _____

☐ Other *(Please specify)* _____

50. Are there any particular service providers or organizations you would recommend to other individuals? *(Please fill out as much information as possible)*

Type of Service:	
Name of Provider:	
Organization:	
Address:	

Type of Service:	
Name of Provider:	
Organization:	
Address:	

Type of Service:	
Name of Provider:	
Organization:	
Address:	

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Thank you for completing this needs assessment survey. Please send the completed survey in the self-addressed and stamped envelope.