

PENNSYLVANIA AUTISM NEEDS ASSESSMENT

Elementary School Module

1284 caregivers of children in elementary school diagnosed with autism spectrum disorders completed this needs assessment module. Item-level survey results for this module are presented here in the same format in which the survey was administered.

1. Please identify yourself:

Mother	84.7%	Foster parent	0.4%
Father	10.8%	Legal guardian	3.1%
Other (<i>Please specify</i>)	1.0%		

2. Which of the following best describes your current marital status?

Married to/Living with child's other parent	72.3%	Widowed	1.3%
Married to/Living with person other than child's parent	6.4%	Never been married	6.8%
		Separated/Divorced	13.2%

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

African American	4.4%	Latino, Hispanic, or Chicano	3.4%
Asian/Pacific Islander	1.9%	Native American	1.0%
Caucasian/European American	89.6%		
Other (<i>Please specify</i>)	0.3%		

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

African American	3.2%	Latino, Hispanic, or Chicano	2.7%
Asian/Pacific Islander	1.7%	Native American	1.0%
Caucasian/European American	81.2%	N/A	8.9%
Other (<i>Please specify</i>)	0.3%		

5. What is your zip code? **See attached map.**

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

Under \$20,000	12.4%
\$20,000-\$39,999	19.5%
\$40,000-\$59,999	20.5%
\$60,000-\$79,999	17.7%
\$80,000-\$99,999	10.6%
\$100,000 or above	19.3%

7. What is your highest level of completed education?

No high school	0.6%	Some college	20.6%
Some high school	2.8%	College degree	31.1%
High school graduate/GED	15.9%	Some graduate studies	4.7%
Vocational/Technical school	7.9%	Graduate degree	16.4%

8. What is the sex of your child? Male 81.7% Female 18.3%

9. How old is your child? Mean: 8.9 years; Standard Deviation: 4.12

10. Is your child adopted? Yes 6.1% No 93.9%

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

African American	6.6%	Latino, Hispanic, or Chicano	4.9%
Asian/Pacific Islander	2.7%	Native American	1.4%
Caucasian/European American	88.9%		
Other <i>(Please specify)</i>	0.2%		

12. How many siblings does he/she have?

Mean: 1.45 siblings; Standard Deviation: 1.18

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

Mean: 0.13 siblings; Standard Deviation: 0.39

14. What is your child's primary diagnosis?

Asperger's Disorder	20.4%	Pervasive Developmental Disorder	
Autistic Disorder/Autism	33.6%	(PDD/NOS)	43.2%
Other <i>(Please specify)</i>	2.8%		

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

Anxiety Disorder	16.0%	Learning Disability	21.6%
Attention Deficit/Hyperactivity Disorder	38.0%	Mental Retardation/ Intellectual Disability	11.9%
Bipolar Disorder	2.1%	Obsessive Compulsive Disorder (OCD)	8.5%
Central Auditory Processing Disorder	4.8%	Oppositional Defiant Disorder (ODD)	10.0%
Conduct Disorder (CD)	2.8%	Seizures/ Seizure Disorder/Epilepsy	6.4%
Depression	2.6%	Speech Disorder	2.6%
Developmental Delays	36.2%	Tourette's Syndrome	0.5%
Hearing Impairment	1.7%	None of these	18.3%
Other <i>(Please specify)</i>	10.5%		

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

Anxiety Disorder	4.4%	Learning Disability	9.7%
Attention Deficit/Hyperactivity Disorder	16.0%	Mental Retardation/ Intellectual Disability	4.4%
Bipolar Disorder	1.2%	Obsessive Compulsive Disorder (OCD)	2.6%
Central Auditory Processing Disorder	1.6%	Oppositional Defiant Disorder (ODD)	5.5%
Conduct Disorder (CD)	1.2%	Seizures/ Seizure Disorder/Epilepsy	4.4%
Depression	1.6%	Speech Disorder	1.0%
Developmental Delays	28.9%	Tourette's Syndrome	0.2%
Hearing Impairment	2.0%	None of these	43.1%
Other <i>(Please specify)</i>	5.7%		

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

Mean: 2.3 years; Standard Deviation: 1.88

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

Developmental Pediatrician	28.3%	Psychiatrist	15.0%
Educational team (IEP or EI)	6.9%	Psychologist	31.6%
Neurologist	7.9%		
Primary Care Physician (Family doctor/Pediatrician)	5.3%		
Other	5.0%		

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

0-20 miles	47.0%
21-40 miles	22.9%
41-60 miles	9.8%
61-80 miles	6.1%
81-100 miles	5.0%
More than 100 miles	9.2%

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

Mean: 4.1 years; Standard Deviation: 2.19

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

Mean: 2.41 professionals; Standard Deviation: 4.58; Range: 0-100 professionals

22. After receiving a diagnosis, what sort of follow-up and resources/services did you receive? (Check all that apply)

Follow-up appointment	44.3%	Referral to support groups	33.2%
Referral to a specialist for further assessment	23.1%	Referral to websites, literature (e.g. handouts, information booklets)	42.1%
Referral to a specialist for treatment	29.1%	None	7.6%
Referral to Early Intervention services	59.0%		
Other (Please specify)	2.0%		

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

Private health insurance	57.4%	Out-of-pocket	21.6%
Medicaid (Medical Access)	84.9%	I don't know	0.6%
Other (Please specify)	0.6%		

24. In the past year, have you taken your child to the emergency room for behavioral or psychiatric reasons? If so, on how many occasions?

Yes	4.7%	No	95.3%
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On how many occasions?

Mean: 1.5 visits ; Standard Deviation: 0.90

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

Yes	2.9%	No	97.1%
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On how many occasions?

Mean: 1.6 hospitalizations; Standard Deviation: 0.85



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 for psychiatric or behavioral reasons? (Check all that apply)

Aggression	2.3%	Running away from home/school	0.6%
Anxiety	0.6%	Self-injurious behaviors	1.3%
Defiant/Oppositional behaviors	1.8%	Significant increase in obsessions	0.4%
Depression	0.3%		
Other (Please specify)	0.3%		

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

	Very Satisfied	Satisfied	Dissatisfied	Very Dissatisfied
25b. Discharge Planning	18.9%	37.8%	37.8%	5.4%
25c. Staff's Inclusion of Parent(s) in Treatment	23.7%	52.6%	21.1%	2.6%
25d. Quality of Treatment	26.3%	42.1%	28.9%	2.6%

25e. How was your child admitted?

My child (under 14) was admitted by his/her parent(s)	94.3%	My adult child (18 or older) admitted him/herself (201, voluntary treatment)	0%
My adolescent child (14 to 18) was admitted by his/her parent(s) and agreed to the admission	5.7%	My adult child (18 or older) was admitted against his/her will (302, involuntary treatment)	0%
My adolescent child (14 to 18) was admitted by his/her parent(s) but did not agree to the admission	0%		

→→→ Please continue answering the questions...

26. In the last year, has your child been placed in a residential facility?

Yes	1.0%	No and not on a waiting list	98.2%
No, but currently on a waiting list	0.8%		



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	15.8%
21-40 miles	36.8%
41-60 miles	10.5%
61-80 miles	5.3%
81-100 miles	15.8%
More than 100 miles	15.8%

→→→ Please continue answering the questions...

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

With parent(s) in a family home	96.4%	Group home	0%
With other relatives in a family home	2.8%	Lives on own with support	0%
Residential facility	0.7%	Lives on own without support	0%

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

Very Satisfied	84.9%
Satisfied	13.1%
Dissatisfied	1.3%
Very Dissatisfied	0.6%

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

	Yes, and needs it	Yes, but does not need	No, but needs it	No, doesn't need it
29a. Self-injurious behaviors	15.6%	0.6%	5.4%	78.4%
29b. Sleep Problems	15.6%	1.4%	15.1%	67.9%
29c. Anxiety	34.6%	0.8%	14.3%	50.3%
29d. Aggressive Behaviors	36.4%	1.7%	7.6%	54.3%
29e. Running Away	13.3%	0.6%	6.0%	80.1%
29f. Toileting	12.8%	0.6%	13.1%	73.6%

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

Time-out/De-escalation room	46.2%	Out-of-school suspension	4.5%
Sent out of classroom	28.0%	Expulsion	0.8%
Detention	4.9%	None	40.8%
In-school suspension	3.3%	N/A (My child is not in school)	1.4%
Other <i>(Please specify)</i>	3.2%		

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

Police called	3.1%	Served time in jail	0%
Police warning issued	0.5%	Served time in a juvenile detention	0%
Child adjudicated	0.2%	None	93.5%
Other <i>(Please specify)</i>	0.2%		

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	3.0%	Designated power of attorney	6.0%
Set up financial trust	11.3%	Currently developing plans	17.4%
Designated guardianship	17.0%	None at this time	64.8%
Other <i>(Please specify)</i>	0.1%		

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

	Me	My Partner
Stopped working outside the home	29.2%	5.9%
Decreased work hours	24.6%	11.2%
Increased work hours	1.6%	5.6%
Changed employer	7.7%	3.8%
Changed type of work	10.1%	4.0%
Changed work schedule	26.1%	14.6%
Changed position with same employer	3.2%	2.0%
Used Family Medical Leave Act	5.0%	3.3%
Lost promotion/advancement opportunities	10.7%	3.8%
Terminated from employment	3.8%	1.2%
Disciplined/Suspended	2.4%	0.9%
None	31.5%	49.4%
N/A	-	12.4%
Other (Please specify)	2.4%	0.9%

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

Yes	90.5%
No, but evaluation complete, waiting for results	0.6%
No, but waiting for an evaluation	1.9%
No	6.3%
I don’t know	0.7%



If your child DOES NOT have an or 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	24.7%	Disagree	21.4%
Agree	48.0%	Strongly Disagree	5.9%

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

Yes	96.6%	No	3.4%
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→→→ Please continue answering the questions...

35. What category of Special Education is your child currently placed? *(Check all that apply)*

Autism	50.8%	Multiple Disabilities	4.3%
Emotional Support	10.1%	None (my child is not receiving special education services)	12.5%
Learning Disabilities	20.6%		
Mental Retardation	4.1%		
Other	12.9%		

36. Is your child capable of the following activities?

	Independently	With help	Not capable
36a. Toileting	69.3%	25.3%	5.4%
36b. Feeding Self	88.0%	11.1%	0.8%
36c. Dressing Self	60.8%	36.3%	2.9%
36d. Requesting things he/she needs	64.5%	31.6%	3.9%
36e. Requesting things he/she wants	68.5%	28.5%	3.0%
36f. Indicating when he/she is sick/hurt	60.2%	26.3%	13.5%

37. Does your child have any siblings? Yes 82.5% No 17.5%



→ Please answer **questions 37a-q** in regard to the sibling closest in age to the child with autism, even if this sibling does not have autism. If your child does not have any siblings, please **SKIP** to question 38.

37a. How old is this sibling? Mean: 10.8 years; Standard Deviation: 6.12

37b. What is his/her sex? Male 47.8% Female 52.2%

37c. Does this sibling currently live in the same home as your child with autism?
Yes 90.1% No 9.9%

37d. What is his/her relationship to your child with autism?
Biological siblings 81.2% Half-siblings 14.9%
Adoptive siblings 2.9% Stepsiblings 0.7%
Other (please specify) 0.3%

37e. Does this sibling have any of the following diagnoses? (Check all that apply)

Anxiety Disorder	4.4%	Learning Disability	5.8%
Attention Deficit/Hyperactivity Disorder	10.2%	Mental Retardation/ Intellectual Disability	1.6%
Autistic Disorder/Autism	7.1%	Obsessive Compulsive Disorder (OCD)	1.9%
Bipolar Disorder	1.1%	Oppositional Defiant Disorder (ODD)	3.1%
Central Auditory Processing Disorder	0.6%	Seizures/ Seizure Disorder/Epilepsy	0.9%
Conduct Disorder (CD)	0.6%	Speech Disorder	0.5%
Depression	3.7%	Tourette's Syndrome	0.2%
Developmental Delays	4.7%	None of these	49.5%
Hearing Impairment	0.5%		
Other (please specify)	5.0%		

37f-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
37f. Was physically aggressive	61.8%	31.7%	5.2%	1.3%
37g. Was verbally aggressive	56.7%	34.5%	6.5%	2.3%
37h. Seemed anxious	49.3%	37.2%	9.8%	3.7%
37i. Seemed depressed	67.6%	26.9%	4.4%	1.1%
37j. Made suicidal threats/ comments	94.6%	4.8%	0.4%	0.1%
37k. Exhibited suicidal/self-harming behaviors	95.5%	4.1%	0.3%	0.1%
37l. Complained that no one loves/cares about him/her	69.2%	25.3%	4.4%	1.2%
37m. Complained about his/her sibling with autism	34.4%	45.8%	14.5%	5.3%
37n. Had conflicts with parents	34.4%	53.7%	9.6%	2.3%
37o. Had conflicts with his/her sibling with autism	21.8%	53.4%	18.0%	6.8%
37p. Had conflicts with peers	54.9%	39.5%	4.4%	1.2%
37q. Had conflicts with authority figures (e.g. principal, teacher)	79.9%	17.1%	2.0%	1.0%

→→→ Please continue answering the questions...

38. How strongly do you agree with the following statements?

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

	Strongly Agree	Agree	Disagree	Strongly Disagree
38a. Primary Health Care	48.0%	41.3%	7.8%	2.9%
38b. Dental Services	48.6%	37.6%	9.5%	4.3%

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

	Strongly Agree	Agree	Disagree	Strongly Disagree
38c. Primary Health Care	40.9%	46.2%	10.9%	2.1%
38d. Dental Services	45.3%	39.6%	10.9%	4.2%

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

Transportation	5.2%	Providers in the area won't see children with autism	5.1%
Scheduling issues	17.6%	Cost of service/My insurance does not cover available services	12.1%
Child's behavior problems	20.2%	None	45.8%
Shortage of service providers in the area	17.2%		
No service providers in the area	3.5%		
Other (Please specify)	4.4%		

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

Transportation	5.7%	Providers in the area won't see children with autism	8.5%
Scheduling issues	14.2%	Cost of service/My insurance does not cover available services	10.1%
Child's behavior problems	23.5%	None	43.5%
Shortage of service providers in the area	15.7%		
No service providers in the area	5.1%		
Other (Please specify)	3.6%		

41. Please tell us about your child's specialty health and education 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
41a. Mental Health Counseling	28.0%	7.7%	0.7%	10.0%	53.7%
41b. Speech/Language Therapy	50.5%	23.2%	0.7%	6.8%	18.8%
41c. Occupational Therapy	41.6%	19.5%	0.7%	12.1%	26.1%
41d. Physical Therapy	14.0%	6.1%	1.1%	8.3%	70.5%
41e. Social Skills Training	33.2%	27.1%	0.3%	25.5%	13.8%
41f. One-to-one Support (e.g. TSS)	46.1%	14.1%	0.4%	11.4%	28.0%
41g. Mobile Therapy	20.9%	4.0%	0.3%	11.2%	63.5%
41h. Case Management	55.9%	7.7%	0.7%	6.8%	28.9%
41i. Neurology Services	17.3%	2.7%	0.6%	11.4%	67.9%
41j. Medication Management	40.4%	4.1%	1.0%	3.1%	51.3%
41k. Summer Camp	27.0%	7.8%	0.5%	21.2%	43.5%
41l. Summer School/ESY	29.0%	10.2%	1.6%	10.5%	48.7%
41m. Sexual Health Education	2.3%	0.4%	1.0%	7.1%	89.2%

42. 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
42a. Mental Health Counseling	41.9%	48.6%	8.6%	1.0%
42b. Speech/Language Therapy	47.5%	45.3%	5.7%	1.5%
42c. Occupational Therapy	45.1%	47.6%	6.2%	1.1%
42d. Physical Therapy	44.1%	47.9%	7.1%	0.8%
42e. Social Skills Training	40.3%	50.0%	8.6%	1.2%
42f. One-to-one Support (e.g. TSS)	45.5%	43.1%	8.2%	3.2%
42g. Mobile Therapy	43.8%	51.2%	4.6%	0.4%
42h. Case Management	39.9%	49.7%	7.9%	2.5%
42i. Neurology Services	57.0%	37.0%	6.1%	0%
42j. Medication Management	53.4%	38.3%	6.7%	1.5%
42k. Summer Camp	42.0%	46.1%	9.1%	2.8%
42l. Summer School/ESY	36.7%	44.8%	12.0%	6.5%
42m. Sexual Health Education	37.5%	45.0%	12.5%	5.0%

43. 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
43a. Mental Health Counseling	32.4%	51.1%	15.3%	1.2%
43b. Speech/Language Therapy	38.2%	45.7%	13.3%	2.8%
43c. Occupational Therapy	36.5%	48.6%	12.4%	2.4%
43d. Physical Therapy	38.6%	49.6%	11.0%	0.8%
43e. Social Skills Training	32.7 %	49.3%	15.5%	2.6%
43f. One-to-one Support (e.g. TSS)	43.4%	44.4%	9.9%	2.3%
43g. Mobile Therapy	36.3%	57.3%	5.7%	0.7%
43h. Case Management	34.1%	52.1%	11.0%	2.8%
43i. Neurology Services	49.8%	42.3%	6.6%	1.3%
43j. Medication Management	46.2 %	44.1%	8.3%	1.4%
43k. Summer Camp	38.2%	49.5%	9.5%	2.8%
43l. Summer School/ESY	33.5%	44.7%	14.2%	7.5%
43m. Sexual Health Education	29.3%	46.3%	24.4%	0%

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

Transportation	7.6%	Providers in the area won't see children with autism	2.9%
Scheduling issues	23.4%	Cost of service/My insurance does not cover available services	16.2%
Child's behavior problems	14.9 %	None	33.1%
Shortage of service providers in the area	30.8%		
No service providers in the area	6.2%		
Other <i>(Please specify)</i>	6.7%		

45. 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
45a. Respite Care	2.8%	3.6%	0.1%	22.3%	71.3%
45b. Babysitting	7.7%	4.1%	0.4%	28.8%	58.9%
45c. Afterschool Care	10.0%	2.6%	0.6%	15.8%	71.0%
45d. Weekend Childcare	2.3%	1.4%	0.3%	18.4%	77.5%
45e. Family Counseling	5.5%	2.3%	0.5%	21.9%	69.8%
45f. Sibling Support Groups	2.1%	0.6%	0.8%	22.9%	73.6%
45g. Sibling Mental Health Counseling	4.5%	1.2%	0.7%	13.0%	80.6%
45h. Parent Support Groups	10.3%	2.7%	0.6%	23.2%	63.1%
45i. Parent Mental Health Counseling	6.4%	2.0%	0.3%	19.4%	71.9%

46. 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
46a. Respite Care	40.0%	49.3%	6.7%	4.0%
46b. Babysitting	40.3%	44.6%	12.2%	2.9%
46c. Afterschool Care	29.4%	46.4%	16.3%	7.8%
46d. Weekend Childcare	45.5%	40.9%	9.1%	4.5%
46e. Family Counseling	34.4%	51.1%	13.3%	1.1%
46f. Sibling Support Groups	26.5%	61.8%	8.8%	2.9%
46g. Sibling Mental Health Counseling	32.8%	56.2%	7.8%	3.1%
46h. Parent Support Groups	32.7%	55.1%	12.2%	0%
46i. Parent Mental Health Counseling	39.4%	50.0%	8.5%	2.1%

47. How strongly do you agree with the following statement?

“This service is effective in meeting my family’s needs.”

	Strongly Agree	Agree	Disagree	Strongly Disagree
47a. Respite Care	33.3%	37.3%	25.3%	4.0%
47b. Babysitting	33.3%	48.6%	15.9%	2.2%
47c. Afterschool Care	30.3%	50.0%	17.8%	2.0%
47d. Weekend Childcare	48.9%	26.7%	22.2%	2.2%
47e. Family Counseling	27.3%	53.4%	13.6%	5.7%
47f. Sibling Support Groups	20.6%	52.9%	23.5%	2.9%
47g. Sibling Mental Health Counseling	29.7%	48.4%	15.6%	6.2%
47h. Parent Support Groups	30.7%	50.7%	18.0%	0.7%
47i. Parent Mental Health Counseling	37.1%	46.4%	14.4%	2.1%

48. What limitations do you face accessing these family support services? *(Check all that apply)*

Transportation	2.7%	Cost of service/My insurance does not cover available services	7.8%
Scheduling issues	12.2%	None	13.9%
Shortage of service providers in the area	11.1%		
No service providers in the area	3.7%		
Other <i>(Please specify)</i>	2.7%		