

PENNSYLVANIA AUTISM NEEDS ASSESSMENT

Pre Elementary Module

279 caregivers of children not yet 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	86.7%	Foster parent	0.4%
Father	9.4%	Legal guardian	1.4%
Other (<i>Please specify</i>)	2.2%		

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

Married to/Living with child's other parent	78.8%	Widowed	0.4%
Married to/Living with person other than child's parent	5.4%	Never been married	8.3%
		Separated/Divorced	7.2%

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

African American	5.7%	Latino, Hispanic, or Chicano	5.0%
Asian/Pacific Islander	4.3%	Native American	0.7%
Caucasian/European American	83.5%		
Other (<i>Please specify</i>)	1.8%		

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

African American	6.8%	Latino, Hispanic, or Chicano	3.9%
Asian/Pacific Islander	4.3%	Native American	1.8%
Caucasian/European American	79.9%	N/A	5.0%
Other (<i>Please specify</i>)	2.9%		

5. What is your zip code (e.g. 19104)? **See Map**

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

Under \$20,000	16.7%
\$20,000-\$39,999	14.8%
\$40,000-\$59,999	17.4%
\$60,000-\$79,999	15.2%
\$80,000-\$99,999	15.5%
\$100,000 and above	20.5%

7. What is your highest level of completed education?

No high school	0.0%	Some college	19.9%
Some high school	1.4%	College degree	34.8%
High school graduate/GED	12.7%	Some graduate studies	3.3%
Vocational/Technical school	5.8%	Graduate degree	22.1%

8. What is the sex of your child? Male 80.3% Female 19.7%

9. How old is your child? Mean: 4.5 years; Standard Deviation: 0.86

10. Is your child adopted? Yes 5.4% No 94.6%

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

African American	9.7%	Latino, Hispanic, or Chicano	7.2%
Asian/Pacific Islander	5.4%	Native American	0.7%
Caucasian/European American	82.4%		
Other <i>(Please specify)</i>	2.2%		

12. How many siblings does he/she have?

Mean: 1.27 siblings; Standard Deviation: 1.24

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

Mean: 0.09 siblings; Standard Deviation: 0.28

14. What is your child's primary diagnosis?

Asperger's Disorder	6.9%	Pervasive Developmental Disorder (PDD/NOS)	43.3%
Autistic Disorder/Autism	48.7%		
Other	1.1%		

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

Anxiety Disorder	7.2%	Learning Disability	11.8%
Attention Deficit/Hyperactivity Disorder	17.2%	Mental Retardation/ Intellectual Disability	3.9%
Bipolar Disorder	1.1%	Obsessive Compulsive Disorder (OCD)	4.3%
Central Auditory Processing Disorder	1.4%	Oppositional Defiant Disorder (ODD)	2.2%
Conduct Disorder (CD)	2.9%	Seizures/ Seizure Disorder/Epilepsy	5.0%
Depression	0%	Speech Disorder	1.1%
Developmental Delays	43.0%	None	30.1%
Hearing Impairment	1.1%		
Other <i>(Please specify)</i>	11.8%		

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

Anxiety Disorder	2.5%	Learning Disability	4.7%
Attention Deficit/Hyperactivity Disorder	4.7%	Mental Retardation/ Intellectual Disability	0.4%
Bipolar Disorder	0%	Obsessive Compulsive Disorder (OCD)	0.7%
Central Auditory Processing Disorder	0.4%	Oppositional Defiant Disorder (ODD)	1.1%
Conduct Disorder (CD)	1.4%	Seizures/ Seizure Disorder/Epilepsy	1.1%
Depression	0%	Speech Disorder	1.8%
Developmental Delays	31.5%	None	49.5%
Hearing Impairment	2.5%		
Other <i>(Please specify)</i>	7.9%		

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

Mean: 1.6 years; Standard Deviation: 0.98

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

Developmental Pediatrician	35.8%	Psychiatrist	12.0%
Educational team (IEP or EI)	7.3%	Psychologist	28.8%
Neurologist	7.3%		
Primary Care Physician (Family doctor/Pediatrician)	6.2%		
Other	2.6%		

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

0-20 miles	46.9%
21-40 miles	14.9%
41-60 miles	13.1%
61-80 miles	9.8%
81-100 miles	5.5%
More than 100 miles	9.8%

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

Mean: 2.6 years; Standard Deviation: 0.82

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

Mean: 2 professionals; Standard Deviation: 2; Range: 0-15 professionals

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

Follow-up appointment	44.4%	Referral to support groups	40.1%
Referral to a specialist for further assessment	19.0%	Referral to websites, literature (e.g. handouts, information booklets)	47.3%
Referral to a specialist for treatment	29.4%	None	3.9%
Referral to Early Intervention services	72.0%		
Other (Please specify)	2.9%		

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

Private health insurance	60.9%	Out-of-pocket	21.1%
Medicaid (Medical Access)	87.1%	I don't know	1.1%
Other (Please specify)	2.2%		

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

Yes 2.9% No 97.1%

On how many occasions?

Mean: 2.25visits; Standard Deviation: 1.83

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

Yes 0.4% No 99.6%

On how many occasions?

Mean: 1 hospitalization



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	0%	Running away from home/school	0%
Anxiety	0%	Self-injurious behaviors	0.4%
Defiant/Oppositional behaviors	0%	Significant increase in obsessions	0%
Depression	0%		
Other (Please specify)	0%		

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

	Very Satisfied	Satisfied	Dissatisfied	Very Dissatisfied
25b. Discharge Planning	0%	0%	0%	100%
25c. Staff's Inclusion of Parent(s) in Treatment Planning	0%	0%	100%	0%
25d. Quality of Treatment	0%	0%	100%	0%

25e. How was your child admitted?

My child (under 14) was admitted by his/her parent(s)	100%	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	0%	My adult child (18 or older) was admitted against his/her will (202, involuntary treatment)	0%
My adolescent child (14 to 18) was admitted by his/her parent(s) but did not agree to the admission	0%		0%



→→→ Please continue answering the questions...

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

Yes	0%	No and not on a waiting list	99.6%
No, but currently on a waiting list	0.4%		



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

➔➔➔ Please continue answering the questions...

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

With parent(s) in a family home	94.9%
With other relative(s) in a family home	4.8%
Residential facility	0%
Group home	0%
Lives on own with support	0.4%
Lives on own without support	0%

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

Very Satisfied	86.1%
Satisfied	11.7%
Dissatisfied	1.8%
Very Dissatisfied	0.4%

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
29a. Self-injurious behaviors	15.0%	1.8%	3.3%	79.9%
29b. Sleep Problems	10.6%	0.7%	17.2%	71.5%
29c. Anxiety	19.9%	0.4%	10.7%	69.0%
29d. Aggressive Behaviors	34.4%	1.1%	7.0%	57.5%
29e. Running Away	21.7%	1.1%	4.8%	72.4%
29f. Toileting	24.7%	1.1%	29.5%	44.6%

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	32.3%	Out-of-school suspension	0.4%
Sent out of classroom	9.7%	Expulsion	0.7%
Detention	0%	None	43.0%
In-school suspension	0%	N/A (My child is not in school)	21.1%
Other <i>(Please specify)</i>	0.4%		

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

Police called	0.7%		
Police warning issued	0%	Served time in a juvenile detention	0%
Child adjudicated	0%	None	95.7%
Served time in jail	0%		
Other <i>(Please specify)</i>	0.4%		

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	2.2%	Designated power of attorney	5.0%
Set up financial trust	8.2%	Currently developing plans	13.3%
Designated guardianship	14.7%	None	71.7%
Other <i>(Please specify)</i>	0%		

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	25.4%	3.6%
Decreased work hours	25.1%	9.3%
Increased work hours	2.2%	7.9%
Changed employer	3.2%	3.9%
Changed type of work	5.7%	3.6%
Changed work schedule	20.4%	13.6%
Changed position with same employer	5.0%	1.8%
Used Family Medical Leave Act	2.2%	0.4%
Lost promotion/advancement opportunities	7.2%	1.8%
Terminated from employment	3.2%	0%
Disciplined/Suspended	2.2%	0.7%
None	38.7%	54.8%
N/A	-	10.4%
Other (Please specify) _____	3.2%	0.4%

34. Does your child have an IFSP (Individualized Family Service Plan) or IEP (Individualized Education Plan)?

Yes	89.7%
No, but evaluation complete, waiting for results	1.6%
No, but waiting for an evaluation	0%
No	5.6%
I don't know	3.2%



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

34a. At what age did your child start using Early Intervention services?

Mean: 1.7 years; Standard Deviation: 1.20

34b. How strongly do you agree with the following statement?

“My child’s IFSP/IEP addresses all of my concerns for my child’s development and education.”

Strongly Agree	28.1%
Agree	53.6%
Disagree	16.1%
Strongly Disagree	2.2%

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

Yes	96.5%	No	3.5%
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→→→ Please continue answering the questions...

35. Is your child capable of the following activities?

	Independently	With help	Not capable
35a. Toileting	26.1%	41.1%	32.8%
35b. Feeding Self	70.4%	26.9%	2.8%
35c. Requesting things he/she needs	40.6%	51.0%	8.4%
35d. Requesting things he/she wants	47.0%	47.0%	6.0%
35e. Indicating when he/she is sick/hurt	35.7%	36.5%	27.8%

36. 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
36a. Primary Health Care	47.4%	39.5%	8.7%	4.3%
36b. Dental Services	39.3%	40.9%	15.5%	4.4%

“The individuals providing these services are able to meet my child’s needs.”

	Strongly Agree	Agree	Disagree	Strongly Disagree
36c. Primary Health Care	38.7%	41.1%	17.4%	2.8%
36d. Dental Services	36.4%	39.3%	19.4%	4.9%

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

Transportation	7.2%	Providers in the area won't see children with autism	2.9%
Scheduling issues	17.9%	Cost of service/My insurance does not cover available services	11.5%
Child's behavior problems	21.5%	None	43.0%
Shortage of service providers in the area	17.9%		
No service providers in the area	4.3%		
Other <i>(Please specify)</i>	6.5%		

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

Transportation	4.3%	Providers in the area won't see children with autism	6.1%
Scheduling issues	7.5%	Cost of services/My insurance does not cover available services	5.4%
Child's behavior problems	24.4%	None	44.8%
Shortage of service providers in the area	14.7%		
No service providers in the area	9.3%		
Other <i>(Please specify)</i>	3.9%		

39. 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
39a. Mental Health Counseling	13.4%	2.4%	0.8%	8.1%	75.3%
39b. Speech/Language Therapy	55.4%	29.9%	0%	7.2%	7.6%
39c. Occupational Therapy	53.9%	24.0%	0.4%	8.7%	13.0%
39d. Physical Therapy	20.5%	7.2%	0.4%	10.4%	61.4%
39e. Social Skills Training	38.6%	27.5%	0.8%	20.7%	12.4%
39f. One-to-one Support (e.g. TSS)	63.2%	15.4%	0.4%	10.3%	10.7%
39g. Mobile Therapy	9.2%	3.6%	1.2%	9.2%	76.9%
39h. Case Management	52.6%	11.3%	0.4%	6.9%	28.7%
39i. Neurology Services	14.6%	2.4%	0.8%	13.0%	69.1%
39j. Medication Management	14.7%	2.0%	1.2%	3.6%	78.5%
39k. Summer Camp	6.0%	2.4%	0.4%	19.4%	71.8%

40. 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
40a. Mental Health Counseling	40.0%	52.5%	7.5%	0%
40b. Speech/Language Therapy	54.9%	36.6%	7.5%	0.9%
40c. Occupational Therapy	52.5%	41.4%	4.5%	1.5%
40d. Physical Therapy	56.7%	37.3%	4.5%	1.5%
40e. Social Skills Training	45.5%	45.5%	7.9%	1.2%
40f. One-to-one Support (e.g. TSS)	47.2%	43.7%	7.6%	1.5%
40g. Mobile Therapy	29.7%	54.1%	8.1%	8.1%
40h. Case Management				
40i. Neurology Services	53.7%	39.0%	7.3%	0%
40j. Medication Management	47.7%	50.0%	2.3%	0%
40k. Summer Camp	36.4%	50.0%	13.6%	0%

41. 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
41a. Mental Health Counseling	35.0%	47.5%	17.5%	0%
41b. Speech/Language Therapy	45.3%	38.2%	12.3%	4.2%
41c. Occupational Therapy	45.4%	44.4%	6.6%	3.6%
41d. Physical Therapy	44.8%	49.3%	4.5%	1.5%
41e. Social Skills Training	39.5%	45.1%	13.6%	1.9%
41f. One-to-one Support (e.g. TSS)	46.7%	42.6%	9.1%	1.5%
41g. Mobile Therapy	30.3%	45.5%	15.2%	9.1%

	Strongly Agree	Agree	Disagree	Strongly Disagree
41h. Case Management	35.3%	44.9%	16.7%	3.2%
41i. Neurology Services	54.5%	38.6%	4.5%	2.3%
41j. Medication Management	42.2%	48.9%	6.7%	2.2%
41k. Summer Camp	27.3%	54.5%	18.2%	0%

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

Transportation	9.7%	Providers in the area won't see children with autism	2.9%
Scheduling issues	21.5%	Cost of service/My insurance does not cover available services	16.1%
Child's behavior problems	10.8%	None	35.8%
Shortage of service providers in the area	30.8%		
No service providers in the area	4.7%		
Other (Please specify)	5.7%		

43. 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
43a. Respite Care	1.6%	0.4%	0.4%	20.0%	77.6%
43b. Babysitting	6.3%	3.6%	0.8%	28.2%	61.1%
43c. Daycare	16.7%	4.0%	0.8%	12.0%	66.5%
43d. Weekend Childcare	1.6%	0.8%	0.4%	14.3%	82.9%
43e. Family Counseling	4.0%	0.4%	0%	22.8%	72.8%
43f. Sibling Support Groups	1.2%	0.4%	0%	17.6%	80.8%
43g. Sibling Mental Health Counseling	2.4%	0%	0.4%	9.6%	87.6%
43h. Parent Support Groups	12.0%	4.4%	0.8%	24.4%	58.4%
43i. Parent Mental Health Counseling	7.1%	1.6%	0%	19.7%	71.7%

44. 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
44a. Respite Care	16.7%	83.3%	0%	0%
44b. Babysitting	36.0%	48.0%	12.0%	4.0%
44c. Daycare	26.4%	35.8%	28.3%	9.4%
44d. Weekend Childcare	16.7%	83.3%	0%	0%
44e. Family Counseling	27.3%	72.7%	0%	0%
44f. Sibling Support Groups	66.7%	33.3%	0%	0%
44g. Sibling Mental Health Counseling	28.6%	57.1%	14.3%	0%
44h. Parent Support Groups	30.0%	62.5%	5.0%	2.5%
44i. Parent Mental Health Counseling	40.9%	59.1%	0%	0%

45. 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
45a. Respite Care	33.3%	66.7%	0%	0%
45b. Babysitting	34.8%	52.2%	8.7%	4.3%
45c. Daycare	34.0%	40.0%	18.0%	8.0%
45d. Weekend Childcare	16.7%	83.3%	0%	0%
45e. Family Counseling	36.4%	63.6%	0%	0%
45f. Sibling Support Groups	66.7%	33.3%	0%	0%
45g. Sibling Mental Health Counseling	16.7%	66.7%	16.7%	0%
45h. Parent Support Groups	28.2%	69.2%	2.6%	0%
45i. Parent Mental Health Counseling	40.9%	54.5%	4.5%	0%

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

Transportation	2.5%	Cost of service/My insurance does not cover available services	5.7%
Scheduling issues	13.6%	None	16.8%
Shortage of service providers in the area	10.8%		
No service providers in the area	2.5%		
Other <i>(Please specify)</i>	0.7%		

