

PENNSYLVANIA AUTISM NEEDS ASSESSMENT Adult Module (Respondents are caregivers)

492 caregivers of adults 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	75.1 %	Foster parent	0.6%
Father	14.1%	Legal guardian	3.3%
Other (<i>Please specify</i>)	7.0%		

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

Married to/Living with child's other parent	58.3%	Widowed	6.2%
Married to/Living with person other than child's parent	10.0%	Never been married	8.3%
		Separated/Divorced	17.1%

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

African American	6.7%	Latino, Hispanic, or Chicano	2.8%
Asian/Pacific Islander	1.4%	Native American	1.2%
Caucasian/European American	87.0%		
Other	0.2%		

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

African American	4.7%	Latino, Hispanic, or Chicano	2.6%
Asian/Pacific Islander	0.8%	Native American	0.8%
Caucasian/European American	70.7%	N/A	16.9%
Other (<i>Please specify</i>)	0.2%		

5. What is your zip code? **See Map**

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

Less than \$20,000	15.0%
\$20,000-\$39,999	26.1%
\$40,000-\$59,999	20.5%
\$60,000-\$79,999	15.7%
\$80,000-\$99,999	9.8%
\$100,000 or more	13.0%

7. What is your highest level of completed education?

No high school	1.9%	Some college	19.2%
Some high school	1.9%	College degree	23.5%
High school graduate/GED	24.2%	Some graduate studies	5.2%
Vocational/Technical school	9.0%	Graduate degree	15.2%

8. What is the sex of your child? Male 79.7% Female 20.3%

9. How old is your child? Mean: 25.2 years ; Standard Deviation: 9.95

10. Is your child adopted? Yes 7.3% No 92.7%

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

African American	8.7%	Latino, Hispanic, or Chicano	3.7%
Asian/Pacific Islander	1.4%	Native American	2.0%
Caucasian/European American	86.0%		
Other	0.4%		

12. How many siblings does he/she have?

Mean: 1.61; Standard deviation: 3.19

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

Mean: 0.13; Standard deviation: 0.47

14. What is your child's primary diagnosis?

Asperger's Disorder	30.3%	Other	7.1%
Autistic Disorder/Autism	41.5%	Pervasive Developmental Disorder	20.7%
Childhood Disintegrative Disorder	0.2%		

15. Is your child **currently** diagnosed with any of the following? (Check all that apply)

Anxiety Disorder	33.9%	Learning Disability	35.4%
Attention Deficit/Hyperactivity Disorder	30.9%	Mental Retardation/ Intellectual Disability	41.9%
Bipolar Disorder	10.8%	Obsessive Compulsive Disorder (OCD)	29.3%
Central Auditory Processing Disorder	6.9%	Oppositional Defiant Disorder (ODD)	10.6%
Conduct Disorder (CD)	3.7%	Seizures/ Seizure Disorder/Epilepsy	13.6%
Depression	22.6%	Tourette's Syndrome	1.8%
Developmental Delays	34.1%	None of these	7.5%
Hearing Impairment	4.7%		
Other	8.3%		

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

Anxiety Disorder	12.4%	Learning Disability	29.3%
Attention Deficit/Hyperactivity Disorder	34.3%	Mental Retardation/ Intellectual Disability	26.4%
Bipolar Disorder	5.9%	Obsessive Compulsive Disorder (OCD)	11.4%
Central Auditory Processing Disorder	4.3%	Oppositional Defiant Disorder (ODD)	11.0%
Conduct Disorder (CD)	3.5%	Seizures/ Seizure Disorder/Epilepsy	7.5%
Depression	11.6%	Tourette's Syndrome	1.6%
Developmental Delays	36.0%	None of these	19.7%
Hearing Impairment	4.3%		
Other	6.3%		

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

Mean: 3.2 years; Standard Deviation: 6.08

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

Developmental Pediatrician	13.1%	Psychiatrist	26.2%
Educational team (IEP or EI)	9.3%	Psychologist	20.3%
Neurologist	16.7%		
Primary Care Physician (Family doctor/Pediatrician)	8.7%		
Other (<i>Please specify</i>)	5.7%		

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

0-20 miles	47.0%
21-40 miles	21.7%
41-60 miles	10.1%
61-80 miles	6.0%
81-100 miles	6.2%
More than 100 miles	9.0%

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

Mean: 8.5 years; Standard Deviation: 7.80 years

21. How many professionals (e.g. psychologist, developmental pediatrician) did you visit before your child received an autism diagnosis? Mean: 4.23; Standard Deviation: 4.02; Range: 0-40

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

Follow-up appointment	33.9%	Referral to support groups	21.3%
Referral to a specialist for further assessment	24.6%	Referral to websites, literature (e.g. handouts, information booklets)	16.3%
Referral to a specialist for treatment	23.8%	None	18.7%
Referral to Early Intervention services	29.7%		
Other	4.9%		

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

Private health insurance	49.2%	Out-of-pocket	24.8%
Medicaid (Medical Access)	75.2%	I don't know	0.6%
Other	1.4%		

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

Yes	10.8%	No	89.2%
-----	-------	----	-------

On how many occasions?

Mean: 2.6; Standard Deviation: 5.54

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

Yes	6.7%	No	93.3%
-----	------	----	-------

On how many occasions?

Mean: 2.3; Standard Deviation: 1.19



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	4.3%	Running away from home/school	0.4%
Anxiety	1.6%	Self-injurious behaviors	3.0%
Defiant/Oppositional behaviors	1.6%	Significant increase in obsessions	0.8%
Depression	1.8%		
Other	0.2%		

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

	Very Satisfied	Satisfied	Dissatisfied	Very Dissatisfied
25b. Discharge Planning	3.2%	32.3%	35.5%	29.0%
25c. Staff's Inclusion of Parent(s) in Treatment Planning	6.2%	37.5%	31.2%	25.0%
25d. Quality of Treatment	3.1%	40.6%	25.0%	31.2%

25e. How was your child admitted?

My child (under 14) was admitted by his/her parent(s)	0%	My adult child (18 or older) admitted him/herself (201, voluntary treatment)	40.0%
My adolescent child (14 to 18) was admitted by his/her parent(s) and agreed to the admission	20.0%	My adult child (18 or older) was admitted against his/her will (302, involuntary treatment)	36.7%
My adolescent child (14 to 18) was admitted by his/her parent(s) but did not agree to the admission	3.3%		

→→→ Please continue answering the questions...

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

Yes	12.3%	No and not on a waiting list	83.1%
No, but currently on a waiting list	4.5%		



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	47.1%
21-40 miles	26.5%
41-60 miles	8.8%
61-80 miles	1.5%
81-100 miles	0%
More than 100 miles	16.2%

→→→ Please continue answering the questions...

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

With parent(s) in a family home	74.1%
With other relatives in a family home	2.7%
Residential facility	5.8%
Group home	10.6%
Lives on own with support	5.2%
Lives on own without support	1.5%

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

Very Satisfied	40.4%
Satisfied	41.1%
Dissatisfied	14.5%
Very Dissatisfied	4.0%

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

	Yes, and needs it	Yes, but does not need it	No, but needs	No, and does not need it
29a. Self-injurious behaviors	14.1%	1.5%	9.8%	74.6%
29b. Sleep Problems	19.9%	1.7%	16.9%	61.5%
29c. Anxiety	44.5%	1.3%	18.9%	35.3%
29d. Aggressive Behaviors	29.1%	2.3%	14.3%	54.3%
29e. Running Away	3.7%	0.4%	2.2%	93.7%
29f. Toileting	7.8%	0.2%	10.2%	81.8%

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	5.7%	Out-of-school suspension	2.0%
Sent out of classroom	3.9%	Expulsion	0.6%
Detention	1.8%	None	25.2%
In-school suspension	1.4%	N/A (My child is not in school)	60.8%
Other	1.8%		

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

Police called	16.3%	Served time in a juvenile detention facility	2.0%
Police warning issued	6.1%	None	73.2%
Child adjudicated	4.1%		
Served time in jail	1.6%		
Other	4.9%		

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	14.0%	Designated power of attorney	15.7%
Set up financial trust	18.3%	Currently developing plans	29.5%
Designated guardianship	23.6%	None at this time	37.2%
Other	4.7%		

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	22.2%	4.9%
Decreased work hours	24.2%	8.5%
Increased work hours	1.0%	3.5%
Changed employer	10.2%	1.4%
Changed type of work	11.6%	2.4%
Changed work schedule	21.1%	8.1%
Changed position with same employer	3.5%	1.0%
Used Family Medical Leave Act	4.9%	0.6%
Lost promotion/advancement opportunities	12.0%	3.5%
Terminated from employment	3.5%	0.4%
Disciplined/Suspended	3.5%	0.2%
None	38.4%	48.0%
N/A	-	22.6%
Other	5.9%	3.7%

34. What is your child's highest level of completed education?

No high school	12.6%	Some college	10%
Some high school	10.7%	College degree	2.1%
High school graduate/GED	59.8%	Some graduate studies	0.2%
Vocational/Technical school	4%	Graduate degree	0.5%

35. Is your child currently in school?

Yes, Four-Year College	3.1%	Yes, Graduate School	0.2%
Yes, Two-Year College	4.7%	No, my child is not in school	73.5%
Yes, Vocational/Technical School	2.4%		
Other (Please specify)	7.3%		

36. Is your child currently employed?

Part-time with support	18.5%	Full-time without support	1.6%
Part-time without support	10.1%	Seeking employment	9.2%
Full-time with support	5.9%	Unemployed	54.7%

37. Is your child capable of the following activities?

	Independently	With help	Not capable
37a. Toileting	79.0%	18.3%	2.7%
37b. Feeding Self	90.1%	9.6%	0.2%
37c. Dressing Self	77.1%	20.4%	2.5%
37d. Requesting things he/she needs	55.4%	39.4%	5.2%
37e. Requesting things he/she wants	61.5%	33.2%	5.2%
37f. Indicating when he/she is hurt/sick	59.1%	26.4%	14.5%
37g. Cooking/Preparing meals	18.0%	45.4%	36.6%
37h. Managing money	4.5%	36.8%	58.7%
37i. Getting around via driving/public transportation/ biking/walking	22.3%	33.9%	43.8%

38. 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
38a. Primary Health Care	28.4%	56.3%	11.0%	4.3%
38b. Dental Services	27.3%	50.0%	12.8%	9.9%

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

	Strongly Agree	Agree	Disagree	Strongly Disagree
38c. Primary Health Care	27.8%	55.8%	12.6%	3.8%
38d. Dental Services	28.2%	50.5%	13.2%	8.2%

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

Transportation	9.7%	Providers in the area won’t see children with autism	6.9%
Scheduling issues	12.4%	Cost of service/my insurance does not cover available services	8.3%
Child’s behavior problems	12.8%	None	43.1%
Shortage of service providers in the area	22.6%		
No service providers in the area	4.3%		
Other	6.9%		

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

Transportation	9.6%	Providers in the area won’t see children with autism	8.3%
Scheduling issues	8.5%	Cost of service/My insurance does not cover available services	13.2%
Child’s behavior problems	12.6%	None	42.3%
Shortage of service providers in the area	18.9%		
No service providers in the area	8.7%		
Other	5.3%		

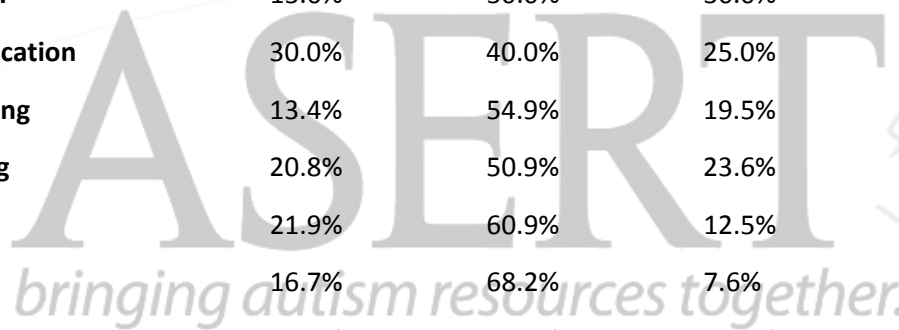
41. Please tell us about your child’s specialty health and education service needs:

	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	32.6%	13.9%	1.1%	17.3%	35.1%
41b. Speech/Language Therapy	5.0%	3.4%	1.6%	21.9%	68.0%
41c. Occupational Therapy	6.2%	5.7%	0.5%	21.3%	66.4%
41d. Physical Therapy	3.0%	0.9%	1.2%	8.5%	86.4%
41e. Social Skills Training	14.6%	14.6%	0.7%	43.5%	26.5%
41f. One-to-one Support (e.g. TSS)	16.8%	8.0%	0.0%	20.9%	54.3%
41g. Mobile Therapy	3.3%	3.1%	0.9%	12.3%	80.4%
41h. Case Management	49.0%	13.9%	0.2%	11.4%	25.5%
41i. Neurology Services	20.1%	2.3%	1.6%	11.9%	64.0%
41j. Medication Management	55.0%	7.3%	1.4%	5.7%	30.5%
41k. Summer Camp	5.1%	2.3%	1.2%	12.6%	78.7%
41m. Sexual Health Education	2.1%	1.6%	2.3%	14.9%	79.1%
41n. Transitional Planning	9.6%	8.2%	2.1%	23.5%	56.5%
41o. Vocational Training	13.8%	10.7%	1.2%	27.8%	46.5%
41p. Support Groups	9.7%	4.9%	1.2%	31.2%	53.0%
41q. Career Counseling	10.0%	6.0%	0.9%	29.7%	53.4%
41r. Academic Tutoring	3.7%	3.2%	0.7%	15.8%	76.6%
41s. Drug and Alcohol Counseling	0.2%	0.5%	1.9%	3.3%	94.1%
41t. Relationship Counseling	5.1%	3.7%	1.2%	26.2%	63.8%
41u. Supported Employment	19.4%	7.4%	1.4%	28.3%	43.5%

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	28.3%	47.0%	18.7%	6.1%
42b. Speech/Language Therapy	31.7%	48.8%	17.1%	2.4%
42c. Occupational Therapy	27.1%	54.2%	8.3%	10.4%
42d. Physical Therapy	30.0%	50.0%	15.0%	5.0%
42e. Social Skills Training	20.2%	55.6%	20.2%	4.0%
42f. One-to-one Support (e.g. TSS)	31.4%	49.5%	14.3%	4.8%
42h. Case Management	28.3%	53.2%	14.7%	3.8%
42i. Neurology Services	44.7%	41.5%	12.8%	1.1%
42j. Medication Management	37.7%	50.7%	8.6%	3.0%
42k. Summer Camp	44.1%	47.1%	5.9%	2.9%
42l. Summer School/ESY	15.0%	50.0%	30.0%	5.0%
42m. Sexual Health Education	30.0%	40.0%	25.0%	5.0%
42n. Transitional Planning	13.4%	54.9%	19.5%	12.2%
42o. Vocational Training	20.8%	50.9%	23.6%	4.7%
42p. Support Groups	21.9%	60.9%	12.5%	4.7%
42q. Career Counseling	16.7%	68.2%	7.6%	7.6%
42r. Academic Tutoring	17.2%	69.0%	13.8%	0.0%
42s. Drug and Alcohol Counseling	28.6%	42.9%	28.6%	0.0%
42t. Relationship Counseling	28.2%	53.8%	10.3%	7.7%
42u. Supported Employment	28.8%	54.1%	15.3%	1.8%



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	22.6%	44.6%	24.6%	8.2%
43b. Speech/Language Therapy	15.0%	65.0%	10.0%	10.0%
43d. Physical Therapy	15.0%	50.0%	20.0%	15.0%
43e. Social Skills Training	18.6%	51.2%	25.6%	4.7%
43f. One-to-one Support (e.g. TSS)	35.2%	38.9%	19.4%	6.5%
43g. Mobile Therapy	35.7%	35.7%	25.0%	3.6%
43h. Case Management	22.8%	51.4%	18.9%	6.9%
43i. Neurology Services	33.3%	53.8%	11.8%	1.1%
43j. Medication Management	30.2%	55.8%	9.4%	4.5%
43k. Summer Camp	44.1%	47.1%	8.8%	0.0%
43l. Summer School/ESY	15.8%	47.4%	21.1%	15.8%
43m. Sexual Health Education	15.8%	47.4%	31.6%	5.3%
43n. Transitional Planning	12.7%	46.8%	26.6%	13.9%
43o. Vocational Training	19.0%	49.0%	23.1%	8.7%
43p. Support Groups	16.9%	56.9%	20.0%	6.2%
43q. Career Counseling	14.1%	56.2%	18.8%	10.9%
43r. Academic Tutoring	17.9%	64.3%	17.9%	0%
43s. Drug and Alcohol Counseling	33.3%	33.3%	16.7%	16.7%
43t. Relationship Counseling	22.5%	50.0%	17.5%	10.0%
43u. Supported Employment	21.4%	61.6%	14.3%	2.7%

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

Transportation	14.6%	Providers in the area won’t see children with autism	6.1%
Scheduling issues	13.4%	Cost of service/My insurance does not cover available services	12.6%
Child’s behavior problems	12.8%	None	26.2%
Shortage of service providers in the area	33.7%		
No service providers in the area	10.0%		
Other	7.3%		

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	6.7%	6.0%	1.4%	21.0%	65.0%
45b. Adult Daycare	11.8%	2.4%	0.5%	9.1%	76.3%
45c. Family Counseling	4.8%	2.1%	1.0%	17.3%	74.8%
45d. Sibling Support Groups	1.0%	0.5%	0.5%	11.1%	87.0%
45e. Sibling Mental Health Counseling	3.9%	0.7%	1.0%	9.9%	84.5%
45f. Parent Support Groups	5.8%	2.2%	1.2%	18.8%	72.1%
45g. Parent Mental Health Counseling	5.0%	1.2%	1.2%	15.3%	77.2%

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	42.1%	50.9%	5.3%	1.8%
46b. Adult Daycare	29.8%	49.1%	17.5%	3.5%
46c. Family Counseling	34.4%	50.0%	12.5%	3.1%
46d. Sibling Support Groups	33.3%	33.3%	33.3%	0.0%
46e. Sibling Mental Health Counseling	40.0%	40.0%	20.0%	0.0%
46f. Parent Support Groups	22.9%	57.1%	17.1%	2.9%
46g. Parent Mental Health Counseling	38.5%	50.0%	11.5%	0.0%

47. 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
47a. Respite Care	25.9%	53.4%	17.2%	3.4%
47b. Adult Daycare	30.0%	38.3%	23.3%	8.3%
47c. Family Counseling	29.0%	45.2%	22.6%	3.2%
47d. Sibling Support Groups	28.6%	28.6%	42.9%	0.0%
47e. Sibling Mental Health Counseling	31.8%	45.5%	22.7%	0.0%
47f. Parent Support Groups	25.0%	47.2%	25.0%	2.8%
47g. Parent Mental Health Counseling	32.1%	50.0%	14.3%	3.6%

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

Transportation	3.5%	Cost of service/My insurance does not cover available services	4.5%
Scheduling issues	4.9%	None	15.0%
Shortage of service providers in the area	8.3%		
No service providers in the area	3.5%		
Other	2.2%		