

1. Introduction/Target Age/Purposes of Survey

2011 Survey of Massachusetts
Young Adults & Adults with Autism Spectrum Disorder (ASD)
Conducted by Advocates for Autism of Massachusetts (AFAM)

Dear Friend,

Thank you for helping AFAM with a “mission critical” project that will benefit you and others in our community.

By completing this survey, you will...

- Help document how many people 14 years and older have been diagnosed with ASD in Massachusetts.
- Help our community understand what supports these people may need, especially when they finish school.
- Advance understanding of both the similarities and differences of needs within our community.
- Increase AFAM’s ability to advocate for the most appropriate services.
- Expand awareness and support for ASD among lawmakers, service providers, and affiliated groups within Massachusetts.

The survey may be answered by the person on the Autism Spectrum, or a family member, guardian, or service provider, acting on behalf of that person.

Only one survey should be completed for each person, to avoid “double-counting”.

Questions that may not apply to you may be left blank. The only required questions are Question #1 and Question #23 (city/state/zip code).

Survey respondents' identities and individual answers will be kept confidential; answers will be compiled, summarized and made available to the public.

We estimate the survey will take about 10 minutes to fill out. We ask you to please complete it, even if you answered the prior survey conducted by AFAM in 2009 – 2010.

Thank you in advance for your participation. We cannot move forward without your help.

Sincerely,
AFAM – Adult Services Committee

2. Background Information

* 1. What is your age?

14-21

22-64

Over 64

2. When were you born (year only)?

3. What is your gender?

Male

Female

3. Diagnosis(es)

4. Have you been diagnosed as being on the Autism Spectrum?

Yes

No

5. If yes, from whom did you receive this diagnosis? (Check all that apply):

Psychiatrist

Neuro-psychologist or Psychologist

Neurologist

Developmental Pediatrician

Other licensed professional

Self-diagnosed

Other (please specify)

6. If you are diagnosed as being on the Autism Spectrum, what was your age at diagnosis?

7. What is your primary diagnosis?

Asperger's Syndrome

Autistic Disorder

Other (please specify)

PDD-NOS (Pervasive Developmental Disorder Not Otherwise Specified)

8. Dual or Secondary Diagnosis(es) (Check all that apply):

- Anxiety
- Asperger's Syndrome
- Attention Deficit Disorder (ADD)
- Attention Deficit Hyperactivity Disorder (ADHD)
- Autistic Disorder
- Bipolar Disorder
- Depression
- Gastrointestinal issues(e.g., reflux, irritable bowel syndrome, celiac disease)
- Other (please specify)
- Learning Disorder
- Mental retardation/Intellectual Disability
- PDD-NOS
- Obsessive Compulsive Disorder (OCD)
- Sensory Processing Disorder
- Sleep Disorder
- Seizure Disorder

4. Communication

9. My communication abilities are as follows (check all that apply):

- I am non-verbal
- I communicate with aids such as pictures, an augmented communication device, or other technical devices
- I have limited verbal communication but can make my basic needs known
- I communicate with sign language
- I am able to speak fluently
- I communicate with friends and family by phone independently
- I communicate with friends and family by phone with help
- I communicate with friends and family by email or letter independently
- I communicate with friends and family by email or letter with help
- I communicate with friends and family by Skype/picture phone technology independently
- I communicate with friends and family by Skype/picture phone technology with help

5. Residence

10. My current living situation is as follows (check all that apply)?

- I live alone
- I live with parents/siblings
- I live with spouse/partner/children
- I live in a residential school/hospital
- I live with a roommate
- I live with multiple people not related by blood or marriage
- I live in a private house/condo unit
- I live in a dorm room
- I live in a nursing home
- I live in a group home operated by the state or by a vendor under state contract
- I live in a publicly subsidized/Section 8 apartment
- I live in private group housing
- I live in another kind of institution (such as military housing, correctional facility, homeless shelter)
- I live in a shared living house or apartment
- Other (please specify)

11. In my current living situation (check all that apply):

- I live independently, without any supports
- I get some help from family, friends or others on an occasional basis (monthly or less often)
- I get some help from family, friends or others on a weekly basis
- I get with some help from family, friends or others on a daily basis
- I get help 24/7/365; I am not independent

Any further comment:

12. If you are currently under the age of 22, please answer this question. (If you are 22 or older, please skip to Question #13.)

In ten years how do you expect to be living:

- Independently with no supports
- Independently with some help from family, friends or others on an occasional basis (monthly or less frequently)
- Independently with some help from family, friends or others on a weekly basis
- Independently with some help from family, friends or others on a daily basis
- Supported 24/7/365 by family, friends or others

Other (please specify)

6. Daytime activity

13. During the day, I do the following (check all that apply):

- Attend school in my local school district
- Attend a collaborative school program
- Attend school in an out-of-district placement funded by my public school district
- Attend a private school not funded by my public school district
- Am home-schooled by a parent or other person
- Participate in the DESE/DDS program
- Work with home-based tutor
- Attend a 4 year college or university
- Attend a 2 year college
- Attend a post-secondary trade or vocational training school
- Serve in the military
- Do post-graduate work
- Am searching for employment
- Am unemployed
- Work sporadically
- Am retired
- Rearing children
- Attend a day habilitation (Day Hab) program (day programs funded and licensed by MassHealth, typically structured around social and recreational activities, with ancillary supports such as occupational therapy, physical therapy, speech and language, and other assistance)
- Work in a supported work environment
- Work in the community with a job coach
- Work in the community independently
- Generally am at home
- Volunteer in the community

Other (please specify)

14. With respect to paid employment:

- I am able to work independently
- I have a job coach who helps me learn the job for a period of time and then leaves
- I have a job coach who helps me during the entire time I am at work
- I work in a supported work setting where staff helps me with my job
- I am not currently employed for money

Other (please specify)

7. Activities of Daily Living

15. Do you receive help with any activities of daily living (ADLs) such as dressing, toileting, bathing/showering, other personal hygiene, eating?

- Yes
- Sometimes
- No

16. If you need help with any of the above ADLs, how many do you need help with?

- Not applicable
- One
- Two
- Three
- Four or more

17. If you need help with the above ADLs, how much help do you need? (select all that apply)

- Not applicable
- Reminder
- Verbal prompts
- Physical prompts
- Greater assistance

8. Transportation; Health Care

18. I am able to:

	Yes	Sometimes	No
Drive a car and have a driver's license	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Take public transportation independently	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use specialized transportation like the Ride	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ride in a van without the help of a monitor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Walk in my neighborhood and cross streets safely and independently	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other (please specify)

19. With respect to my health care:

	Yes	With Help	No
I am able to make appointments with doctors and dentists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am able to understand the doctor's and dentist's instructions and explanations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am able to manage any medications I may take periodically or on a regular basis by myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

9. Household Activities and Skills

20. I am able to:

	Independently	With some help	With help throughout the day	Not at all
Do housekeeping activities (such as laundry, cleaning, shopping for food and other things)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Plan and prepare meals and cleanup after meals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
manage my finances (including budgeting, paying bills, and banking)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Travel out of town	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Arrange leisure activities with friends and family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. Eligibility For and Receipt of Services

21. I have applied for eligibility for funding or services from the following federal or state agencies or programs (check all that apply):

	Never applied	Applied at some point	Accepted; waiting for service	Receiving service	Received service in the past	Denied service due to eligibility criteria
Mass. Dept of Mental Health (DMH)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mass. Dept of Developmental Services (DDS, formerly DMR)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mass. Division of Autism (within DDS)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mass. Rehabilitation Commission (MRC)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mass. Commission for the Blind (MCB)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mass. Commission for the Deaf/Hard of Hearing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Subsidized Housing/Section 8 Voucher	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
SSI	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
SSDI	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicaid	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MassHealth/Medicaid	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CommonHealth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Children's Medical Security Plan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Commonwealth Care Health Plan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health Safety Net Program	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Adult Foster Care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Private Coaching	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Case Management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other (please specify)

11. Demographics

22. The person who completed this survey is (check all that apply):

- the person about whom the information was provided
- a parent of or other relative of the person on whose behalf the survey was completed
- a legal guardian of the person on whose behalf the survey was completed
- staff of an agency serving the person on whose behalf the survey was completed

Other (please specify)

*** 23. The only required demographic information below is your city, state and zip code. The additional information, while not required, would be helpful to us. Your answers will be kept confidential. The "name" should be completed for the person actually filling out the Survey. Thank you so much for your participation in this Survey.**

Name:	<input type="text"/>
Company:	<input type="text"/>
Address:	<input type="text"/>
Address 2:	<input type="text"/>
City/Town:	<input type="text"/>
State:	<input type="text"/>
ZIP/Postal Code:	<input type="text"/>
Country:	<input type="text"/>
Email Address:	<input type="text"/>
Phone Number:	<input type="text"/>