1. Introduction/Target Age/Purpose of Survey

The Adult Services Committee of Advocates for Autism of Massachusetts (AFAM) is compiling information concerning the needs of individuals ages 14 and older who have an Autism Spectrum Disorder (ASD) and have needs or will have needs for intensive and specialized day, employment, and residential supports when they reach the age of 22.

This survey is not targeted to individuals with ASD who are living or expect to be living relatively independently as adults. The Adult Services Committee expects to conduct further surveys in the future targeted to a broader number of adults or young adults on the spectrum and concerning a number of topics. This first survey is directed at a more narrow group of individuals as described above.

The information obtained through the results of this survey will be used by AFAM to substantiate the need for increased and more intensive services for adults with ASD in the Commonwealth of Massachusetts.

There are a number of areas of need identified in this survey, including health, transportation, and behavior management, some of which may not have any application to the individual with ASD for whom the answers are given. Please feel free not to answer those questions that do not apply.

The questions have been framed as though the individual about whom information is sought will be answering them. We understand that, in most cases, a family member or service provider will be supplying the answers.

Please complete this survey only once on behalf of each individual who meets the above survey criteria so as to ensure accuracy of our data. If you have more than one family member or client with ASD who meets the above survey criteria, please complete a separate survey for each individual. (If you completed a draft survey for us as a trial run, please feel free to complete this online survey. As a result of your feedback, some of the questions have been edited and new ones added to our prior draft survey.)

We anticipate that it will take approximately 10 - 15 minutes to complete the survey. We appreciate your time in doing so because data to substantiate unmet needs for this population is sorely needed.

Thank you so much for your participation.

Sincerely, AFAM Adult Services Committee,
Chris Hubbard, Chair

2. General Background Information

* 1. Age

- 14-17
- 18-21
- 22-35
- 36-64
- 64+

2. Was the person with the disability ever classified by a professional (i.e., psychiatrist, psychologist, or neurologist) as having an Autism Spectrum Disorder?

- Yes
- No

Other (please specify)

3. What is the primary diagnosis?

- Angelman Syndrome
- Anxiety
- Asperger's Syndrome
- Attention Deficit Disorder
- Autism/PDDNOS
- Bi-polar Disorder
- Cerebral Palsy
- Childhood Disintegrative Disorder
- Chromosome Disorder
- Complex medical needs
- Cri du Chat Syndrome
- Depression
- Down syndrome
- Emotional or behavioral disability
- Fetal Alcohol Syndrome
- Fragile X Syndrome
- Gastrointestinal disease (e.g., reflux, irritable bowel syndrome, celiac disease)
- Head injury
- Hearing impairment
- Intellectual limitations
- Lesch-Nyhan Syndrome
- Mental retardation
- Neurological disorders (inc. epilepsy or seizures)
- Obsessive Compulsive Disorder
- Physical limitations
- Pica
- Prader-Willi Syndrome
- Rett Syndrome
- Spina Bifida (Myelomeningocele type "MMC")
- Tuberous Sclerosis
- Visual impairment
- Williams Syndrome
- Other (please specify)

4. Do you have or can you obtain this diagnosis in writing from a qualified professional (i.e., psychiatrist, psychologist, or neurologist)?

- Yes
- No

Other (please specify)

5. Secondary/additional diagnosis(es) (select any that apply):

- Angelman Syndrome
- Anxiety
- Asperger's Syndrome
- Attention Deficit Disorder
- Autism/PDDNOS
- Bi-polar Disorder
- Cerebral Palsy
- Childhood Disintegrative Disorder
- Chromosome Disorder
- Complex medical needs
- Cri du Chat Syndrome
- Depression
- Down syndrome
- Emotional or behavioral disability
- Fetal Alcohol Syndrome
- Fragile X Syndrome
- Gastrointestinal disease (e.g., reflux, irritable bowel syndrome, celiac disease)
- Head injury
- Hearing impairment
- Intellectual limitations
- Lesch-Nyhan Syndrome
- Mental retardation
- Neurological disorders (inc. epilepsy or seizures)
- Obsessive Compulsive Disorder
- Physical limitations
- Pica
- Prader-Willi Syndrome
- Rett Syndrome
- Spina Bifida (Myelomeningocele type "MMC")
- Tuberous Sclerosis
- Visual impairment
- Williams Syndrome
- Other (please specify)

6. Do you have or can you obtain this secondary diagnosis(es) in writing from a qualified professional (i.e., psychiatrist, psychologist, or neurologist)?

- Yes
- No

Other (please specify)

7. Current residential setting?

- Home with family
- Residential school
- 24/7 Group home
- Shared living home or apartment
- Generally independent living situation with individual supports
- Generally independent living situation with no supports
- Other (please specify)

3. Activities of Daily Living

1. With respect to activities of daily living (ADLs):

Do you require help with?

	Yes	No	Sometimes
Dressing	∈	∈	∈
Toileting	∈	∈	∈
Bathing	∈	∈	∈
Other personal hygiene	∈	∈	∈
Eating	∈	∈	∈
Scheduling/arranging personal activities	∈	∈	∈

2. How many of the above ADLs do you need assistance with?

∈ one

∈ two

∈ three

∈ four

∈ more

3. How much assistance do you need with the above ADLs? (Check as many as may apply)

∈ reminder

∈ verbal prompts

∈ physical prompts

∈ greater assistance

4. With respect to household chores or instrumental activities of daily living(IADLs):

Do you require help with?

	Yes	No	Sometimes
Laundry	∈	∈	∈
Cleaning	∈	∈	∈
Shopping	∈	∈	∈
Meal prep and cleanup	∈	∈	∈
Transportation	∈	∈	∈
Basic household finance and paperwork	∈	∈	∈

5. How many of the above IADLs do you need assistance with?

- one
- two
- three
- four
- more

6. How much assistance do you need with the above IADLs? (Check as many as apply):

- reminder
- verbal prompts
- physical prompts
- greater assistance

7. I need help:

	Yes	Sometimes	No
To use public transportation			
To use specialized transportation for people with disabilities (e.g., the Ride or vans)			
I need help from a monitor when I ride a van			
I need help walking in my neighborhood I need help to cross streets safely			
I need help to keep from bolting			

8. I need help:

	Yes	Sometimes	No
To participate in social opportunities			
To participate in events and activities with my family or friends			
To communicate with friends and family (phone, email, letters)			

4. Eligibility for Services

1. I have applied for eligibility for services from the following state agency(ies) (check all that apply):

- Dept. of Developmental Services (formerly DMR)
- Division of Autism (within DDS (formerly DMR))
- Mass. Rehabilitation Commission
- Mass. Commission for the Blind
- Mass. Commission for the Deaf/Hard of Hearing
- Mass. Health

Other (please specify)

2. I have been told I am eligible for services from the following state agency(ies) as a child:

- Dept. of Developmental Services (formerly DMR)
- Division of Autism (within DDS (formerly DMR))
- Mass. Rehabilitation Commission
- Mass. Commission for the Blind
- Mass. Commission for the Deaf/Hard of Hearing
- Mass. Health

Other (please specify)

3. I have been told I am eligible for services from the following state agency(ies) as an adult:

- Dept. of Developmental Services (formerly DMR)
- Mass. Rehabilitation Commission
- Mass. Commission for the Blind
- Mass. Commission for the Deaf/Hard of Hearing
- Mass. Health

Other (please specify)

4. If a state agency(ies)listed above has rejected your eligibility application, what was the explanation?

- Not Applicable

Other (please specify)

5. Please describe the type and level of services you are receiving or expect to receive as an adult (e.g., 24/7 residential supports, no residential supports, supported employment, day habilitation, family support)

5. Health/Dental Care

1. I need help finding a doctor, dentist or other basic health care specialist.

- Yes
- Sometimes
- No

Other (please specify)

2. I need help accessing specialized health care services like psychiatric services, physical therapy, occupational therapy, speech therapy, or home nursing care.

- Yes
- Sometimes
- No

Other (please specify)

3. I need help planning and coordinating my health care services.

- Yes
- Sometimes
- No

Other (please specify)

4. I need help taking medications.

- Yes
- Sometimes
- No
- Not taking any medications

Other (please specify)

5. In coordinating my health care support, I need help:

- Daily
- Weekly
- Monthly
- Not at all

Other (please specify)

6. I need help in asking questions, understanding my medical conditions and remembering discussions with my health care providers.

- Yes
- Sometimes
- No

Other (please specify)

6. Employment/Day Activities

1. During the day I (check all that apply):

- Attend school in my public school
- Attend a collaborative
- Attend a private 766 school
- participate in the DOE/DMR program
- Attend a day habilitation 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 (sometimes referred to as enclaves or sheltered workplaces; generally in a group with staff supervision)
- Work in the community with a job coach
- Work in the community independently

Other (please specify)

2. The ratio of staff or direct care assistants to students or attendees in my day setting is:

- One to one
- One to Two
- One to Three
- One to Four
- One to Six

Other (please specify)

3. In this area I need support

- Throughout the day
- Daily
- A few times a week
- Weekly
- A few times each month
- Monthly or at different times each year

Other (please specify)

4. In my day setting as an adult, I will need or need:

- A highly structured program
- A somewhat structured program
- A loosely structured program

Other (please specify)

5. In my day setting as an adult, I will need or need a program that includes (check all that apply or will apply):

- Functional communication training
- Adaptive skill development
- Social skill development
- Opportunities for independent employment in the community
- Opportunities for employment in the community with a job coach
- Opportunities for employment in a supported work environment (sometimes referred to as enclaves or sheltered workplaces; generally in a group with staff supervision)
- Strategies to address my sensory challenges
- Strategies to address my behavioral challenges
- Opportunities for volunteer work in the community
- Opportunities for social and recreational activities
- Therapeutic ancillary supports (such as occupational therapy, physical therapy, speech and language, and other assistance)

Other (please specify)

7. Behavior Support

1. With respect to my residential, day and/or educational program, I require a behavior support plan that assists me in the following areas (check all that apply):

- Functional communication training
- Adaptive skill development to replace challenging behaviors
- Environmental modifications and other antecedent management strategies (e.g., picture schedules)
- Strategies for increasing desirable behaviors
- Strategies to address my sensory issues
- Not applicable

Other (please specify)

2. With respect to my residential, day and/or educational program, I need access to a structured program that has highly trained and specialized staff in the area of behavior support strategies (such as applied behavior analysis principles or other comprehensive, positive approaches).

- Yes
- No

Other (please specify)

3. With respect to my residential, day and/or educational program, I need access to the following types of specialists (check all that apply):

- Speech Pathologist
- Occupational Therapist
- Physical Therapist
- Behavior Psychologist
- Developmental Psychologist
- Board Certified Behavior Analyst
- Other (please specify)

4. With respect to my residential, day and/or educational program, the current level of education/training of the direct care staff is (check all that apply):

- High school diploma or equivalent
- Bachelor's degree in related field
- Master's degree in related field
- In-service training offered by employer
- Special education certification/license/endorsement
- Do not know
- Certification as Board Certified Behavior Analyst
- Other (please specify)

5. With respect to my residential, day and/or educational program, I need to have access to professional consultation from an expert on autism experienced in comprehensive, positive approaches to write my behavior support plan, monitor its implementation and/or provide consultation.

- Yes
- No

Other (please specify)

6. I need a behavior support plan that requires:

- Ongoing behavior consultation (weekly)
- Behavior consultation every 2 weeks
- Behavior consultation once a month
- Behavior consultation once every 3 months
- Not applicable

Other (please specify)

7. Due to my behavior challenges, I need access to extensive staffing resources (1:1 or enriched patterns during certain times of the day).

- Yes
- No

Other (please specify)

8. At times I have significant challenging behaviors (self-injury, aggression) that may require access to behavior management programming.

- Yes
- No

Other (please specify)

9. Due to my behavior challenges I need environmental modifications to the places I live and work to maintain my safety.

- Yes
- No

Other (please specify)

10. My current environmental modifications include (check all that apply):

- Wall modifications
- Alarms on doors and windows
- Window modifications
- Lock boxes for cleaning products, toiletries, and other hazards
- Transportation modifications
- Not applicable

Other (please specify)

11. Due to my behavior challenges I require supportive and protective equipment to maintain my safety.

- Yes
- No

Other (please specify)

12. The following supportive and protective equipment is part of my current programming (check all that apply):

- Helmet
- Splints
- Mitts
- Goggles
- Not Applicable

Other (please specify)

13. Due to my behavior challenges and/or a co-existing diagnosis I require collaboration with psychiatry for psycho pharmacological treatment. I have the following diagnosis that must be treated in addition to my primary diagnosis:

- Depression
- Anxiety
- OCD
- Bi-polar disorder
- Seizure Disorder
- Not applicable

Other (please specify)

14. I currently require psycho pharmacological medication(s) (check all that apply):

- once a day
- twice or more per day
- on a prescribed as needed basis (prn)
- Not applicable

Other (please specify)

8. Final Comments and Demographics

1. Any final comments that you feel might be helpful for the purposes of this survey?

2. The person who completed this survey is:

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

Other (please specify)

* 3. 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:

Company:

Address:

Address 2:

City/Town:

State:

ZIP/Postal Code:

Country:

Email Address:

Phone Number: