What Works

Meeting needs + improving access to services
Findings from the AANE Massachusetts Survey for Adults on the Autism Spectrum without an Intellectual Disability

NOVEMBER 2019
Acknowledgements

We are grateful to the adults, families, and caregivers throughout Massachusetts who trusted AANE and disclosed their personal needs, shared their experiences with seeking support, and provided thoughtful recommendations for how to improve access to appropriate services for adults on the autism spectrum without an intellectual disability.

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The Asperger/Autism Network (AANE) works with individuals, families, and professionals to help people with Asperger Syndrome or similar autism spectrum profiles build meaningful, connected lives. We do this by providing information, education, community, support, and advocacy -- all in an atmosphere of validation and respect.

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# Findings from the AANE Massachusetts Survey for Adults on the Autism Spectrum without an Intellectual Disability

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Findings from the AANE Massachusetts Survey for Adults on the Autism Spectrum without an Intellectual Disability

1.0 Executive Summary

Purpose

The Asperger/Autism Network (AANE) conducted an online survey from October 19, 2018 until November 16, 2018 to identify the current needs and access to services in Massachusetts for adults on the autism spectrum who do not have an intellectual disability. AANE initiated this survey to evaluate the impact of the Massachusetts Autism Omnibus Act of 2014. This law enables adults on the autism spectrum, who were formerly ineligible for services if their IQs were above 70, to apply for Department of Developmental Services (DDS) programs and supports.

The recommendations from this survey aim to identify “what works” for adults on the autism spectrum without an intellectual disability regarding 1) meeting their needs and 2) improving access to appropriate services.

Serving adults on the autism spectrum without an intellectual disability can enable them to build meaningful, connected lives, and empower them to maximize their strengths and participate in their communities. Many of these adults have the potential to gain competitive employment and be economically self-sufficient when provided with appropriate supports. Ultimately, providing these adults with adequate assistance will not only benefit them and their families, but also provide the Commonwealth with more productive, healthy citizens, who need fewer state resources.

This report is intended to be a resource for policy makers, legislators, agencies, providers, insurers, and organizations that support this population.

“We need to do more of what works.” Parent respondent

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1 Individuals 18 years old or older.
2 In this report, acronyms will be indicated after the first use of a name or term, and then only the acronym will be used. A list of acronyms is provided in the Appendix.
Key Finding #1: Critical Unmet Needs

- Adults on the autism spectrum without an intellectual disability have a unique profile with significant and highly variable needs which are often underestimated because of their average or above-average IQ. These adults are unique because despite their intelligence, many of them have significant challenges with social communication, executive function skills, and mental health (e.g., anxiety, depression).

- Due to this unique profile, these adults are often not able to live independently and maintain employment without appropriate support. For adults who do attend college, as many as 85% of college graduates affected by autism are unemployed in the US\(^3\).

- Critical needs for autistic adults without and intellectual disability identified in this survey are 1) employment, 2) housing, 3) mental health support, and 4) social and community engagement.

Key Recommendation #1: Address Priority Needs

- Provide one-on-one assistance to obtain and maintain employment

- Provide skill development and direct supports for adults to live independently and offer physical housing options

- Provide appropriate treatment and supports for adults with autism and co-occurring mental health challenges, and those with significant behavioral needs

- Offer opportunities for social and community engagement

- Provide transportation assistance as needed

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Key Finding #2: Limited Access to Services

- The Autism Omnibus Act of 2014 granted access to public services for adults with autism regardless of their IQ, but access to appropriate services remains limited. Key barriers are: lack of awareness; lack of state funding; difficulty navigating the system; the need for more flexible guidelines so that adults can choose the services they need; and lack of qualified service providers.

- Individualized supports that “wrap around” an adult to leverage home, higher education, work, community and family networks, along with clinical services, can be life changing. However, comprehensive wrap-around supports are often lacking because service navigation and high-quality case management is needed to coordinate the complex support system and ensure optimal outcomes.

Key Recommendation #2: Improve Access to Services

- **Raise awareness** about the services available as a result of the Autism Omnibus Act

- Ensure and **maintain adequate funding** for the Autism Omnibus budget (line item 5920-3020)

- **Modify DDS eligibility criteria** to reflect unique profile and variable needs

- **Streamline DDS application** process

- **Provide high-quality, accessible service navigation** for all adults and families, regardless of DDS eligibility, in order to gain access to the complex system

- **Communicate** annual funding allocation to each DDS-eligible adult

- Provide high-quality wrap-around **case management service** for each DDS-eligible adult

- Allow DDS-eligible adults to **choose supports and services they need** within flexible guidelines

- **Build a network of providers** with expertise in working with autistic adults with this unique profile across Massachusetts including rural and underserved communities

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4 “DDS-eligible adult” is an adult who qualifies for DDS services by meeting DDS eligibility criteria.
Thank you for all that you do.

Thank you for trying.

Thank you for asking.

Thank you for listening.

Thank you for understanding.

Thank you for trying to understand.

Thank you for all that you offer.

Thank you for your advocacy.

Thank you for your time."

- Survey respondent
2.0 Methodology

Process

The target population for this survey is adults with “Autism Spectrum Disorder without an Intellectual Disability” (ASD no ID) as defined by DDS, or sometimes called the “Newly Eligible.”\(^5\) To be eligible for DDS services in Massachusetts, adults on the autism spectrum without an intellectual disability must also demonstrate functional impairment (in three or more of seven major life areas).\(^6\)

In this survey report, the term “adult” refers to individuals 18 years or older on the autism spectrum without an intellectual disability. AANE recognizes both “people first” language, which promotes all people as community members first, and “identity first” language, which promotes acceptance of neurodiversity; therefore, “on the autism spectrum” and “autistic” are used interchangeably throughout this report.

All participants were informed that the results were anonymous, and only aggregate findings would be used to assess current needs and access to appropriate services. No respondents were paid for their participation. Survey Monkey was used as the platform for 37 questions and the survey link was distributed electronically via AANE, other advocacy groups, and some autism centers. Respondents included either the individual adult on the autism spectrum, or their parents/caregivers. Responses representing 260 adults were analyzed.\(^7\) Quantitative data and qualitative data in the form of respondent comments were collected. 78% of adults in the survey were over the age of 21, and 61% of adults over the age of 21 had the survey completed by their parent/caregiver. 66% of all adults identified as male. The DDS regions represented were: Metro 35%, Northeast 25%, Central/West 22%, Southeast 11%, and region not provided 7%.

Although this survey is the first of its kind in Massachusetts to focus on adults on the autism spectrum without an intellectual disability, the results are limited because it was disseminated electronically through existing autism resource networks. Therefore, it does not capture individuals who did not receive the survey because they are not connected to autism support resources, do not have access to the internet, do not speak English, or did not choose to respond. Even with these limitations, the high number of responses and level of survey completeness are notable and indicative of high interest in this issue.

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\(^5\) “Newly Eligible” emerged as a term when the Autism Omnibus Law in 2014 was passed and adults who were previously not eligible became “newly eligible.” In 2019, the term “newly” is no longer applicable.


\(^7\) Over 300 individuals responded but only 260 met the inclusion criteria for this survey: adults at least 18 years old, on the autism spectrum, living in Massachusetts, with an IQ of 70 or above.
Quantitative and Qualitative Data

The following categories of needs were evaluated:
● Education
● Pre-Employment / Employment
● Health Insurance
● Health Care / Mental Health Care
● Housing
● Independent Living
● Transportation
● Social and Community Engagement
● Family Support

This report focuses on the highest reported needs: 1) employment, 2) housing, 3) mental health, and 4) social and community engagement. Please contact AANE if you are interested in a category not included in this report.

Each need was analyzed according to:
● 18-21 year-olds vs. 22+ year-olds
● Self vs. parent or caregiver reporting
● Gender identification
● DDS region

Primarily, totals for all respondents are included in this report. Please contact AANE if you are interested in a sub-analysis not included in this report.

Respondents were able to select multiple options for each need, which means that quantitative data may add up to more than 100%. Respondents also provided comments for each need and wrote narrative answers to questions regarding access to services. This qualitative data was analyzed thematically. Anonymous quotes from respondents are included in this report using quotation marks and italics.

Dissemination of Results

AANE will disseminate the results of this survey through the publication of this report, as well as presentations to members of the Department of Developmental Services (DDS), Massachusetts Rehabilitation Commission (MRC), Department of Mental Health (DMH), the Massachusetts Autism Commission sub-committees, advocacy organizations, providers, and academics. Please contact AANE if you would like a presentation of these results. This report is available on AANE’s website www.aane.org.
3.0 Unique Profile and Highly Variable Needs

Unique Profile

Adults on the autism spectrum without an intellectual disability have a unique profile with significant and highly variable needs which are often underestimated because of their average or above-average IQ.

These adults have a unique profile because despite their intelligence, many of them report challenges with social communication, executive functioning (time management, goal-setting, planning/organizing), extreme need for routine, black and white thinking, social isolation, sensory sensitivities, and mental health issues often related to anxiety and depression. An autistic person’s IQ does not always correlate with their functional need.

Moreover, adults’ needs are highly variable -- as Stephen Shore once said, “If you’ve met one person with autism, you’ve met one person with autism.” Adults’ needs for services can change in type, intensity, and duration throughout their lifetime. Their ability to function can also be highly dependent on the environment.

Many adults can camouflage their challenges and they sometimes have extreme splinter skills - they excel in one aspect of life, and struggle significantly in another - which can lead to misunderstanding the adult’s true needs. Lastly, a parent’s perspective of what their adult son or daughter needs may be very different from the autistic person’s perspective of his or her own support needs.

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Findings

The unique profile of adults on the autism spectrum without an intellectual disability presents significant obstacles to employment and independent living as revealed in this survey. The exact number of autistic adults who do not have an intellectual disability in Massachusetts is unknown. However, the number of adults who may need services is suggested by AANE’s support of 6,810 parents of adults, and 4,360 adults as of May 1, 2019 in Massachusetts alone.

“The perception is HFA [High Functioning Autism] = competence, BUT my son needed individualized accommodations.”

“DDS needs to create an entirely new model for those with autism! Person-centered, not one-size-fits-all. Taking into account splinter strengths and advanced skills in certain areas.”

“We need a lot more services for this population. They’re terribly misunderstood.”

“We need to move away from the idea that the accommodations that they desperately need (i.e., life coach, social skills, etc.) are more of an optional thing...The adult world requires they master these skills and because Autism has only in the past decade really been recognized as a significant disability, many adults are out there without the support they need.”

Challenges with executive functioning were a major theme throughout the survey and not only impacted adults’ employment, housing, mental health, and social engagement, but also significantly impacted the adult’s ability to access services. Nearly 30% of adults did not know how to find the DDS application or were overwhelmed and confused by it. 51% of adults had challenges in scheduling and attending doctor’s appointments, and 48% of adults needed assistance to refill prescriptions or take medicine on time as reported by their caregiver. Executive function training can be helpful for some adults, but many reported needing direct, ongoing, and reliable executive function support to access services and manage aspects of daily living throughout their lifetime.

“Needs a ‘mom’ to check in.”

“Executive function skills as in being able to arrange my life so that I get to work on time, have clean clothes to wear, etc. which I don’t think of until it’s already time to be at work.”

“I wish there were more services he could get to help coach him and teach him how to structure his time and life...he needs a lot of guidance on everything he does and does not do.”

“He needs help remembering when his appointments are and not making more than one appointment that are too close in time to be able to make it to both.”
Considerations Regarding Support of Autistic Adults without an Intellectual Disability

Because of this unique profile and variable needs, the following considerations should be made when designing and delivering services to support autistic adults without an intellectual disability.

- Appropriate supports can be life-changing
- Proactive support can prevent crisis situations
- It is essential that providers and those offering support know how to support someone with this particular profile
- Services must respond to the variability of this profile as well as the variability of need from person to person
- Services must be flexible to respond to needs that can vary over time and can include times of intense needs and crisis
- Supports do not need to be designated special needs support, but can include the use of naturally occurring community supports. This destigmatizes supports
- High-quality service navigation is the gateway to access resources
- Parents and adults requested supports that “wrap around” an individual to leverage home, higher education, work, community and family networks, along with clinical services. Case management is essential to coordinate all these supports, and should continue to be available when parents can no longer participate in the life of their child
- Participants want to be able to choose which supports they feel will work for them
- Many adults and families do not have money to pay for supports. They must be accessible free or at low cost
- Those who are aging and isolated, often without family, friends or natural supports, need additional and sometimes different assistance
4.0 Recommendations: Provide Appropriate Services

4.1 Priority #1 - Employment

Findings

Obtaining and maintaining gainful employment is the primary need identified in this survey. Over 90% of respondents reported the need for employment support, and more than 60% of individuals needed assistance with social, self-advocacy, and executive function skills at work. Only 9% reported that they had no needs regarding employment. Lack of transportation was also identified as a barrier to employment in respondents’ comments. It was also unclear to some respondents how to access employment supports via DDS, MRC, or other state agencies.

“I am very smart and well educated, but my social skills make it hard to keep employment.”

“If we do not expect this group of young adults to live off the state benefits, better partnerships with employers MUST be developed.”

“This population has much higher potential in the workforce than employers believe.”

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9 Percentiles do not add up to 100% as respondents were able to select more than one option.
Recommendations to Support Employment

1) Publicize DDS, MRC, and other public and private employment supports with a concerted effort to reach under-served adults

2) Provide individualized PRE-employment support from providers with expertise in autism
   - Provide traditional job readiness support and placement services: skills training; interviewing skills; and finding an appropriate job which fits the strengths, skills, and interests of the individual
   - Offer pre-employment support throughout the adult’s lifespan as needed, and not only during the transition to adult services (ages 18-22)

3) Offer individualized support DURING employment from providers with expertise in autism
   - Support job maintenance with job coach
     ○ Coaching can help adults manage the myriad, varied, and unpredictable hidden agendas and unclear expectations on any job that are not directly outlined but simply understood by neurotypical individuals. These include, but are not limited to: social communication skills (how to relate to co-workers, how to collaborate and communicate effectively, how to solicit and accept feedback); self-advocacy skills (managing performance reviews, asking for advancement/more responsibility, asking for needed accommodations); and executive function challenges (organization, time management).
     ○ Without these supports during employment, adults are at significant risk of being misunderstood, to the point of being terminated from a job that they might otherwise have the intelligence and skills to do successfully.
   - Support both employee and employer with job coach
     ○ Job coach does not need to be on-site, but should be readily available to provide support to both employee and employer to improve relations, ensure productivity, and manage conflict. Or, for larger employers, the job coach could be part of human resources (e.g., Microsoft model\(^\text{10}\))

4) Develop partnerships with employers to encourage hiring and supporting a neurodiverse workforce, and provide training on how to best communicate with employees on the autism spectrum

5) Assess best practices for supporting employment for adults with challenging behaviors and more significant needs

6) Find creative transportation solutions: vouchers for ride sharing app services, carpools, etc.

4.2 Priority #2 - Housing

Findings

More than 70% of all respondents reported a housing need and many adults live with their parents. The continued reliance upon parents is reflected in AANE’s support of 6,810 parents of adults in Massachusetts as of May 1, 2019. Individuals commented that they often do not qualify for residential support through DDS or other agencies, yet they reported wide-ranging needs including:

- ongoing support with independent living skills in their own home
- a place to live because they cannot afford one on their own due to underemployment, but could live independently with minimal support
- a residential home that provides direct support for those with significant needs

Furthermore, lack of information and misinformation about available housing supports, scarcity of and 8-10 year waitlists for Section 8 vouchers, and confusion around rules were reported. The needs and barriers to housing identified in this survey are similar to those reported in the Massachusetts Housing Think Tank report.12

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11 Percentiles do not add up to 100% as respondents were able to select more than one option.
“If I die, my adult will be homeless. I don’t know what to do.”

“There is a total lack of supported independent living situations for high-functioning people on the spectrum.”

“A major challenge for me would be finding a living setup where I am not socially isolated.”

“She needs help with keeping up with basic care of her living space.”

**Recommendations to Support Housing**

1) Ensure adults and caregivers have access to accurate housing and financing information throughout the adult’s life, especially during school-to-adulthood transition planning.

2) Provide independent living supports for DDS-eligible adults, without IQ as a criterion

- Enable use of the adult’s allocated DDS funding for direct services and ongoing case management to support those living independently in their own homes (e.g., executive function support; help with home organization and cleaning; budgeting and bill paying; food shopping, preparation, and cooking safety; personal hygiene and self-care; medication, health, and mental health management as described in section 5.7)

3) Provide physical housing options for DDS-eligible adults, without IQ as a criterion

- Allow use of the adult’s allocated DDS funding for physical housing
- Increase affordable housing options with set aside housing subsidies/vouchers for those with autism without an intellectual disability
- Provide better pathways for adults to own their own home, which is less expensive than renting over the long term (e.g., increase ABLE account amount limits; exclude ABLE accounts from asset tests for low income housing; and allow the use of Section 8 vouchers or DDS funds for down payment when applying for a mortgage for low income housing)
- Offer full residential housing for adults with more significant needs regardless of IQ
- Implement recommendations provided by Housing Think Tank and Autism Housing Pathways (AHP) and the Housing Sub-Committee of the Autism Commission

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4.3 Priority #3 - Mental Health

Findings

Survey respondents described mental health support as the foundation for successful employment, independent living, and social engagement. More than 85% of respondents reported that the adult has mental health needs. Respondents commented that accessing mental health services is very challenging because mental health is often disconnected from other services and usually delivered and funded separately.

Anxiety and depression are commonplace for adults on the autism spectrum. More than 43% of survey respondents reported needing - but not being able to find - a psychologist or therapist who accepts their insurance, or has reasonable out-of-pocket fees, and is nearby. Individuals living outside of the greater Boston area have a more difficult time accessing mental health services.

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Mental Health Needs Across All Ages

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17 Percentiles do not add up to 100% as respondents were able to select more than one option.

Moreover, mental health needs varied over the course of an adult’s lifetime and varied considerably between ages, as greater mental health needs and issues such as computer misuse were reported higher in 18-21-year olds. Also, executive function issues such as attending appointments, managing medications, and following doctor’s advice impeded access not only to mental health services, but also limited access overall health care services.

“Mental health is key to success”

“Psychologists and psychiatrists are in short supply. It is EXTREMELY difficult to find one good with asperger anxiety and depression who has openings. This is very frustrating.”

“I’ve been struggling to find a therapist...mostly because my (public) insurance changed.”

“She is very smart...and struggled with depression, anxiety, and agoraphobia.”

“Greatest need is finding/establishing a relationship with psychiatrist/counselor. Many do not accept insurance. Those affiliated with clinics are so busy they do not have time to address issues, nor do they have flexibility for more appointments at times of greater need.”

“[Need help] Finding a mental health professional who has expertise in Asperger’s, is a reasonable distance from home, and takes my insurance.”

“Internet addiction x 1000”

“[Need] crisis programs that don't turn people away because they have autism.”

“I have a hard time e.g. calling when the doctor or hospital gives me a referral form and asks me to pick a specialist and call to set up an appointment, there is no end to that thread.”

“Getting appointments when I need them and healthcare professionals allowing me to speak for myself and share my own experiences/feelings, etc.”

“It is so difficult to get him mental health services. He was hospitalized recently and sent to a psychiatric hospital that just housed him for 3 days! Very discouraging.”

“Our healthcare system causes me health worsening stress.”
Recommendations to Support Mental Health

1) Improve access to providers who specialize in autism

- Provide high-quality service navigation and effective case management to access mental health providers (see sections 5.5 and 5.7)
- Create financial incentives through competitive pay and reimbursement rates by state agencies and private insurance companies to encourage providers to serve individuals on the autism spectrum
- Encourage medical schools and continuing medical education programs to include autism in their training and designate autism as a specialty
- Create more inpatient and partial hospitalization programs, and urgent care clinics with expertise in autism

2) Improve access to mental health funding

- Help adults identify available sources of funding for mental health services (i.e., DMH, MassHealth, hospitals, or private insurance)
- Continue cooperation between DDS and DMH to integrate, develop, and fund appropriate services for those on the autism spectrum with co-occurring mental health conditions
- Enforce mental health parity with public and private insurers

3) Allow use of the adult’s allocated DDS funding for mental health services that are not otherwise accessible via DMH or MassHealth

4) Identify and use best practices

- Provide intensive, wrap-around, clinical case management for adults and their families
- Support cognitive behavioral therapy and other effective interventions, beyond the ‘talk therapy’ and ABA that are typically offered

5) Provide quality mental health programs in underserved populations

- Identify the number and needs of senior adults (65+ years) on the autism spectrum and provide training and support to elder care service providers
- Identify the number and needs of homeless adults on the autism spectrum and provide training and support to service providers for the homeless
- Identify the number and needs of incarcerated adults on the autism spectrum and provide training and support to Department of Corrections facilities

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4.4 Priority #4 - Social and Community Engagement

Findings

Social isolation was evident among respondents. When adults reported on behalf of themselves, 50% of them reported needing support to participate in community activities and finding/keeping friends. When social needs were reported by someone else (parent/caregiver), over 75% of individuals needed support engaging with the community and finding/keeping friends. A desire for a romantic relationship was also reported by many. Most comments about social needs were from parents/caregivers. It is important to note that the desire for social inclusion is highly variable and very dependent on the individual.

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Social Needs as Reported by Self (Adult) or by Someone Else (Caregiver)

Percentiles do not add up to 100% as respondents were able to select more than one option.
“What my adult needs most is a community of their peers and transportation to connect with them.”

“My son does feel very isolated and lonely.”

“I don’t operate well in groups. I’d love to have a girlfriend.”

“We haven’t found one thing that gets him out of his room…his anxiety and epilepsy sometimes keeps him from going to classes.”

“I don’t participate in social things except work…”

“Social outings and groups of other young adults (similar to her level of ASD/Aspergers) to connect with is what we can’t seem to find closer to our area.”

“His happy self-worth has plummeted without 1 friend, nor any girls & he feels unworthy.”

“Currently he has friends, hard to tell whether or not they’re close friends. He would benefit from support around understanding the complexities of romantic and long-term intimate relationships.”

**Recommendations to Support Social Engagement**

1) Prevent isolation by improving access to social activities

- Use naturally occurring community supports. This destigmatizes supports. Social activities do not need to be designated special needs support
- Offer in-person meetups throughout Massachusetts and online platforms open to all

2) Enable use of the adult’s allocated DDS funding for to pay for:

- **Fees for natural, interest-based community activities** (i.e., hobbies, arts, movies, sports)
- **Mentors** who can support adults to identify community activities, get to events, and provide adult companionship as needed
- **Direct coaching** to support social networking, dating, relationship and friendship assistance, as well as managing the many hidden expectations involved in socializing
4.5 Other Needs including Transportation

In addition to the highest needs reported above including employment, housing, mental health, and social/community engagement, other reported needs include:

- Transportation
- Higher Education
- Independent Living
- Family Support
- Safe and Healthy Intimate Relationships
- Day Programs
- Criminal Justice

Detailed findings related to these other needs are not included in this report due to space constraints, but highlights of respondents’ comments are below to illustrate the huge variability in needs. It is important to acknowledge that many of the needs included in this report are shared with other disability populations, but the unique profile and variable needs of adults on the autism spectrum without an intellectual disability require individualized and flexible services.

Comments - Transportation

“Transportation is super difficult in the suburbs and rural areas. A barrier when getting to jobs.”

“DDS does not help with transportation to and from college I was told.”

“[Need] Discounts for Lyft, Uber applications”

“I don’t use Uber or Lyft as I have trouble with social interaction...”

Comments - Higher Education

“They need to consider funding for other college like programs. We want and need our young adults with autism to continue to learn and grow post-22. Why should they be warehoused for the rest of their lives upon leaving school?”

“Limiting the access to funds to support vocational or certificate-based education is appalling and isn’t inclusive to the people with autism who may prefer an alternative career path.”

“Work with local colleges so they are more supportive of this population and offer on-campus living assistance programs for high functioning autistics.”
Comments - Independent Living Skills

“I could definitely use some help in working out a sustainable budget. I can also draw a blank in navigating or reacting to unsuspected situations, including “emergencies…”

“I do need help with the paperwork and can't always find someone for advice or a second opinion.”

Comments - Family Support for Parents/Caregivers of Adult

 “[I need] for my parents to understand.”

“I cannot work full time and care for him.”

“Why aren’t support groups for parents of adults or offer parent-to-parent matching? I also need community, for support and networking.”

Comments - Safe and Healthy Intimate Relationships

“I'd love to have a girlfriend, but I'm [over 60 years old]...I have had abusive relationships in the past. I'm not holding my breath for the future.”

“...I'm not sure my partner always takes my diagnosis seriously, or understands its impact on a daily basis. And that can be a problem in meeting my own needs, or even sense of safety at times.”

“He needs direct hands-on instruction on how to use a condom that I have had to do, but I wish I had a trusted professional that could help him with it, and lots of other supports he would benefit from regarding sexual activity.”

“[Need information on] Birth control options, human sexuality”

Comments - Older Adults

“The needs of the ever-growing population of older adults on the spectrum are compounded by new issues: relating to changes in health, in relationships, losses, housing needs and circumstances, and in functioning abilities, not to mention financial concerns...This population has a large number of baby boomers. Nearly all of us were diagnosed late in life. We have unique issues.”
Comments - Day Programs

“Day programming dollars limit of 20K is inadequate to hire and retain quality staff, especially for the diverse programming/employment coaching needed by the 70+ IQ ASD population.”

“Every adult day program we looked at was really just “warehousing.” There was not intellectual stimulation. There was a ridiculous age range. At 22 he’d be placed with 50-70 year olds!”

Comments - Criminal Justice

“[How to live] in a safe manner without risk of abuse or being taken advantage of or have the cops called on them or being misunderstood?”

“For those ASD persons in the criminal justice system...no services exist.”

“Meaningful help is needed from agencies when those on the spectrum find themselves down the rabbit hole with interacting with the criminal justice system. More and more ASD persons will find themselves in horrifying situations with the law...and usually their disability will not be considered in court. Jails and prisons are filled with ASD persons who have been badly let down by our justice system and their agencies...”
5.0 Recommendations: Improve Access to Services

The findings below illustrate the current status of access to services and include recommendations for how to improve access to services. Recommendations came directly from the 260 survey respondents, and emerged from discussions with stakeholders about the findings of this survey, and AANE’s expertise in serving adults on the autism spectrum without an intellectual disability for over 20 years.

Service delivery questions were limited to DDS because the Autism Omnibus budget is within their domain. However, other federal, state and local agencies also have a critical role in supporting this population and include, but are not limited to: the MRC, DMH, Department of Elementary and Secondary Education (DESE), Department of Labor (DOL), and local housing authorities. In addition, many adults build their support network with private resources through insurance or pay out of pocket. It is important to recognize that many agencies, providers, and organizations dedicated to serving this population are aware of some of these issues and are making a concerted effort to address them. Also, many of these recommendations to improve access to services are applicable for all individuals living with a disability.

Recommendations:

● **Raise awareness** about the benefits of the Autism Omnibus Act

● **Ensure adequate funding** for the Autism Omnibus budget (line item 5920-3020)

● **Modify DDS eligibility criteria** to reflect unique profile and variable needs

● **Streamline** DDS application process

● Provide **high-quality, accessible service navigation** for all adults and families, regardless of DDS eligibility

● **Communicate annual funding allocation** to each DDS-eligible adult

● Provide high-quality wrap-around **case management service** for each DDS-eligible adult

● Allow DDS-eligible adults to **choose supports and services** they need within flexible Guidelines

● **Build a network of providers** with expertise in autism across Massachusetts

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22 “DDS-eligible adult” is an adult who qualifies for DDS services by meeting DDS eligibility criteria.
5.1 Raise Awareness of the Benefits of Autism Omnibus Act

Findings

Overall, 50% of survey respondents were not aware that eligibility for DDS adult autism services expanded so that IQ is no longer a criterion indicating significant lack of awareness. This is surprising because the survey was distributed through AANE, other advocacy organizations, and some autism centers. It is not known exactly how many adults are on the autism spectrum without an intellectual disability in Massachusetts, but given that AANE supports over 11,000 adults and parents of adults in Massachusetts as of May 1, 2019, there is a substantial number of adults who may need services.

Did you know that under the 2014 MA Autism Omnibus Act, eligibility for DDS adult autism services expanded so that IQ is no longer a criteria?

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YES 110 (42.3%)
NO 130 (50%)
Blank 20 (7.7%)
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“We did not know he could qualify for any assistance. We need to look into this.”

“I’ve never heard of this and am unsure if I would qualify.”

“I have never encountered such services for adults.”
Recommendations to Improve Awareness

- **Raise awareness about the benefits of the Autism Omnibus Act** specific to the new non-IQ based eligibility criteria for DDS services through direct outreach to: 1) psychologists and psychiatrists who are typically the first point of contact with the system upon an autism diagnosis, 2) special education departments at schools, 3) special education parent advisory councils at schools, 4) autism support centers and organizations

- **Promote available services** from all government agencies, public and private providers, and non-profit organizations with a list of up-to-date state-wide resources on the internet

- **Design outreach campaigns** with input from adults on the autism spectrum without an intellectual disability with a deliberate effort to reach under-served communities

5.2 Ensure Adequate Funding for Autism Omnibus Budget

Findings

**Lack of funding is a major barrier to accessing services.** Fortunately, the FY2020 Autism Omnibus budget was increased to help reduce these funding gaps. However, this budget is not guaranteed as it is subject to the annual state budgeting process. **Maintaining adequate funding for the Autism Omnibus line item is essential.**

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5.2.1 Not All DDS-Eligible Adults Enrolled

43% of respondents in the survey who are eligible/accepted for DDS services are not enrolled in/receiving DDS services. These eligible/accepted adults can receive service coordination support, but they are not actually receiving any direct services paid for by DDS. This finding is corroborated by the Autism Commission 2018 Annual Report which found that 44% (824) of eligible adults were not enrolled in/receiving DDS services, out of 1,853 newly eligible adults. Anecdotally, it has been suggested that some DDS-eligible/accepted adults are not enrolled in/receiving services because the adult did not accept services. The number of adults who refuse services is not publicly available and the reasons why merit further research. In this survey, no respondents reported the adult refused services.

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24 “Eligible/accepted adult” is defined as an adult who has applied for and been deemed eligible to access DDS adult autism services.

25 “Enrolled in/receiving services” is defined as an adult who has been deemed eligible for DDS adult autism services and receives funding for or direct provision of services.

5.2.2 Many DDS-Eligible Adults Told “No Funding”

When asked why the DDS-eligible/accepted adult was not enrolled in/receiving services, 65% of respondents said they were told there is no funding. One respondent shared that alongside each of the services listed on her son’s Individual Service Plan, “no funding” was written. 41% of respondents indicated they were still waiting for services to be offered; in essence, these respondents still hoped for funding.

“We expended a great deal of time, energy, and money to have our son deemed eligible under the new criteria established under the 2014 Autism Law. While it is our understanding the legislative intent in passing the law is to address unmet needs of individuals with ASD and reflect recommendations of the Autism Commission and Autism Center, funds have not been included in the state legislature’s budget that reflect a commitment to actually address the needs of the growing adult population.”

27 Percentiles do not add up to 100% as respondents were able to select more than one option.
“It was a complete waste of time to even go through the process of having my son become eligible only to be told they weren’t going to help him.”

“It has been very frustrating to complete the lengthy and arduous application process...only to find out that there is no funding.”

“Technically is in, but we are told budget is frozen. He gets scraps.”

“There is no money for any services. This has been the story since my son was approved.”

“I find the DDS folks great and supportive with my questions. However, that stops when you request funding. Then I cannot get them on the phone and they do not return my phone calls. I know it is not their fault if there is no funding - I just wish they could tell me that up front and not make me call, and call, and call - until I just give up.”

“My son was approved over 2 years ago and every year they tell us they do not have any funding for him.”

“Our son was found eligible in April 2018; however, we were never contacted by DDS. We called DDS in August 2018 to inquire and were told there wasn’t any funds. They never even contacted him to find out what his needs were!”

“Recently was deemed eligible but was told there was not enough funding to cover the life coaching/social skills services he needs. It has been almost 6 months and we have not heard of any changes in this regard. It is very disappointing.”

“We are in the middle of DMH and DDS and trying to get services that will provide our son with a productive life that he once had before he transferred to Adult Services. He came from a vibrant program to a hot mess of adult living with a road leading to nowhere.”
5.2.3 Many DDS-Eligible Adults Miss Turning 22 Funding

Funding for the “Turning 22” Program supports state services for young adults with disabilities who graduate from high school, or age out of funding by their local school districts at the age of 22. Turning 22 funding for DDS services is a separate budgetary line item from the Autism Omnibus line item. The Turning 22 line item has increased since FY2017 to accommodate the increasing numbers of young adults who qualify.

More than 60% of applicants for DDS services in this survey missed the Turning 22 funding because they applied AFTER they turned 22. This is significant because these adults fall under the Autism Omnibus line item which is not fully funded, and therefore, although the adults may be eligible/accepted into DDS, they are often not enrolled in/receiving services due to lack of funding (see section 5.2.2).

For adults currently 22+, how old was the adult when applied?

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- Under 18
- 18-21
- 22-30
- 31-40
- 41-50
- 51-64
- 65+
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“*I have been told when there is funding, it will go to those transitioning from an IEP or age 22 leaving school and needing to go into something else!! Where does that leave all the other adults that “fall thru [sic] the cracks” now eligible and still not getting anything?”*

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Recommendations for State Funding

● **Ensure adequate funding** for the Autism Omnibus budget line item 5920-3020

● **Maintain/publish an accurate list of those eligible/accepted, but not enrolled/receiving services because of lack of funding**
  ○ Inform clients that they are on a “not funded” list to avoid over-promising and under-delivering
  ○ Enable legislators to have clear data on what funding is required

● **Assess the number of eligible/accepted adults who do not accept services and identify the reasons why**
  ○ Identifying this number of people and their reasons would illuminate why some adults refuse services and assist with future service design

● **Optimize coordination and funding across Executive Office of Health and Human Services (EOHHS) agencies** by building on emerging information sharing, cooperation, and budget agreements among DDS, MRC, DMH, DESE

● **Maximize all state agency resources to support adults on the autism spectrum without an intellectual disability** by developing autism support capacity of other state agencies, such as the Departments of Career Services, and Housing and Community Development, to create a “comprehensive state-wide approach.”

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5.3 Modify DDS Eligibility Criteria to Reflect Unique Profile and Variable Needs

Findings

Adults on the autism spectrum without an intellectual disability have a unique profile because despite their average or above-average IQ, many of them describe significant and highly variable needs which are often underestimated when their needs are assessed. An autistic person’s IQ does not always correlate with their functional need.

Respondents commented they were grateful that the use of IQ as a criterion for accessing DDS services was removed by the Autism Omnibus Act of 2014. 75% of those adults in this survey who did apply for DDS services were deemed eligible/accepted, and actual DDS approval rates are not publicly known. However, many respondents commented that the interpretation of the existing eligibility criteria based on the Federal Developmental Disability Act definition of functional impairment does not adequately assess the adults’ ability to function, and take into consideration deficits in executive function skills and social skills along with frequent co-occurring mental health issues which significantly impair the individual’s ability to manage the demands of employment and daily life independently.

Moreover, many adults were diagnosed with autism well after they were 22, which makes meeting the requirement to prove that autism manifested prior to age 22 nearly impossible, and these older adults are often not able to access DDS services.

“I feel like Asperger’s syndrome gets second-class treatment because all the eligibility criteria for DDS seem to be based on autism [with an intellectual disability].”

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31 Public Law 106 (8)
(A) The term “developmental disability” means a severe, chronic disability of an individual that:
(i) is attributable to a mental or physical impairment or combination of mental and physical impairments;
(ii) is manifested before the individual attains age 22;
(iii) is likely to continue indefinitely;
(iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:
(I) Self-care.
(II) Receptive and expressive language.
(III) Learning.
(IV) Mobility.
(V) Self-direction.
(VI) Capacity for independent living.
(VII) Economic self-sufficiency; and
(v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.
“When I applied for DDS, DDS did not capture all of my day to day challenges. My impression was that the screening tool was designed for people with at least some degree of intellectual impairment, and does not adequately capture the impairments of those who do not have an intellectual disability.”

“I drove myself to the appointment and the examiner said that alone would disqualify me. But the measures used were clearly focusing on intellectual disability and extreme behavioral issues (biting in the movie theater for example). Because I’m smart enough to be able to see that’s not a good idea, the fact that I haven’t been able to work since 1999 with two master’s degrees and an almost PhD…that I can’t support myself…that I spend my days alone at home mostly watching TV or out walking around the world not able to organize my time or affairs…keep up with the tasks of daily living without help because of ENERGY and cognitive functions not because I don’t know how to do these things…that didn’t seem to matter. The examiner said the measures they use have not been adapted for high IQ autistics but they still had to rely on those measures for their determinations.”

“They told us there wasn’t any funding and I feel it was after they discovered from our conversation that he was able to drive a car and attend college even if it was part-time.”

“My son’s refusal to accept his diagnosis fuels him to report that he is more capable than he actually is. The interview relied more on his self-reporting than on reporting from family and therapists.”

**Recommendations for Eligibility**

- **Adapt eligibility criteria to reflect unique profile and high variability of needs**
  - Focus on functional limitations that present significant obstacles to employment and independent living

- **Eligibility and needs determination should not be budget-driven**
  - Accurate assessment of individual needs allows for well-informed legislative budgeting and agency resource allocation

- **Include the family/caregiver** in the eligibility and needs determination process

- **Support efforts to consistently apply eligibility and needs determination guidelines across the state**

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5.4 Streamline DDS Application Process

Findings

Given the lack of awareness about the benefits of the Autism Omnibus Act, all potentially eligible adults are not applying for DDS services, as discussed in Section 5.1. If the adult did not apply for services, respondents were asked the following question, “Why didn’t the adult apply?” Beyond lack of awareness, other barriers during the application process were identified by respondents, including the following:

- **Complicated application process**: respondents were confused or overwhelmed which was only exacerbated by any executive function challenges
- **Lack of required documentation**: such as a recent neuropsychologist evaluation which is expensive to obtain and often not covered by insurance
- **Assume there is no funding for services**: respondents did not think they would receive services so did not want to go through the effort of the application process. “We were told there is no money and not to bother,” one respondent said.
- **Stigma concerns**: some adults do not want to be labeled as disabled, or seen as needing and receiving state hand-outs

“I hope that she will qualify for DDS if we can manage to complete the application.”

“The bottom line is that it is very expensive and time consuming to turn 18 in Massachusetts. Family usually have to pay private fees for attorneys and mental health providers in order to acquire the necessary documentation and then apply for services and file legal documents.”

“They are requesting a new neuropsych evaluation to confirm his autism diagnosis, despite an initial diagnosis from 2000. I am trying to arrange it. So frustrating.”

“Was told I wouldn’t get help finding mental health providers.”

“Thought we could financially manage without assistance, but not proving out to be the case.”

“Biggest concern: goes on my son’s record and it can be accessed against our will sometime in the future.”
Misinformation is another reason adults are not applying. Neither IQ nor financial need is a criterion for accessing DDS services; however, respondents commented as follows:

“My son receives no adult autism services. He has been home [for three years] since he left his [residential school]. He is not eligible for DDS because his IQ is too high.”

“The provider told us that our child could not access DDS because of high intelligence.”

“We were told we were over the financial threshold.”

Recommendations for Application Process

- **Provide accurate information** to all providers, schools, parent organizations, and autism support organizations
- **Streamline** application process
- **Provide direct support to applicants to complete the application** process and secure necessary documentation
- **Ensure access to diagnostic evaluations** by expanding insurance coverage for diagnosticians, and referrals to specialists especially with expertise in later life diagnosis
- **Assess ways to de-stigmatize application process** by focusing on improving the adult’s quality of life, not the disability, and using online resources
5.5 Provide Quality Service Navigation for All, Regardless of DDS Eligibility

Findings

The complex service delivery system itself is a barrier to accessing services. Adults and caregivers reported numerous challenges with navigating the very complex health care system made up of multiple federal, state, and local agencies, various public and private insurance payers, hard-to-find providers, numerous non-profit resources, and inconsistent rules. This system is especially challenging to navigate for someone with social communication and executive function challenges, sensory sensitivities, mental health issues, or language, cultural, or economic barriers.

56% of respondents reported needing help to navigate public agencies such as DDS and the MRC, and 50% needed assistance navigating public health insurance. Over 40% need assistance managing claims and paperwork. Less than 20% reported no needs in this area. For those respondents who have accessed DDS service navigation, they reported a wide range in quality from outstanding to inadequate.

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Percentiles do not add up to 100% as respondents were able to select more than one option.
“Total system is too complicated and too hard to navigate”

“[We need a] single website that clients can access to show all services available, what can be accessed and how to request”

“We did not know what services were available for adults with Asperger’s so we have not accessed any.”

“There may be available resources but it is difficult to locate and access them.

“I have only heard about these supports through parent groups - but I do not have a formal source of information.”

“It’s hard to find out about information as most Family Support Centers have terrible or out-of-date websites.’

“Because we are not able to see what [public] services are available except what is communicated to us via case manager, we are not aware of all that is available to access. Am unaware if there is a single website clients can access to show all services available, what can be accessed and how to request it.”

“I have recently been diagnosed and am completely unsure of how to find assistance and what assistance is right for me.”
Current complex system

The list below illustrates the complexity of the current system, and is not all inclusive. Support is available from a wide range of agencies, providers and organizations. Each resource has a separate application process, its own eligibility criteria, its own budget, its own service coordination and oversight system, and its own method for paying providers. This is incredibly confusing to adults and their families. It requires significant time, the ability to complete the paperwork, and the know-how to manage this web of resources. Navigating this inherently complex system is further compounded by executive function and social communication challenges in this population.

Disability-specific agencies/organizations:

Executive Office of Health and Human Services (EOHHS)
Department of Developmental Services (DDS) and related Autism Centers
Massachusetts Rehabilitation Commission (MRC)
Department of Mental Health (DMH)
Department of Public Health (DPH)
MassHealth
Adult Foster Care (AFC)
Social Security Administration
Supplemental Security Income and Social Security Disability Income (SSI, SSDI)
Department of Elementary and Secondary Education (DESE) - for adults 18-22
Local School Districts - for adults 18-22

Other non-disability specific agencies/organizations:

Department of Labor (DOL), Department of Career Services
Department of Housing and Community Development (DHCD)
  Section 8 Housing Choice Voucher Program (HCVP)
  MassHousing
  Community Action Agencies
Department of Transitional Assistance (DTA)
  SNAP (food stamps)
Department of Transportation (DOT)
Executive Office of Elder Affairs (EOEA) (part of EOHHS)
Layered upon this state agency-centered service network are private health and mental health care professionals and non-profit organizations where adults accessed clinical or other support services through insurance, fee-for-service, or sliding scale payments. More than 52% of all survey respondents self-pay for non-DDS services, or have access to private insurance, and many commented they go without services.

Private and non-profit service providers:

Medical doctors
Mental health professionals
Pharmacies for medicine
Life / school / job coaches
Case management programs
Specialized employment agencies
Schools - classes (i.e., cooking, coding), vocational schools, colleges
Tutors
Physical therapists
Board Certified Behavioral Analysts (BCBA) / Applied Behavioral Analysis (ABA) therapists
Occupational therapists
Speech therapists
Support groups
Driving schools (sometimes adaptive)
Specialized community/recreational activities - e.g., Special Olympics
Independent living support - cleaning, shopping, adult companion
Respite care providers for caregivers of adults

Also, legal services were often needed to complete applications, create special needs trusts, enforce disability rights, or resolve access to service issues.
Recommendations for Service Navigation

High quality service navigation is the gateway to improving access to services.

- Ensure that service navigation is available for all adults and families regardless of DDS eligibility and provides:
  - Information and referrals across the entire complex system of state agencies, public/private providers, and non-profit organizations, and
  - Direct application support for federal, state, and local services

- Expand the number of Autism Support Centers to reach under-served geographical areas and use technology to maximize outreach.

- Increase the number of reliable, consistent service navigators who understand the unique profile, variable needs and strengths of adults, and who are well-versed in the resources available

- Contract service navigators to independent Autism Support Centers, not DDS, to improve navigators’ awareness of all resources and help clients navigate across all agencies, public and private providers

- Maintain an up-to-date state-wide database of ALL agencies, providers, and their services

- Offer targeted service navigation for adults transitioning from school to adult services

- Provide communication and executive function support to facilitate adults’ follow through with service navigation recommendations

- Ensure dignity and privacy, and de-stigmatize service navigation, by having resources available online, so that adults – particularly those with anxiety or executive function issues - can access them from the privacy of their own homes.

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5.6 Communicate Annual Funding Allocation to Each DDS-Eligible Adult

Findings

Many respondents who receive funding for DDS services stated that they do not know how much money will be allocated to them each year, which reduces their ability to plan effectively and ensure continuity of services. The following quotes from respondents illustrate the need for predictable funding rather than today’s “crazy quilt of cobbled together disjointed services which are thrown together when funding is available,” as one stakeholder described.

“We have to beg our family support provider every time there is a need, it’s demeaning and embarrassing.”

“Other areas have an annualized stipend assigned, but we seem to have to beg for funding every time there is an issue...often leading to crisis level financial need.”

“He receives some money after the people who are allotted money don’t use their money.”

It is important to note that some respondents reported receiving excellent coordinated support when they knew what funds were available as described in section 5.7.

Recommendations to Improve Funding Allocation

- Communicate annual funding allocation to each DDS-eligible adult prior to service planning and delivery
- Allow adults to use their DDS funding allocation to purchase services from the full array of qualified providers, agencies or organizations (see Section 5.8)
5.7 Provide High-Quality Wrap-Around Case Management for DDS-Eligible Adults

Findings

DDS-eligible adults who receive funding access services with the support of a DDS Service Coordinator, Support Broker or Autism Specialist who helps manage multiple provider payment models. This Service Coordination function is different than Service Navigation as discussed above in section 5.5.

The current status of service coordination ranges in quality and effectiveness.

Strengths

Service coordination works well when: 1) funding is available; 2) the service coordinator is knowledgeable; 3) the service coordinator has time to manage the adult’s case; and 4) the service coordinator effectively works in conjunction with other agencies, public and private providers, and non-profits. With these elements in place, DDS service coordination can be very helpful and “life changing,” as one adult said.

“Current DDS services have been very helpful in helping her obtain a job and continue to do well at her job. Social companion has also helped as well.”

“Yes, critical to growth, skills acquisition, behavior management, socialization, and emerging independent living skills.”

“Many many other very helpful services. This has been life changing.”

“They are very helpful. They keep my son in the community learning and generalizing skills for safety and community integration.”

“Many service providers are outstanding.”

“Providers and peers that she is currently with are building MUCH NEEDED relationships.”

“The job coach is helpful.”

“Coach is supporting her in college, however, I would love to see a program that meets her needs on campus.”

“Our son is doing very well with our team... I wish everyone could be so lucky!”

“Services provided so far are helpful but not adequate.”

“I am grateful for the services my son receives through DDS. I know there is only a limited amount of money.”

“Yes, the services are of high quality...she is very happy and has gained a lot of skills which will prepare her for her career.”

“Independent living supports provided by [our provider] are great.”

Challenges

It is important to recognize that service coordinators are expected to do an extraordinary number and variety of tasks while ensuring quality for a large client base with limited resources.

Service coordination does not work as it is designed when there is limited funding as discussed above. Furthermore, service coordination breaks down when there are high caseloads, agency-centric planning, and when the adult needs more comprehensive high-quality wrap-around case management services than current service coordination can provide. These constraints result in an enormous burden for families and caregivers, and limit access to the full array of available services.

1) High Service Coordination Caseload

Respondents who were unsatisfied with service coordination reported high caseloads, high staff turnover or shortages, and minimal use of technology.

In 2017, 23 service coordinators and 4 autism regional coordinators were added to address the staff shortage.

“[Need] more funded support case managers that can spend time and get to know the individuals and their families.”

“I gather that they are so overloaded with cases that they find it hard to take and return phone calls without considerable delay.”

“DDS is extremely difficult to work with or to get a straight answer from. Not helpful and always very last minute.”

“[Our autism service center] for our region serves a large geographic area and is not active in our area.”

“Still fighting. System is so difficult to navigate. Parents need to “hound” state employees whose job it is to help us!”

“Spent a morning filling out forms and listening to talk of help going forward. Not a word back since; not a yes/maybe or don’t bother us again.”

“Adult has a service coordinator, who is nice, but she has 70 clients. Doesn’t have time for us really. I can get a few questions answered, but mostly I am floundering and frustrated.”

“Lack of consistent meetings with DDS reps.”

“Why doesn’t DDS allow their Service Coordinators to text with their clients? That is my adult’s preferred form of communication and it’s how most people their age communicate.”

“Use email and other online communications in addition to telephone.”

2) Agency-siloed planning

Respondents reported that the current agency-centric planning whereby they are viewed as a DDS, MRC, or DMH client leads to lack of service coordination across all available public and private resources, and lack of communication and accountability across siloed agencies.

“MRC and DMH will not pay for other services while DDS is in place, even if there is no funding.”

“Department of Mental Health took him on when I couldn’t get DDS.”
3) Need for High-Quality Wrap-Around Case Management Services

Respondents reported that adults often need more comprehensive and individualized case management support than what the current level of service coordination can provide, especially given the challenges outlined above.

Case management is often referred to as “wrap-around services” and in this report it is defined as a dedicated team of autism experts who:

- Have the capacity to provide comprehensive planning and oversight of services and supports across the full range of needs and providers (including all federal, state and local agencies, public/private medical and therapeutic providers, family caregivers, and other natural and community-based supports)

- Provide responsive, personalized daily/weekly support to enable adults to work and live as independently as possible, while effectively managing both lifelong responsibilities and everyday tasks across all domains of adult life

- Implement evidence-based, clinically-informed tools and techniques (e.g., for executive function support) to promote independent living, employment, and social/community engagement to the greatest extent possible; and monitoring the overall health, well-being, and safety of each individual on a consistent and ongoing basis

- Ensure ongoing assessment of functional living skills as they change over time, and modification of the support plan as needed
Overall Burden on Families/Caregivers

The current challenges with service coordination often result in an overwhelming burden on families. Parents described their role as both case managers and service providers. 83% of respondents who reported on behalf of an adult in this survey were mothers, which illustrates the active role mothers still play in their child’s life, even though the child is an adult. More than 76% of caregivers are worried about who will take care of their adult after the caregiver passes away. Case management was reported as a current and life-long need, not just an issue after the adult’s parent/caregiver passes away.

Caregivers Concerned about Coordinating Services for Adult after Caregiver Passes Away

“I am a single mom...living paycheck to paycheck and piecing together multiple sources...I cannot reasonably take on another layer of case management.”

“So far he is with us. I hope we live a long time.”

“Who will support my child when I die?”

“My small family of friends is all my own age...who will take care of me if I outlive them?”

“As care partners (in our seventies) we are a bit exhausted.”
“After finally getting approval...and after years of being up nights losing sleep over what would happen when I was no longer here to take care of him, at least I could have a sigh of relief that should something unexpected happen to me, the DDS would take care of him: provide housing and supports...Then I learned that was not the case....I don’t have a magic pill that will allow me to live indefinitely and see to his needs myself, and I know I am not alone with this dilemma; I just don’t have a solution.”

“I’m concerned for lifelong needs if can’t be self-sufficient and money runs out.”

“I am in my mid-60s and worry about supporting her (emotionally, medically, and financially) after I am gone.”

“Two big concerns: how to manage my finances for my son’s benefit after I die and establishing lifelong support services for him.”

Recommendations to Ensure High-Quality Case Management

- **Support existing service coordination** with adequate funding, reasonable caseloads, training, and inter-agency planning support

- **Provide high-quality wrap-around case management services** as described above, either directly or allow the use of the adult's allocated DDS funding for case management services (see section 5.8)
5.8 Allow DDS-Eligible Adults to Choose Supports and Services They Need within Flexible Guidelines

Findings

As discussed above in Section 3.0, adults on the autism spectrum without an intellectual disability have a unique profile and their needs for services can change in type, intensity, and duration throughout their lifetime. The priority needs for this population include, employment, housing, mental health support and social and community engagement as reported in section 4.0. In addition to the wide variety of currently available services, there is an opportunity to create new services to meet these priority needs.

Strengths - Current Services Received

Respondents reported currently receiving a variety of services which are listed below. The list is not inclusive of all services that DDS or other agencies provide.

All DDS-eligible adults, regardless of whether they are allocated funding, can receive service coordination support, although many were not aware of this service.

DDS stipend
Cash stipend for recreational activities (karate, health club, Special Olympics, YMCA, museum membership, special needs chorus)

Community activities
Reimburse transportation to get to activities in the community
Social activities
Support giver to access services in the community

Educational supports
Specialized vocational/community college education programs and transportation
Reimbursement for trades/job skills classes

Employment supports
Job exploration / job seeking support (resume writing, interviews)
Training (individual, group, on site, and at colleges)
Job coaching (on and off site)
Vocational services
Group employment
Transportation to and from work
Life coaching / mentor services
One-on-one support via various providers

Family support services
Family support center
Support in the home
Respite caregivers
DESE/DDS (at-home supports)
Home security monitoring system

Individual support hours
In-home support (assist with self-care, laundry, house cleaning, food shopping, errands, budgeting, mail, managing medication)
Adult companion

Therapy
Behavioral support
Therapeutic activities (e.g., horseback riding, piano lessons)
Noise cancelling headphones
Referrals to mental health providers

Day programming
Day habilitation

Housing
Shared living
Residential facility
Housing and Urban Development (HUD) subsidized apartment
DMH housing

Transportation
The Ride
Transportation reimbursement
Stipends for ride share app services

37 Day Habilitation (DH) — a service, for individuals with an intellectual disability (ID) or a developmental disability (DD), that is based on a day habilitation service plan that sets forth measurable goals and objectives, and prescribes an integrated program of activities and therapies necessary to reach the stated goals and objectives. MassHealth, Day Habilitation Manual, (Commonwealth of Massachusetts Provider Manual Series, 2018), https://www.mass.gov/files/documents/2018/08/24/regs-dayhab.pdf, Subchapter 4.
Other services that adults found helpful are illustrated by the following quotes:

“I feel very fortunate to live in an area of the state where my school district supports students in transition.”

“We were very lucky to get the Money Follows the Person waiver.”

“Collaboration among medical and mental health providers is essential”

“He is in a supported living community with good case management services. He also receives regular psychotherapy from a psychologist who specializes in high-functioning autism.”

“He has grown so much in Scouts where the model is to educate, demonstrate, guide and evaluate. He does well where he knows the expectations, where people are positive and genuine not condescending or placating him.”

“Council on Aging is helping me with Medicare”

“The Diverse Scholars (MAICEI) program”

**Challenges**

In addition to the variety of services currently received and the positive feedback outlined above, respondents reported numerous challenges with accessing all services they need.

The priority needs – employment, housing, mental health, and social and community engagement – are not being met for many adults, nor is the intensity or frequency of service delivery often adequate as discussed in section 4.0.

Also, adults have difficulties accessing the full array of available supports and services due to the complexity of the system as described in sections 5.5 and 5.7, and not all options are available within the current DDS guidelines.

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“How does anybody do this?”

Recommendations to Improve Use of DDS Funding Allocation

- **Allow DDS-eligible adults to use their allocated funding to choose supports and services they need** from the full array of providers within more flexible guidelines for:
  - Employment
  - Independent Living and Physical Housing
  - Mental Health
  - Social and Community Engagement
  - Case Management
  - Other services to enable adults to live and work as independently as possible and manage lifelong responsibilities and everyday tasks (e.g., transportation, education, family support, mentors)

- **Simplify and provide more administrative support to manage DDS funding allocations** so that adults’ challenges relating to executive function and social communication are accommodated

These recommendations would:

- **Meet the adults’ individual needs**

- **Enable access** to the wide array of public and private services that exist, but are not all currently available within DDS regulations

- **Incentivize providers to create new, innovative services**

- **Ensure quality** because if adults do not receive adequate services, they can easily change providers

- **Enable flexibility** to meet the changing level of needs of adults throughout their lifetime

- **Improve equity** of services received, as individuals could choose services that best meet their own needs

- **Improve timing** between funding and receiving services

- **Reduce burden on adults and families** with effective case management and administrative support with funding
5.9 Build Network of Providers with Expertise in Autism Across Massachusetts

Findings:

Respondents reported the need for qualified and consistent public and private providers across the state. The lack of providers who have expertise in autism, who are authorized state providers or take the adults’ insurance, and who are within geographic reach were common themes. Specifically, the lack of mental health providers for getting a diagnosis and receiving support was evident in this survey with 43% of respondents reporting the need for a psychologist, and 26% needing a psychiatrist. Building and maintaining a quality workforce of providers is an issue across the disability community.40

Findings - Staffing

“[Services are] helpful but staffing is erratic, [and] shortage of qualified support people. Lots of transition with staff members - some drop the ball and there are gaps in services or needs are not being met.”

“We need more providers and more services.”

“5 hours/week someone comes to the house and helps the adults with errands...we are lucky if they show up. We’re not getting the full 5 hours.”

“We are trying agency with choice to hire assistant...[but after not finding] anyone to fill role after 2 months my daughter stays home alone day after day.”

“The services are very helpful [but] the turnover is very high with the staff. After my son has a relationship with the person they seem to leave for a better job opportunity.”

“He needs a mentor but was told they do not have one available; I found one and provided DDS with the information for the past year with no response.”

“[Our current provider] has been incredible. The staff is excellent. We cannot say enough positive things. [Our former provider] was and is useless...what is needed for ASD no ID is very different and individualized. We need life coaches who are accountable to DDS and clients.”

Findings - Expertise of Providers

“Finding skilled, competent and individualized support has been incredibly difficult, even privately.”

“There is such a poor understanding of autism/psychosis. We’ve had to really design our own program!”

“Finding a “talking doc” who understands the needs of folks on the spectrum.”

“Transitioning from pediatrician to adult provider is difficult. Still with pediatrician because comfortable and searching for an adult physician who is Asperger friendly is not possible. Doctors don’t put Asperger/autism info in their biographies.”

“Locating providers who are autism aware and awake.”

“Need people who can manage the complex combination of psychiatric and autistic behavior [this] adult has.”

Findings - Funding for Providers

Anecdotal accounts from providers who participated in the survey design indicated that it is extremely difficult to recruit and keep line staff due to low Medicaid and other agency reimbursement rates and complicated paperwork. This is a disincentive for private practitioners to serve individuals with autism. Some providers lose money by serving DDS or other state agency clients.

Findings - Geographical Limitations with Providers

“Western MA has nothing”

“Services offered, but not where we live. Really need services on Cape Cod.”

“I routinely travel almost 5,000 medical miles in a year [to Boston] because healthcare in Western MA [is not adequate].”
Recommendations to Build Provider Network

● **Build network of public and private providers with specialized expertise in autism ACROSS Massachusetts**
  ○ Pay competitive market-based rates for providers by agencies and private insurance companies
    
    “*If DDS provides a certain amount of money, let the person pick good providers even if the adult with autism has to pay above what DDS allows*”
  ○ Expand existing professional and continuing education programs in autism
  ○ Create autism specialty in the medical and psychological professions
  ○ Incentivize service provider career paths
    
    “*Staff should be offered tuition forgiveness, regular bonuses, a clear career path, and profit sharing so that quality staff can be retained year after year.*”

● **Maximize technology** to increase availability of providers and broaden geographic access to services

● **Expand the role of and fund mentors/coaches** who can provide support with challenges relating to the adults’ unique profile, specifically with executive function issues, and provide overall support and encouragement
6.0 Conclusion

The Massachusetts Autism Omnibus Act of 2014 granted access to public services for adults with autism regardless of their IQ. DDS and other state agencies provide many important services to these adults, when adults can access them.

However, this survey clearly found that access to services remains limited. Key barriers are lack of awareness, lack of overall state funding, difficulty navigating the system, the need for more flexible guidelines so that adults can choose the services they need, and lack of qualified service providers.

This survey also found that adults with autism without an intellectual disability currently have critical unmet needs. These individuals have the potential to work and live more independently, but often need specific targeted support services in order to do so. Regardless of their average or above average IQ, these adults typically have difficulty effectively navigating the demands of employment and independent living due to challenges with social communication, executive function skills, and mental health issues. Their needs vary throughout their lives.

Priority needs include:

1. Obtaining and maintaining employment with an adequate living wage
2. Independent living support and physical housing
3. Mental health support
4. Social and community engagement
5. Transportation

The following recommendations emerged from this survey and are highlighted in this report.

1. Raise awareness/improve outreach to all adults. While many adults are unaware that they can access services through DDS or other agencies, there is also misinformation about eligibility and available services, as well as stigma issues.

2. Ensure adequate funding. The Autism Omnibus Act has never been fully funded, causing some individuals to be deemed eligible for services, but not able to receive services due to lack of funding.

3. Ensure eligibility criteria can accurately identify the needs of this population. Some adults were denied eligibility because they were assessed based on criteria that does not always capture the challenges of people with autism without an intellectual disability.
4. **Streamline the DDS application process.** The application process is confusing for many adults on the autism spectrum which is compounded by difficulty with executive function skills.

5. **Provide high-quality service navigation for all adults and their families regardless of DDS eligibility.** Not all adults or families knew service navigation was available, and they also need application support for state services. Maximizing technology would increase access to information (e.g., one Massachusetts-wide online service directory).

6. **Support existing service coordination for DDS-eligible adults with adequate funding, reasonable caseloads, training, and inter-agency planning support.** Annual funding allocations for each individual should be clearly identified and communicated to the adult ahead of service delivery, to allow planning and continuity of care.

7. **Enable access to wrap-around case management services provided by a dedicated team of autism experts.** High-quality case management would minimize the overwhelming burden on adults and their families to access the complex system and ensure optimal outcomes.

8. **Improve flexibility of service provision.** Given that these adults have variable profiles and thus variable needs, it is important that they can choose the supports and services they need within more flexible guidelines.

9. **Build a network of autism-informed providers.** There is a lack of medical, psychological and other providers who are geographically accessible, are DDS-eligible providers or take insurance, and are knowledgeable about autism.

Serving adults on the autism spectrum without an intellectual disability can enable them to build meaningful, connected lives, and empower them to maximize their strengths and participate in their communities. Many of these adults have the potential to gain competitive employment and be economically self-sufficient when provided with appropriate supports. Ultimately, providing these adults with adequate assistance will not only benefit them and their families, but also provide the Commonwealth with more productive, healthy citizens, who need fewer state resources.

“My son is very bright and very capable of doing SOMETHING worthwhile.”

“Wake up Commonwealth - the tsunami is coming and we are not prepared. We need better services for the adult community...we need to think way outside the box…”
# 7.0 Acronyms / Definitions

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<thead>
<tr>
<th>Acronym</th>
<th>Definition</th>
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<tbody>
<tr>
<td>AANE</td>
<td>Asperger/Autism Network</td>
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<tr>
<td>ABLE</td>
<td>Achieving a Better Life: tax-favored account to cover disability related expenses</td>
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<td>AFAM</td>
<td>Advocates for Autism of Massachusetts</td>
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<tr>
<td>AFC</td>
<td>Adult Family Care or Adult Foster Care</td>
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<td>AHP</td>
<td>Autism Housing Pathways</td>
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<tr>
<td>ASD no ID</td>
<td>Autism Spectrum Disorder without an Intellectual Disability</td>
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<tr>
<td>DDS</td>
<td>Department of Developmental Services</td>
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<tr>
<td>DDS-eligible/accepted adult</td>
<td>An adult who has applied for and been deemed eligible for DDS adult autism services</td>
</tr>
<tr>
<td>DDS-eligible adult enrolled in/receiving services/funded</td>
<td>An adult who has been deemed eligible for DDS adult autism services and receives funding or direct provision of services</td>
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<tr>
<td>DESE</td>
<td>Department of Elementary and Secondary Education</td>
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<td>DH</td>
<td>Day Habilitation</td>
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<td>DHCD</td>
<td>Department of Housing and Community Development</td>
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<td>DMH</td>
<td>Department of Mental Health</td>
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<tr>
<td>DOL</td>
<td>Department of Labor (federal)</td>
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<td>DPH</td>
<td>Department of Public Health</td>
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<td>DTA</td>
<td>Department of Transitional Assistance</td>
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<td>EOEAA</td>
<td>Executive Office of Elder Affairs (part of EOHHS)</td>
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<td>EOHHS</td>
<td>Executive Office of Health and Human Services</td>
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<tr>
<td>FCSN</td>
<td>The Federation for Children with Special Needs</td>
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<td>HCVP</td>
<td>Section 8 Housing Choice Voucher Program</td>
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<tr>
<td>HMEA</td>
<td>Horace Mann Educational Associates</td>
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<tr>
<td>HUD</td>
<td>Housing and Urban Development (federal)</td>
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<td>IEP</td>
<td>Individualized Education Program</td>
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<td>MAC</td>
<td>Massachusetts Advocates for Children</td>
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<td>MAICEI</td>
<td>Massachusetts Inclusive Concurrent Enrollment Initiative Program</td>
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<tr>
<td>MassHealth</td>
<td>Combined Medicaid and Children’s Health Insurance Program (CHIP) in MA</td>
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<tr>
<td>MassHousing</td>
<td>Independent agency providing financing for affordable housing in MA</td>
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<td>MGH</td>
<td>Massachusetts General Hospital</td>
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<td>MRC</td>
<td>Massachusetts Rehabilitation Commission</td>
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<td>SNAP</td>
<td>Supplemental Nutrition Assistance Program (food stamps)</td>
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<td>Social Security Disability Insurance</td>
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<tr>
<td>SSI</td>
<td>Supplemental Security Income</td>
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8.0 Bibliography


AANE works with individuals, families, and professionals to help people with Asperger Syndrome or similar autism spectrum profiles build meaningful, connected lives. We do this by providing information, education, community, support, and advocacy—all in an atmosphere of validation and respect.

Questions or comments please contact:  advocacy@aane.org