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
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 executive summary highlights the survey report findings and is intended to be a resource for policy makers, legislators, agencies, providers, insurers, and organizations that support this population. The full report can be accessed at https://www.aane.org.

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

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1 Individuals 18 years old or older.
**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\(^2\).

- 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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3 “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
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