

Senator Michael Barrett and Representative Kay Khan
Co-Chairs, Joint Committee on Children, Families, and Persons with Disabilities

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My name is Lydia Brown, and I am an autistic¹ and multiply-disabled Massachusetts resident currently attending Georgetown University. I also work as Project Assistant for the Autistic Self Advocacy Network's national office and previously served on the Adult Services Subcommittee to the Governor's Autism Commission.

I am writing in support of the four autism-related bills on the docket for today's hearing:

- H-78 (also S-908), regarding expansion of eligibility for services provided by DDS
- H-76, regarding revisions to Medicaid coverage for augmentative and alternative communication
- H-77, regarding the creation of an integrated confidential data system to track information on service provision for autistic people
- H-75, regarding the creation of a pilot program for employment services for autistic adults

Each of these bills, if passed, will significantly improve the availability of and access to necessary supports and services for autistic people in Massachusetts.

The most important provision of H-76, an Act to provide equal access to medical treatments essential for children with autism, is the requirement for the Massachusetts Division of Medical Assistance to cover the cost of augmentative and alternative communication (AAC) devices. This bill specifically enumerates both dedicated and non-dedicated AAC devices, meaning both those with the sole purpose of functioning as a communication device, and those that have other uses in addition to serving as a communication device, such as iPads and tablets. Many people with intellectual and developmental disabilities, including many autistic people, have significant speech and communication impairments. AAC devices and education for AAC users give non-speaking people or those with limited speech the ability to communicate.

Unfortunately, many disabled people and their families face significant financial barriers to accessing AAC devices or education, which is why many turn to public health insurance options to assist in funding necessary services and supports. This bill will broaden the scope of services currently eligible for funding through Medicaid, which has the potential to improve access to AAC devices for many individuals and families. Access to communication is an integral part of community living, and for those for whom conventional speech is not a reliable or available option, access to AAC can greatly improve quality of life and ability to self-advocate and direct one's services.

H-75 will direct the Rehabilitation Commission to establish a pilot program for employment-related services to autistic adults with the goal of paid, customized, and sustained employment. While not as far-reaching as H-76, the pilot program that H-75 will establish (and has proposed in previous sessions' filings of this bill) a strong precedent for the development of future employment-centered programming targeted toward autistic and other developmentally disabled adults. Autistic adults face

¹ I intentionally use identity-first language (e.g. "autistic person") instead of person-first language (e.g. "person with autism") because I consider autism to be an integral part of my identity in the same way as my race or gender.

many barriers to employment, and are disproportionately unemployed or underemployed; the state has the opportunity to both improve employment outcomes in the short-term for participants in the pilot program and to improve the framework for service provision in the long-term for all autistic adults seeking employment-related services from state agencies.

H-77 will augment the goals outlined in both of the previous bills by directing the Executive Office of Health and Human Services to establish a single integrated data system across all state agencies that serve autistic people. Such a data system will enable the identification of continuing gaps in service provision and new areas potentially in need of reform or reconstruction in order to sustain improvements in access to and scope of services for autistic people in Massachusetts.

Finally, H-78 will overhaul the current eligibility requirements for services offered through the Department of Developmental Services in order to include people with developmental disabilities who do not meet the diagnostic criteria for intellectual disability. The present eligibility criteria require individuals to meet the IQ threshold for a diagnosis of intellectual disability, thus excluding many people with developmental disabilities who do have significant functional impairments from eligibility for services that would be enormously beneficial in improving quality of life and promoting community living.

Massachusetts is one of only four states that continue to use this outdated definition for eligibility to receive adult services. Forty-six other states have revised eligibility criteria for adult services to use a definition of developmental disability in accordance with the federal Developmental Disabilities Assistance and Bill of Rights Act (last amended in 2000), which broadens access to services to include adults with a variety of intellectual and developmental disabilities. In the present system, an enormous number of autistic adults and adults with other developmental disabilities are unable to receive appropriate services from *any* state agency due to these outmoded eligibility criteria. This must change.

Revising eligibility criteria for DDS services to include adults with developmental disabilities is the number one recommendation for policy changes by the Autism Commission, whose report was released this spring. This bill represents an initiative to follow that recommendation, and if passed, will greatly benefit thousands of individuals and families across the state by allowing people to receive the supports and services that they need and to which they have been denied access.

It is imperative that this committee considers the necessity of all four pieces of legislation before you today to systemic improvements for scope of benefits, access to services, and community inclusion for all Massachusetts residents with intellectual and developmental disabilities, and particularly, to autistic residents of the state. These four bills share the common goal of better quality of life, better access to support and services, and better, more inclusive communities. I urge this committee to report these bills favorable and advocate zealously for their passage in general session.

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