



Commonwealth of Massachusetts
Massachusetts Developmental Disabilities Council

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Testimony of Anna Krieger
Joint Committee on Children, Families and Persons with Disabilities
Friday, October 29, 2021
S. 122/H. 261: An Act relative to persons with developmental disabilities

Good Morning Chairperson Gomez, Chairperson Finn, and Honorable Committee Members.

I appreciate the opportunity to address you on an important bill for the disability community, S. 122/H. 261: An act relative to persons with developmental disabilities.

My name is Anna Krieger and I am the Director of Public Policy at the Massachusetts Developmental Disabilities Council. The Council an independent state agency that is federally mandated by the Developmental Disabilities Assistance and Bill of Rights Act to empower intellectually and developmentally disabled people and their families to help shape policies that impact them. We work to promote self-determination, community integration, and inclusion. A central aspect of this work is educating policymakers about issues that impact the disability community, including bills like this one which would improve the system of supports that allow disabled people to live full and inclusive lives.

Currently, under Massachusetts law, many developmentally disabled people are not able to access services and supports they need when they reach adulthood because of their diagnosis. This is because Massachusetts' definition of "developmental disability" is overly restrictive.¹ These measures would amend the law in the Commonwealth to instead use the federal definition² of developmental disability, which is not limited by diagnosis.

(continued)

¹ Mass. Gen. L. Ch. 123B, Sec. 1, "Person with a developmental disability."

² See Developmental Disabilities Assistance and Bill of Rights Act of 2000, 42 U.S.C. § 15002(8). The federal definition is identical to the language in S. 122/H.261 excerpted in the table below.



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CURRENT DEFINITION OF DEVELOPMENTAL DISABILITY <i>(emphasis added)</i>	CHANGE IN S. 122/H.261 TO USE FEDERAL DEFINITION³ <i>(emphasis added).</i>
<p>“Person with a developmental disability”, (1) an individual 5 years of age or older with a severe, chronic disability that: (i) <u>is attributable to a mental or physical impairment resulting from intellectual disability, autism, smith-magenis syndrome or Prader–Willi syndrome</u>; (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: (1) self-care; (2) receptive and expressive language; (3) learning; (4) mobility; (5) self-direction; (6) capacity for independent living; and (7) economic self-sufficiency; and (v) reflects the individual's need for a combination and sequence of special, interdisciplinary or generic services, supports or other assistance that is of a lifelong or extended duration and is individually planned and coordinated....</p> <p>Gen. L. Ch. 123B, Sec. 1</p>	<p>“Person with a developmental disability,” (1) an individual 5 years of age or older with a severe, chronic disability that: (i) <u>is attributable to a mental or physical impairment or combination of mental and physical impairments</u>; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial function limitations in 3 or more of the following areas of major life activity: (1) self-care; (2) receptive and expressive language; (3) learning; (4) mobility; (5) self-direction; (6) capacity for independent living; and (7) 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 a lifelong or extended duration and are individually planned and coordinated....</p> <p>S.122 (at 1, lines 3-12); H.261 (at 1, lines 4-13)</p>

Under the current Massachusetts definition above, people are only considered developmentally disabled if their functional impairments are caused by certain disabilities. The definition breaks down as follows:

- One, the person must have a disability that results in “substantial functional limitation” in three areas of life;⁴
- Two, the person’s disability must reflect a need for certain types of supports and services.⁵
- Third, the person’s impairment and need for services *must be* “resulting from” one of four diagnoses: “intellectual disability, Autism, Smith-Magenis syndrome or Prader-Willi syndrome.”⁶

³ Federal definition of “developmental disability,” Developmental Disabilities Assistance and Bill of Rights Act of 2000, 42 U.S.C. § 15002(8).

⁴ Mass. Gen. L. Ch. 123B, Sec. 1, “Person with a developmental disability” (1)(iv).

⁵ Mass. Gen. L. Ch. 123B, Sec. 1, “Person with a developmental disability” (1)(v).

⁶ Mass. Gen. L. Ch. 123B, Sec. 1, “Person with a developmental disability” (1)(i).

As a result, people who diagnoses are *not* among those listed in the definition are not considered developmentally disabled, even if they otherwise meet the requirements around the functional impairment and need for services.

The narrow definition of developmental disability in Massachusetts law means that if a person does not meet the definition, they cannot get services as adults from the Department of Developmental Services. This leaves behind people with Fetal Alcohol Spectrum Disorder, cerebral palsy, and other developmental disabilities not among those currently listed in the law, despite the fact that they might otherwise meet the criteria. Further, some people who have a functional impairment and need for services do not meet the IQ standard to be considered to have an intellectual disability⁷ under the law, and these individuals would also be unable to access needed services under the current definition.

As you will hear from the community today, the impact of this definition is significant. We know that fetal alcohol syndrome is common for youth in foster care and people in correctional facilities.⁸ Studies have also shown racial and socio-economic disparities in cerebral palsy.⁹ We should not be leaving these and other populations behind as they reach adulthood and are in need of services to live full lives in community, whether those services will help them obtain competitive integrated employment, or find stable housing.

The move to use the federal definition of developmental disability would be in keeping with national trends. At present, Massachusetts' definition is one of the most restrictive.¹⁰ It is time to correct this and move forward so that we are providing services driven by need rather than diagnosis.

The Massachusetts Developmental Disabilities Council believes that S.122/H.261 will move the Commonwealth forward to a more equitable eligibility criteria that allows developmentally disabled people to access services that will allow them to live full, community-based lives. We welcome the opportunity to provide further information to the Committee.

Sincerely,

/s/

Anna Krieger
Director of Public Policy

⁷ Mass. Gen. L. Ch. 123B, Sec. 1, "Person with an intellectual disability"

⁸ National Organization on Fetal Alcohol Syndrome, "FASD: What the Foster Care System Should Know," <http://www.nofas.org/wp-content/uploads/2012/05/fostercare.pdf>.

⁹ Yvonne W. Wu, et al. "Racial, ethnic, and socioeconomic disparities in the prevalence of cerebral palsy." *127 Pediatrics* 3 (2011) (available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3387914/>).

¹⁰ Compare Mass. Gen. L. Ch. 123B, Sec. 1 with, e.g., N.C. Gen. Stat. § 122C-3(12a) (see <https://www.ncdhhs.gov/divisions/mental-health-developmental-disabilities-and-substance-abuse/intellectual-and-developmental-disabilities>); R.I. Gen. L. § 40.1-21-4.3 (2012) (see <https://bhdh.ri.gov/developmental-disabilities/eligibility-and-application>).