



An Update on Advocacy & Successes in Expanding Eligibility for the Department of Developmental Services

(Last Revised. 2/13/13):

The past year, and especially the past six months, has been an active time for DLC in advocating with our constituents for expanding of services of the Department of Developmental Services.

Definition of Intellectual Disability

We first became involved in this issue after representing families affected by rigid eligibility criteria which denied services to individuals with an IQ over 70, regardless of their adaptive or functional skills. Many applicants with a IQ score of 71 or 72 were in great need of DDS services but were denied eligibility regardless of their circumstances. We decided that a systemic solution was needed and began supporting a bill originally filed by Representative Dan Winslow, which became H. 4252 of the 187th (2011-2012) General Court <http://www.malegislature.gov/Bills/187/House/H4252>.

DLC took the lead on legislative advocacy on this measure, while working closely with the Arc of Massachusetts <http://www.arcmass.org/>, and other active supporters, family members, advocates and attorneys.

Meanwhile, DDS was ordered to adopt new regulations, following an Appeals Court decision in a case brought by private attorney Thomas Frain. DLC began working with other stakeholders to oppose the draft regulations issued by the Department. On November 15, 2012, there was a very well attended public hearing with oral and written testimony by family members, advocates and attorneys, including staff of DLC. You can read our written testimony [here](#). Following the public hearing and further reconsideration and reflection, DDS issued new final regulation which largely addressed our previous concerns with the draft regulations.

DDS's new final eligibility regulations(12/21/12) may be found here:

<http://www.mass.gov/eohhs/docs/dmr/reg-115cmr001.pdf>

<http://www.mass.gov/eohhs/docs/dmr/reg-115cmr002.pdf>

<http://www.mass.gov/eohhs/docs/dmr/reg-115cmr006.pdf>

The regulations adopt the definition of intellectual disability (ID) used by the leading research and advocacy organization in the field, the American Association on Intellectual and Developmental Disabilities, or AAIDD, <http://www.aaidd.org/>. We commend the Department for adopting this standard, which is more flexible and holistic, and which considers the limitations in measuring IQ precisely, as well linguistic and cultural factors and other individual circumstances.

After the new regulations were adopted, DLC continued to work on the parallel bill pending in the state legislature. This measure was finally passed, and was signed by the Governor on January 8, 2013, and became law as Chapter 433 the Acts of 2012, available in [pdf](#) and transcribed in [Word](#). This state law now provides additional support for a more flexible and person centered approach to assessing intellectual disability, using the AAIDD standard.

Covering Adults with Developmental Disabilities

More advocacy work remains. One significant problem is that, unlike about 43 other jurisdictions, the Department of Developmental Services in Massachusetts only provides eligibility to adults with intellectual disabilities. For the most part, it does not cover adults with developmental disabilities that cannot establish that they also have an intellectual disability (i.e., an IQ of around 70-75 or below). For example, there are many individuals on the autism spectrum who have IQ scores higher than this, in one or more areas, and are in great need of services, yet they are ineligible in Massachusetts.

To their credit, both DDS and EOHHS have begun exploring solutions to this problem. However, for

individuals utterly without services, and their families, aging caregivers, and advocates, a proactive solution is long overdue. In January 2013, DLC helped research and draft a bill for advocates from autism community, including AANE (<http://www.aane.org/>) which would reconstruct the eligibility criteria for the Department of Developmental Services to include services to both individuals with intellectual disabilities, as well as individuals with developmental disabilities (as defined under federal law). This bill has now been filed as HD 02945 <http://www.malegislature.gov/Bills/188/House/HD2945> and SD 00777 <http://www.malegislature.gov/Bills/188/Senate/SD777>.

On March 27, 2013 the 31 person Autism Commission appointed by Governor Patrick is scheduled to release its report, following over two years of intensive study and investigation. We expect that the Autism Commission's report will recommend expanding DDS's eligibility criteria to include adults with developmental disabilities, including individuals on the autism spectrum. Please stay up to date using the Commission's website, <http://www.mass.gov/hhs/autismcommission>.

In addition, DLC is partnering with the Arc of Massachusetts on advocacy in support of "Bridges to Success", HD 523, <http://www.malegislature.gov/Bills/188/House/HD523>, a transition services bill which also addresses eligibility for persons with developmental disabilities. "Bridges to Success" is intended to help correct the lack of coordination and cooperation in some parts of the state between school districts serving transition age youth in the special education system, and the adult service agencies that will or will not provide services after age 22. This year, "Bridges to Success" has been re-filed and now includes a pilot program to provide eligibility to a limited number of Turning 22 youth with developmental disabilities who cannot also meet the definition of having an intellectual disability. While we prefer the larger systemic solution of HD2945 & SD0777, Bridges to Success also provides an alternative strategy for beginning to address this important problem.

We would urge individuals and families to stay up to date on these important bills through the Arc of Massachusetts website, <http://www.arcmass.org/StateHousePolicy.aspx> and the Arc list serve. Please participate actively in supporting these bills and making your voices heard!