



## Massachusetts Down Syndrome Congress

TO: Members of the Public Health Committee  
FROM: Maureen Gallagher, Executive Director  
RE: H. 3271 An Act concerning nondiscrimination in organ transplantation  
DATE: October 20, 2015

Good afternoon. I am Maureen Gallagher, executive director of the Massachusetts Down Syndrome Congress or, the MDSC, an advocacy organization representing 5,000 Massachusetts families who have a member with Down syndrome. Thank you Chairmen Lewis and Hogan for allowing our priority bill, House 3271 – An Act concerning nondiscrimination in organ transplantation --to be heard today before the Public Health Committee.

The MDSC is the lead sponsor of this bill that is also supported by our national affiliate, the National Down Syndrome Society, the Massachusetts Developmental Disabilities Council (MDDC), who you will hear from today, and the Autistic Self Advocacy Network.

This legislation, filed by our friend, Representative Jim Cantwell, is intended to prevent discrimination against anyone with an intellectual or developmental disability in need an organ transplant. While there have been no previous public reports -- of which we are currently aware -- regarding anyone with an intellectual or developmental disability in need of an organ transplant being discriminated against in Massachusetts, our sole intent is to prevent such a potentially tragic occurrence.

The Rehabilitation Act of 1973 prohibited discrimination on the basis of disabilities by entities receiving federal funds, and the Americans with Disabilities Act of 1990 extended this protection more broadly into other areas of society. However, it has been historically difficult to enforce federal civil rights law within the area of medical decision-making. Due to the lack of medical knowledge on the part of the average patient or family member, people with intellectual or developmental disabilities face limited recourse if denied transplantation or even a referral for consideration for such a procedure.



## Massachusetts Down Syndrome Congress

Life expectancy for people with Down syndrome has increased dramatically in recent decades – from 25 in 1983 to 60 today.

Today, with a continuum of supports both public and private --people with Down syndrome are healthy, active and engaged participants in their communities.

Healthcare and medical science have advanced to the point where people with Down syndrome are thriving. And while we are all so grateful that people with Down syndrome and other intellectual or developmental disabilities live longer, we need to be mindful that as people age, it may come with additional and potentially serious health concerns. Living longer could mean that more people with Down syndrome may be, at some point in their life, in need of an organ transplant.

This legislation is intended to stop the potential for discrimination at the point where a physician declines to advance the patient for referral, or when a transplant center's team of physicians and professional staff makes a decision as to which patient will be placed on an organ transplant waiting list. At either point, there is the potential to reject a patient based upon the misconception that people with intellectual disabilities, such as Down syndrome, are unable to manage the complicated post-operative treatment plans and are therefore less likely to benefit from the transplant.

Providers may also assume that people with disabilities have a lower quality of life and would not benefit as much from the life-saving transplant as people without disabilities. We believe that denying transplantation based upon on either of these false assumptions is tantamount to discrimination.

A 2014 report was written for the Harvard Ethics Leadership Group in response to the Boston Children's Hospital Task Force Request for 'Community Input on the Use of Psycho-Social Criteria, focusing on children with Intellectual or Developmental Disabilities by its advisory committee, the Community Ethics Committee. The committee determined "that no matter how many matrixes and grids were found, we could not judge someone else's quality of life." They added that the psycho-social



## Massachusetts Down Syndrome Congress

criteria commonly used by a transplant center in making the organ transplant listing decision “is problematic and ethically challenging.”

The advisory committee concluded “that all patients with medical need who would receive a sufficient medical benefit should be included in the opportunity to be listed for an organ transplant. Patients with intellectual developmental disorders should not be categorically excluded from that opportunity. We (the committee) have concluded that a decision to list a particular patient on an organ transplant list must be based upon strictly medical eligibility criteria and the insertion of any other criteria must be (a) transparent, (b) justified by its relevance, (c) subject to revision and review, and (d) compliant with values of equity and ethics.”

The 2004 National Work Group on Disability and Transplantation survey reported that only 52% of people with intellectual or developmental disabilities orders requesting referral to a specialist for evaluation receive such a referral, and approximately one-third of those for whom referral was provided are never evaluated. No medical justification exists for these patterns of discrimination. According to a 2006 review of the available research literature in Pediatric Transplantation, little scientific data exists that might support the idea that intellectual or developmental disability would constitute a heightened risk of poorer outcomes in the aftermath of a transplantation procedure, provided necessary supports in postoperative regimen compliance were provided.

As I previously stated, while we aware of no publicly-reported cases of discrimination against a Massachusetts resident with an intellectual or developmental disability, there have been several cases reported in California, New Jersey and New York, to name a few. In 1995, a 34 year-old woman from California with Down syndrome and a terminal heart condition was referred by her physician for a combined heart and lung transplant. The state’s two transplant centers denied the procedure, one without ever meeting or examining the patient, and the second center concluding that she was unable to follow the complex post-operative care that would be required of her. After the story went public and there was substantial public backlash, one of the centers reversed its decisions. A similar case was made public in New York, when a young



## Massachusetts Down Syndrome Congress

toddler with a developmental disability was denied a heart transplant. Fortunately, this child had a mother who would not accept the doctors' repeatedly rejections. She searched for a hospital – and found one in Boston – that performed a successful transplant on her young child. And in New Jersey, the mother of a three year-old child with an intellectual disability in need of a kidney transplant took her case public. A very loud public outcry prompted the hospital to reverse its denial and the little girl is thriving and growing following a successful kidney transplant in 2013.

In all of these cases it was the patient's caretaker who acted as the relentless advocate for the patient. They armed themselves with education and against all odds accepted the challenge of fighting the system. The fact is, few people with intellectual or developmental disabilities have such a champion and must resort to accepting denial of a lifesaving transplant.

California, New Jersey and Maryland have all passed legislation banning organ transplant discrimination and similar legislation has been introduced in Pennsylvania.

The intent of our bill, H3271 is to:

Clarify that doctors, hospitals, transplant centers and other health care providers are prohibited from denying access to necessary organ transplants solely on the basis of a qualified individual's disability;

Require that health providers consider, in evaluating the likelihood of a transplant's success, the full range of supports available to help a person with a disability manage their post-operative care;

Include a fast-track procedure for challenging discrimination to ensure that people in urgent need of an organ transplant can obtain timely resolutions to their claims.

The MDSC is asking that Massachusetts not wait for a catastrophic emergency to protect its citizens and families with intellectual or developmental disabilities from



## Massachusetts Down Syndrome Congress

blatant discrimination. This is a matter of equity, fairness and compassion for those whose voices are too often silent.

On behalf of our entire organization, we thank you for taking the appropriate steps in ensuring a timely approval of this bill.

For further comment, you can reach MDSC Executive Director Maureen Gallagher at 781-221-0024 x201 or [mgallagher@mdsc.org](mailto:mgallagher@mdsc.org).