

## Legislation Prohibiting Discrimination against Potential Organ Transplant Recipients on the Basis of Disability

### Issue

In 2004, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) expressed concern that many people with disabilities are “denied evaluation and referral for transplantation.”<sup>1</sup> According to a web-based survey of persons with disabilities and their family members conducted by the National Work Group on Disability and Transplantation via the Arc of the United States’ website, 80% of the 205 respondents believed that individuals with intellectual disabilities are discriminated against regarding access to organ transplant operations. The results of this survey are supported by 20 published studies which also address the issue of accessibility of people with intellectual disabilities to transplant operations.<sup>2</sup> In response to these findings, JCAHO expressed their concerns that many with disabilities are denied evaluation and referral for transplantation at the primary care level.

### Concern

Although people with intellectual disabilities have had increased access to organ transplants since the 1990s, many individuals with disabilities continue to experience discrimination when attempting to access critical health care services. The Arc of New Jersey is concerned that people with disabilities continue to be denied life-saving organ transplants based on outdated and erroneous assumptions that individuals with disabilities have a poor quality of life and are thus less worthy of critical health services, that they are unable to understand the process of transplantation, and that they are incapable of complying with complex post-transplant medical regimens, or lack the supports do to so.<sup>3</sup> In reality, survival rates of transplant recipients with intellectual disabilities are comparable to the nationally reported rates for the general population at follow-up intervals of 1 and 3 years, indicating that recipients with intellectual disabilities are able to adhere to post-transplant medical regimens whether on their own or with the support of family members or caregivers.<sup>4</sup>

### Recommendation

The Arc of New Jersey urges you to support A2390/S1456. This bill would prohibit discrimination against potential organ transplant recipients on the basis of mental or physical disability. Passage of A2390/S1456 would help ensure that New Jersey residents with intellectual and developmental disabilities who require an organ transplant are not discriminated against on the basis of their disability and have equal access to this life saving treatment.

<sup>1</sup> Joint Commission on Accreditation of Healthcare Organizations (2004) “Health Care at the Crossroads: Strategies for Narrowing the Organ Donation Gap and Protecting Patients.” [http://www.jointcommission.org/assets/1/18/organ\\_donation\\_white\\_paper.pdf](http://www.jointcommission.org/assets/1/18/organ_donation_white_paper.pdf)

<sup>2</sup> Martens, Marilee, Linda Jones and Steven Reiss (2006) “Organ transplantation, organ donation and mental retardation.” *Pediatric Transplantation*. Volume 10, pages 658-664. <http://nisonger.osu.edu/papers/LWSarticle.pdf>

<sup>3</sup> Pannocchia, N., Bossola, M., and G. Vivanti (2010) “Transplantation and mental retardation: What is the meaning of discrimination?” *American Journal of Transplantation*; Volume 10, pages 727-730.

<sup>4</sup> Martens, Marilee, Linda Jones and Steven Reiss (2006) “Organ transplantation, organ donation and mental retardation.” *Pediatric Transplantation*. Volume 10, pages 658-664. <http://nisonger.osu.edu/papers/LWSarticle.pdf>