



## Charlotte Woodward Organ Transplant Discrimination Prevention Act (H.R. 1520)

### Fact Sheet

The National Down Syndrome Society (NDSS) has long advocated for organ transplant discrimination prevention initiatives due to the prevalence and impact the issue has on the Down syndrome community. In 2019, the National Council on Disability (NCD), an independent federal agency, released a report on organ transplant discrimination against people with disabilities. Below are key findings.

- The **Americans with Disabilities Act** and **Section 504** of the Rehabilitation Act prohibit organ transplant centers from discriminating on the basis of disability, however, discrimination persists.
- **Healthcare provider bias** has affected organ transplant decisions negatively for people with disabilities for as long as there have been organ transplant procedures.
- People with disabilities, especially intellectual disabilities, have been denied access to organs because of **subjective judgements** about the value of a life with a disability, **assumptions** about their quality of life, and **misconceptions** about their ability to comply with post-operative care.
- Organ transplant programs have policies that exclude people with disabilities as candidates for a transplant - some with **categorical exclusions** based on disability, refusing to even evaluate a person's medical suitability for an organ transplant because of their disability.
- Only **52%** of people with disabilities who requested a referral to a specialist regarding an organ transplant evaluation actually received a referral, while **35%** of those "for whom a transplant had been suggested" never even received an evaluation.
- A survey of pediatric transplant centers found that **43%** always or usually consider intellectual disabilities an absolute or relative contraindication to transplant due to assumptions about quality of life.
- About **60%** of transplant centers report having serious reservations about giving a kidney to someone with a mild to moderate intellectual disability.

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