

# Organ Transplantation and People with I/DD: A Review of Research, Policy and Next Steps

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## Introduction

Since organ transplantation was introduced as a viable treatment option, people with disabilities have faced significant barriers to accessing the life-saving procedure. The Rehabilitation Act of 1973 prohibited discrimination on the basis of disability by entities receiving federal funds, and the Americans with Disabilities Act of 1990 extended this protection more broadly across other areas of society. However, it has historically been 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 I/DD often face little recourse when denied transplantation or even referral for consideration for such a procedure. In the last twenty years, some progress has been made on this issue, yet the need for further action on the part of activists and policymakers remains exceptionally clear.

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## Background

### People with I/DD and Organ Transplantation: A History of Discrimination

In 1995, Sandra Jensen, a 34-year old woman with Down Syndrome and a terminal heart condition, was referred by her physician for a combined heart and lung transplant as the only available means of saving her life<sup>1</sup>. Her insurer—the California State Medicaid system—approved the procedure with the requirement that it be performed at one of California’s two designated transplant centers. Both centers refused to approve Sandra for transplantation, each providing its own reason for refusal. The first hospital refused Sandra’s request without ever meeting or examining her, indicating that people with Down Syndrome were considered categorically inappropriate for heart/lung transplants<sup>2</sup>. The second found no medical basis for excluding Sandra, but refused her nonetheless, concluding that her condition made her unable to follow the complex post-transplantation medical regimen that would be required of her<sup>3</sup>.

*The Autistic Self Advocacy Network (ASAN) is a non-profit organization run by and for autistic people. ASAN provides support and services to individuals on the autism spectrum while working to change public perception and combat misinformation. Our activities include public policy advocacy, community engagement to encourage inclusion and respect for neurodiversity, quality of life oriented research and the development of autistic cultural activities. [www.autisticadvocacy.org](http://www.autisticadvocacy.org)*

Sandra's case inspired a national outcry, in part because of her past work on behalf of disability rights causes and because of the efforts of Dr. William Bronston, her treating physician. Eventually, one of the hospitals in question relented and Sandra did receive a life-saving heart/lung transplant, becoming the first person with an intellectual disability to receive such a procedure. Although other people with I/DD have received transplants since Sandra, the practice of discrimination remains widespread. Sandra's case illustrates the issues facing people with I/DD seeking transplantation services. Grounds for refusal are various and it is often difficult for the average observer to differentiate between discriminatory practice and clinical judgment.

Consider the two hospitals where Sandra sought transplants and their different reasons for denying her. The first was an obvious case of discrimination—a judgment on the part of a medical institution that certain individuals are unworthy of the scarce resource of organ transplants. Surprisingly, such a perspective is considered legitimate in many medical circles. In 2001, the British Medical Journal published an editorial from Dr. Julian Savulescu, Director of Ethics at Murdoch Children's Research Institute at Royal Children's Hospital in Melbourne, Australia. In the piece, Dr. Savulescu argues that quality of life considerations—include the presence or absence of intellectual disability—should be utilized to determine who has access to scarce medical resources, such as organ transplantations. To quote the article, "With a severe shortage of hearts, transplanting a child with Down's syndrome implies that a child without Down's syndrome will die who would otherwise have received a transplant.... It is probably unlawful to place lower priority on children with Down's syndrome and other disabilities who need heart transplants. But is it unethical?" Fundamentally, when physicians argue for denying transplants to people with disabilities, they are saying that non-disabled lives are more worth saving than those of disabled people.

Such views are not isolated and have emerged much more recently. In the midst of a 2012 case involving a young Autistic adult seeking and being denied access to a heart transplant, Arthur Caplan, the Director of Medical Ethics for New York University's Langone Medical Center, wrote in a Medscape editorial, "If the potential recipient is severely intellectually impaired, or is basically almost in a coma, I do not think it makes sense to consider that child for a transplant either<sup>5</sup>." While Caplan goes on to stress that no diagnosis should categorically exclude an individual from transplantation and states that he believes that physicians currently "discriminate too much", his underlying point is clear: both due to increased difficulty with post-operative procedures and as a function of quality of life, some people with I/DD should not be considered for organ transplants.

### **Does the Data Prove Discrimination Against People with I/DD in Organ Transplantation?**

Data suggests that discrimination against people with I/DD in access to organ transplants does exist and continues to hold. A 1992 survey of 411 transplant centers by Levenson and Olbrisch found that individuals with IQs between 50 and 70 would be considered absolutely contraindicated from receiving a heart transplant in 25% of transplant centers, with 59% stating a relative contraindication<sup>6</sup>. When the same question was asked for patients with IQs under 50, almost 3 in every 4 transplant centers indicated an absolute contraindication<sup>7</sup>. More recent data supports these concerns as well, while suggesting that some progress has been made since the Levenson and Olbrisch's 1992 survey.

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A 2008 survey of 88 transplant centers conducted by researchers at Stanford University found that 85% of pediatric transplant centers consider neurodevelopmental status as a factor in their determinations of transplant eligibility at least some of the time, with heart transplant centers being more restrictive in their decisions than kidney or liver programs<sup>8</sup>. For example, 46% of heart programs indicated that even mild or moderate cognitive impairment would be a relative contraindication to eligibility, whereas no liver or kidney programs considered such levels of impairment to be a relative contraindication. 71% of heart programs surveyed always or usually utilized neurodevelopmental status in determinations of eligibility for transplantation, while only 30% and 33% of kidney and liver programs utilized such factors. Evidence suggests that insofar as progress in addressing discriminatory practice has been made, it has been weakest in the context of heart transplantation. The International Society for Heart and Lung Transplantation's heart transplantation criteria specifically states, "Mental retardation or dementia may be regarded as a relative contraindication to transplantation<sup>9</sup>."

Notably, 62% of all programs indicated that informal processes guided their use of neurodevelopmental status as a decision-making factor and no programs described their process as "formal, explicit, and uniform"<sup>10</sup>. As a result, it is often difficult to prove discrimination on the part of transplant centers. Decision-making done on the basis of disability can often be officially attributed to non-discriminatory motives, due to the largely opaque process of medical judgments. Case studies on priority setting in access to heart transplants bear this out, noting that subjective factors influence clinical decision-making, leading to "unfair and inconsistent decisions" across various settings<sup>11</sup>. Many potential transplant recipients never get as far as evaluation by a transplant center. The 2004 National Work Group on Disability and Transplantation survey reports that only 52% of people with I/DD requesting referral to a specialist for evaluation receive such a referral, and approximately a third of those for whom referral is provided are never evaluated<sup>12</sup>.

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<sup>13</sup>.

There are over fifty published cases of kidney transplants for people with intellectual disabilities<sup>14</sup>. Success and medical adherence rates are comparable to that of the general population<sup>15</sup>, though access to sufficient support from a family member or caregiver is a factor in medical adherence<sup>16</sup>. A 2006 Japanese study found that of 25 patients with intellectual disability who had received renal transplantation, all persons providing primary support to the recipients of transplantation found that quality of life was significantly improved for the recipients and caregivers<sup>17</sup>. To quote a 2010 review in the *American Journal of Transplantation*, "Currently, there is no scientific evidence or compelling data suggesting that patients with MR should not have access to organ transplantation<sup>18</sup>."

The presence of widespread explicitly discriminatory practice against people with I/DD seeking organ transplants is profoundly concerning. Of equal concern, however, is the second rationale offered to deny Sandra Jensen and others like her access to

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transplantation. This concern—focused on the ability of patients with I/DD to manage their own postoperative care—is somewhat less straightforward and thus harder to combat. That people with intellectual and developmental disabilities may struggle to comply with a complex and long-term post-operative procedure is not a controversial proposition. As a result, many opponents of allowing people with I/DD access to transplantation have depended on this as rationale<sup>19</sup>. And yet, support services enable people with I/DD to successfully participate in all manner of life experiences that might not be feasible unsupported, ranging from inclusive educational settings at both the K-12 and higher education levels to integrated employment opportunities. The American Society of Transplantation recommends that renal transplant candidates who might be unable to provide informed consent for the transplantation procedure and postoperative medical regimen requirements be assessed for “the presence of a reliable primary support person<sup>20,21</sup>.” That successful compliance with a postoperative medical regimen can be included within this scope of “supportable” activities should elicit no surprise whatsoever<sup>22</sup>. Further efforts to educate clinicians and disability service providers as to the availability and nature of such support services should be a high priority for future systems change activities.

### Implications for law and practice

Like the Jensen case, more recent national conversation on discrimination in organ transplantation has been shaped by public outrage at high profile cases of discrimination. In January 2012, the family of Amelia Rivera—a 3-year old child with intellectual disability and Wolf-Hirschhorn syndrome—was told by Children’s Hospital of Philadelphia (CHOP) that she was considered ineligible for kidney transplantation as a result of her disability<sup>23</sup>. National outcry ensued, resulting in CHOP reversing its decision. Later that year, a similar case developed centered around Paul Corby—a 23-year old adult on the autism spectrum—who was denied a heart transplant as a result of his disability<sup>24</sup>. Although it also sparked national outcry, Paul’s case failed to result in a reversal on the part of the hospital—Penn Medicine—that denied him. The divergent outcomes of these two cases suggest that an ad hoc approach to fighting discrimination against people with I/DD in organ transplantation remains insufficient. A systemic law and policy response remains critically important.

### Policies Regarding Organ Allocation and Waiting Lists

Policies regarding the allocation of donated organs and tissue differ depending on the type of organ or tissue in question. Local, regional, and national waiting lists of potential recipients are organized by priority, using complicated point systems. The greater the number of points that are associated with a potential recipient, the higher priority that potential recipient has on the list. Factors that affect the number of points an individual has include mortality risk (the probability that he or she will die without the new organ) and age. People with higher mortality risk are higher priority, and children are higher priority than adults. Priority on the waiting list is determined by factors pertaining to each individual. The “list” is really a registry or database of patients and their medical information. Potential recipients are **not** ranked in comparison to each other, and their place on the list does not shift when other people receive transplants.<sup>25</sup>

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The process of actually getting onto a local, regional, and/or national waiting list for donated organs occurs at the individual level, and is facilitated between hospitals, physicians, and patients. In order to get on a transplant waiting list, a patient must receive a referral from his or her physician articulating the medical need for an organ transplant. He or she must seek out a hospital that facilitates and performs transplants, and undergo evaluation to determine if he or she is a viable candidate for transplantation. The hospital's transplant team—a panel of physicians and other professionals involved in the transplant process—makes the ultimate decision as to whether an individual is a good candidate, and they either add the person to waiting list or refuse access to the list depending on their decision. As a result, efforts to address discrimination against people with I/DD in accessing organ transplantation must focus on both discriminatory referral practices and the transplant center evaluation process. To accomplish this, a number of policy options present themselves.

### **State Legislation**

In the aftermath of Amelia Rivera's case, state legislators in New Jersey introduced legislation (A2390/S1456) to prohibit discrimination against people with disabilities in the context of organ transplantation. The legislation—which as of this writing has passed the New Jersey State Senate and cleared an Assembly Committee—prohibits denying a person with a disability referral, evaluation and recommendation for transplantation solely on the basis of a non-medically significant disability and notes that individuals who have the necessary support system to comply with post-transplant medical requirements should not have the inability to independently comply with those requirements held against them when being evaluated for transplantation consideration. The legislation is based on a similar law passed in California in the aftermath of the Sandra Jensen case<sup>26,27</sup>. If passed, the New Jersey bill would open up new policy momentum regarding disability rights in the context of organ transplantation, addressing both of the major barriers to transplant consideration for people with I/DD.

### **ADA/504 Enforcement**

Although health care providers are already prohibited from discriminating on the basis of disability on the grounds of both the Americans with Disabilities Act and Section 504 of the Rehabilitation Act, insufficient guidance has been provided to the field as to what actions would and would not constitute discrimination under ADA/504 within the context of organ transplantation. Many clinicians presume that, given the subjective nature of clinical judgment regarding organ transplantation decisions, disability civil rights laws may not be relevant or applicable. It is imperative that clear policy be provided that stipulates that this is not the case.

Organ and tissue donation is one of the most highly regulated areas of health care. The federal agency responsible for overseeing the transplant system in the United States is the Health Resources and Services Administration (HRSA). The following agencies also play a role in the system: Centers for Medicare and Medicaid Services (CMS), Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH), Agency for Healthcare Research and Quality (AHRQ), and the Food and Drug Administration (FDA). All of these agencies are part of HHS. Section 1138 of the Social Security Act requires hospitals receiving Medicare and Medicaid reimbursements to be members

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of the Organ Procurement and Transplantation Network (OPTN), a private non-profit entity contracted with by HHS to administer and maintain a national system of organ procurement and allocation<sup>28</sup>. Although OPTN has the ability to develop and promulgate practice guidelines and a process to turn them into HHS regulations, until such time as the HHS Secretary approves and promulgates OPTN's guidelines into regulation, its determinations have no legal authority. As a result, HHS has significant influence over OPTN and the national organ procurement and allocation system.

Given its oversight role over transplant centers, HRSA's Division on Transplantation is a likely choice to take the leadership role in crafting guidance in collaboration with the HHS Office on Civil Rights (OCR) and CMS. Consideration should be given to issuing a "Dear Colleague" letter or other clear guidance to the field outlining the requirements of the ADA/504 as applied to the topic of organ transplantation. Such a letter should explicitly prohibit discrimination on the basis of a non-medically relevant disability, clarify that the need for available support services to comply with a postoperative medical regimen should not be counted against a person with a disability in consideration for a transplant, and describe the scope of covered decision-making and processes. Such scope should include at minimum the four areas outlined in California's current statute prohibiting disability discrimination in organ transplantation: "(1) The referral from a primary care provider to a specialist; (2) The referral from a specialist to a transplant center; (3) The evaluation of the patient for the transplant by the transplant center; (4) The consideration of the patient for placement on the official waiting list<sup>29</sup>."

### **Availability of postoperative support services**

The ADA's prohibition on disability discrimination is only applicable insofar as a disability is not medically relevant to the success or failure of the organ transplant. In light of that, focus must also be given to ensuring the availability of necessary postoperative support services to ensure that people with I/DD are provided support for managing ongoing and long term postoperative medical procedures associated with their new organ. Such efforts will require both policy and practice approaches. With regards to policy, CMS should explicitly clarify within its technical assistance to states that both acute care services and long term services and supports funded via the Medicaid program will support assisting an individual who requires it with postoperative medical care after an organ transplant. At the same time, private foundations and community organizations must mobilize to develop enhanced provider competency to manage and implement said support services. The emergence of organizations like the American Academy of Developmental Medicine and Dentistry (AADMD) and other similar disability focused health care initiatives represent a positive trend in facilitating greater provider interest in education surrounding the unique health care needs of this community.

### **Representation of Disability in Bioethics**

As documented earlier in this policy brief, overt discrimination against people with I/DD in health care contexts is not only a reality but one that remains actively defended by leading practitioners and academics in the world of bioethics. Such discourse has a profound impact on a field with limited legal oversight and a culture of high deference to clinical judgment and subjective determinations of quality of life. Many

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concepts in applied and academic bioethics explicitly discriminate against people with disabilities by design. For example, the British National Health Service utilizes the Quality Adjusted Life Year (QALY) system to determine how to allocate scarce medical resources, including organ transplants. The QALY system assesses the relative worth of a year of life with a particular medical condition, disability or functional impairment as compared to the worth of a “healthy” year. For example, the QALY adjustment for a moderate mobility impairment is 0.85, meaning that the British health system will value extending the life of a non-disabled, healthy adult for 8.5 years as equivalent to extending the life of an adult with a moderate mobility impairment for 10 years<sup>30</sup>. That this system discriminates against people with disabilities is self-evident.

The State of Oregon briefly attempted to utilize the QALY system as the basis for an early health reform plan—the Oregon Basic Health Services Act of 1989. This effort was halted due to a refusal on the part of the first Bush Administration to issue a necessary Medicaid waiver on the grounds that the QALY system constituted a violation of the ADA<sup>31</sup>. Though the QALY system was not allowed to proceed in Oregon, its principles are still defended by many with influence in American health policy. As recently as 2005, the American Medical Association’s Journal of Ethics’ *Virtualmentor.org* website published a commentary arguing that the QALY system should have been considered “responsible” and “defensible” in the context of Oregon’s proposed health plan<sup>32</sup>. Of even greater concern is the existence of the World Health Organization (WHO) Disability Adjusted Life Year (DALY) system, which operates on the basis of similar principles and is utilized widely in global public health conversations<sup>33</sup>. The mainstream acceptance of quality metrics that explicitly devalue the lives of people with disabilities should be a cause of grave concern to disability rights advocates. As legal, legislative and professional development strategies are pursued to secure policy change in the context of organ allocation and other areas of health care policy, a robust disability rights critique in bioethics must be supported and cultivated. Only through such strategies will the disability rights movement make progress in shifting “hearts and minds” in the medical community, a necessary complementary measure alongside the establishment of new legal requirements and practical resources.

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## Summary of Recommendations

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Effective action to address the issue of discrimination against people with I/DD in organ allocation will require steps on the part of multiple stakeholders. The evidence outlined in this policy brief suggests that the following components will be key:

**FIRST**, states should follow California’s example and pass legislation explicitly clarifying legal protections against discrimination for people with disabilities seeking organ transplants. Such legislation should explicitly include the following points: a) a prohibition against discriminating against people with disabilities that are not medically relevant to the transplantation process; b) clarification that support services should be considered when assessing the ability of a transplantation candidate to comply with postoperative procedures, and c) the scope of services and health care interactions relevant to the law, including referrals, evaluation and recommendation for access to the transplantation list.

**SECOND**, HHS should seriously consider issuing guidance to the field explicitly clarifying the applicability of the ADA and Section 504 to organ transplantation settings, indicating examples of acceptable and unacceptable criteria for evaluation and clarifying that non-medically relevant conditions, including I/DD, should not be held against an individual in seeking access to organ transplantation. In conjunction with this, the HHS Office of Civil Rights to seek to enforce the ADA and 504 to organ transplantation settings in collaboration with the I/DD community.

**THIRD**, both policymakers and national leaders in the I/DD community should consider measures to elevate the priority of services designed to assist people with I/DD in postoperative care management. The availability of such services—and the willingness of the Medicaid program to pay for them—will play a critical role in clinical decision-making as to the suitability of organ transplantation for people with I/DD. Of particular concern is the need to build a competent provider network aware of these services and prepared to integrate them within the broader scope of Home and Community Based Services available to people with I/DD. Researchers have documented for some time that people with I/DD face diminished quality in acute care in many community-based settings, reinforcing the need for additional efforts to close health disparities as a vital component of the larger de-institutionalization project. Attention to care management strategies for people with I/DD is an integral aspect of this work. Particular emphasis should be given to building collaborative relationships between clinicians, self-advocate groups, family organizations and managed care organizations towards this end.

**FOURTH**, the I/DD community must learn to effectively defend its interests in the bioethics realm. Growing numbers of hospitals, medical schools and other health care settings make use of the bioethics literature as a tool for setting standards and guiding clinical judgment. Given the difficulty in determining if a clinical judgment on the part of a health care provider was made for legally permissible or impermissible reasons, proactive efforts to influence the world of ideas in healthcare decision-making are absolutely essential. Consideration should be given to the establishment of infrastructure for advancing a disability rights critique in bioethics. Possible measures include the establishment of a journal focusing on these issues from a disability rights perspective, additional support to the publication efforts of researchers and academics friendly to the disability rights perspective, the organizing of a conference on disability rights priorities in bioethics to allow for coordination and discussion between activists and academics and a wide variety of other social change strategies. To succeed in accomplishing our objectives, the disability community must consider tactics focused on influencing both public policy and the cultural and scientific discourses that precede and shape the actions of government.

**FIFTH**, additional resources must be given to providing people with I/DD and their families with advocacy services to fight discrimination when it becomes apparent. Since 1975, the Protection and Advocacy agencies located in every state and territory have provided a consistent, high quality network of federally mandated advocacy organizations focused on provided legally-based advocacy services to people with disabilities. Congress should allocate additional fiscal resources to Protection and Advocacy agencies to monitor hospitals, medical establishments and other medical entities, train provider groups, and investigate potential violations of the civil and human rights of individuals with disabilities in regards to due process protections within health care settings.

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These issues are by no means new, and progress towards achieving the community's goal of equal access to services will take time and additional investment on the part of activists, self-advocates, family members, service providers and others. Yet, the progress shown since Sandra Jensen's initial experience with discrimination demonstrates that change can be made in this area. By pursuing a multi-pronged strategy focusing on enforcement of existing federal civil rights law, the development and passage of new state legislation, provider education and a renewed investment in defending the inherent worth of all lives in the realm of ethics, we can fulfill the promise of the ADA in the realm of health care. In pursuit of the long sought after dream of equal access and equal rights under the law, the disability community stands united. Such unity signifies great promise for the years ahead.

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