



# Children With Intellectual and Developmental Disabilities as Organ Transplantation Recipients

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The demand for transplantable solid organs far exceeds the supply of deceased donor organs. Patient selection criteria are determined by individual transplant programs; given the scarcity of solid organs for transplant, allocation to those most likely to benefit takes into consideration both medical and psychosocial factors. Children with intellectual and developmental disabilities have historically been excluded as potential recipients of organ transplants. When a transplant is likely to provide significant health benefits, denying a transplant to otherwise eligible children with disabilities may constitute illegal and unjustified discrimination. Children with intellectual and developmental disabilities should not be excluded from the potential pool of recipients and should be referred for evaluation as recipients of solid organ transplants.

## INTRODUCTION

The American Academy of Pediatrics policy statement “Pediatric Organ Donation and Transplantation” published in 2010 provides recommendations to promote awareness for increased organ donation and the role of organ donation as an integral part of end-of-life care but does not discuss recipient candidacy and eligibility.<sup>1</sup> The demand for transplantable solid organs far exceeds the supply of deceased donor organs. Patient selection criteria are determined by individual transplant programs. Given the scarcity of solid organs for transplant, organs are allocated to those most likely to experience maximal benefit, taking into consideration both medical and psychosocial factors. Historically, patients with intellectual and developmental disabilities (IDDs) have often been excluded as potential recipients of organ transplants. The issue of intellectual disability (ID) in donors is not in the scope of this statement. IDD is defined as “a group of developmental conditions characterized by significant impairment of cognitive functions, which are associated with limitations of learning, adaptive behaviour and skills.”<sup>2</sup> Patients with an

## abstract

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autism spectrum disorder can also be considered to have an IDD. IDDs may be secondary to genetic syndromes, chromosomal abnormalities, exposures during pregnancy (fetal alcohol syndrome, exposure to teratogenic drugs or toxins), congenital anomalies, intrauterine insult (stroke, placental problems), or postnatal insults (infections, trauma).

Intellectual impairment refers to deficits in general mental abilities, including reasoning, planning, problem-solving, abstract thinking, academic learning, and learning from experience, and is commonly defined as an IQ of  $\leq 70$ . Adaptive functioning deficits refer to impairments in social, conceptual, and practical skills needed for self-care, self-direction, communication, home living, use of community resources, and functional academic skills.<sup>3</sup> In the case of developmental disabilities, it is recognized that cognitive testing alone is inadequate to characterize a person's level of disability. More important is the individual's level of adaptive functioning, which describes the skills with which an individual lives in his or her environment.<sup>4</sup>

People may function at, above, or below what would be expected on the basis of their cognitive ability, largely as a result of the quality of the environmental supports they receive. In this way, disability is a social construct; people with a physical or cognitive difference are also disabled by the inability of society to support them. Studies that do not take into account adaptive capabilities find a higher prevalence of ID than those taking into account a person's adaptive capability or level of functioning.<sup>5</sup> It is this larger view of adaptive functioning that should be examined as part of the transplant evaluation.

Richards et al<sup>6</sup> highlighted the inconsistencies across major pediatric transplant centers in how the presence of IDD is used as a criterion

in the listing decisions for solid organ transplant. Thirty-nine percent of programs stated that they consider IDD "rarely" or "never" in the listing process, whereas 43% of programs "always" or "usually" do. The degree of a patient's delay also affects the listing decision, with 14% of programs reporting mild or moderate IDD as a relative contraindication to listing and 22% reporting that IDD was "irrelevant" to the listing decision. There was also discordance among the solid organ programs (heart, liver, and kidney). Heart programs tend to consider neurodevelopmental status more often in their listing decisions compared to liver and kidney programs, which use IQ more restrictively.<sup>6</sup> The official guidance from the International Society for Heart and Lung Transplantation does specifically mention "mental retardation" as a relative contraindication to heart transplant.<sup>7</sup> The inconsistencies among programs serve to highlight that the use of the criterion of neurodevelopmental delay for listing is heterogeneous, likely reflecting individual programmatic biases.<sup>6</sup>

The Americans with Disabilities Act (ADA)<sup>8</sup> and the Rehabilitation Act<sup>9</sup> prohibit disability-based discrimination by doctors' offices, state-run hospitals, and recipients of federal funding, including health care providers who are paid through Medicaid or Medicare and organizations funded through federal contracts such as the United Network for Organ Sharing (UNOS). The Organ Procurement and Transplantation Network (OPTN) is the nation's organ procurement, donation, and transplant system.<sup>1</sup> It is overseen by the US Department of Health and Human Services (HHS). UNOS is the nonprofit organization that operates the OPTN under a contract from the federal government. All organ procurement organizations and transplant programs in the United

States are OPTN and/or UNOS members and follow OPTN policies.<sup>1</sup>

Discrimination under the ADA includes both the refusal to provide services to qualified individuals with disabilities and refusal to make reasonable modifications in policies and practices that are necessary to ensure people with disabilities may access services. When transplant is likely to provide significant health benefits, denying transplant to otherwise eligible people with disabilities may constitute illegal and unjustified discrimination.<sup>8</sup>

In 1995, Sandra Jensen, a 34-year-old woman with Down syndrome and congenital heart disease was initially refused a heart-lung transplant solely because she had trisomy 21 and mental retardation (current terminology at the time). She, with her family and other advocates, mounted a national campaign to protest this discrimination. She subsequently received her transplant on January 23, 1996, and became the first person in the world with trisomy 21 to do so. Dr William Bronston, a state rehabilitation administrator and coordinator of the campaign, in a speech delivered to the National Down Syndrome Society after Sandra's transplant in 1996, said, "Sandra's story has opened a window into the chaos and incompetence of the national transplant system as it currently exists."<sup>10</sup>

## STATEMENT OF THE PROBLEM

Transplant centers contend with conflicting priorities that may affect the evaluation and listing of recipients with IDDs, including the need to have high transplant success rates for accreditation and to remain in payer networks. Transplant centers want to allocate limited resources to those most likely to benefit but also want to avoid negative media attention around the perception of discrimination in the referral,

acceptance, or listing processes for solid organ transplant.<sup>11</sup>

Among transplant centers, there is inconsistency in defining IDD, which affects referral and listing and excludes patients from the qualifying pool of recipients. The use of IDD as a medical criterion by transplant centers is inconsistent and varied. When transplant centers use IDD as a social value criterion rather than a medical criterion, they make implicit rationing decisions that favor candidates without an IDD.<sup>12</sup>

The study of “implicit bias” helps us understand how unconscious assumptions about groups of people may influence perception and decision-making.<sup>12</sup> Tests have been designed to assess implicit bias toward individuals with developmental disabilities,<sup>13</sup> and unsurprisingly, clinicians are susceptible to such biases.<sup>14</sup> Just as transplant centers need to ensure that implicit bias does not influence decisions because of race, ethnicity, or sex, clinicians need to be aware of the existence of implicit bias toward individuals with disabilities and thoughtfully examine this bias in listing decisions for organ transplant.<sup>15</sup>

There is the misconception that transplant recipients with disabilities are unable to comply with posttransplant medical regimens, lack adequate support systems to ensure such compliance, have decreased life expectancy, and have a lower likelihood of transplant success.<sup>12</sup> There is the biased presumption that people with disabilities have a lower quality of life than those without disabilities and, therefore, do not receive as much benefit from the transplant as a person without disabilities or that they cannot be expected to derive any benefit by having their life extended by a transplant. For children with IDDs, a social value criterion focuses on their limitations and discounts the

contributions that these children make to their families and society.<sup>12</sup> The variance in the defining of IDD and the inconsistent use of IDD as a medical criterion result in the unjustified exclusion of children with IDDs from access to solid organ transplant.

Correspondence in October 2016 from the US Congress to Jocelyn Samuels, the director of the Office for Civil Rights in the HHS, urged the agency to address what congress called “persistent” organ transplant discrimination. The letter called for guidance from the HHS clarifying that denying an organ transplant on the basis of a person’s disability would violate the ADA.<sup>16</sup>

The most appropriate outcomes to consider when determining if a patient should be evaluated or listed for transplant are organ and patient survival with the same minimum thresholds for all patients with or without developmental disability.<sup>17</sup> In the determination of a qualifying pool of potential recipients, the literature suggests that there is no substantial difference in patient or organ survival between children with and without IDDs.<sup>17,18</sup> Studies have shown that patients with developmental or intellectual disabilities and appropriate posttransplant support have outcomes comparable to those of children without disabilities.<sup>18</sup>

Benedetti et al<sup>19</sup> described an institutional experience from 1968 to 1996 in renal transplant in adult recipients with ID. A psychologist and a social worker assessed the ability and commitment of the primary support person (the individual from the family or from the institution caring for the patient in charge of the daily medications and clinical follow-up). Only patients with expected long-term survival with a “cooperative” personality or a qualified primary support person were accepted as candidates. The average IQ was 56,

chronological age range was 17 to 45 years, and average developmental age was 7.7 years (range: 3–14 years). The 1- and 5-year patient and graft survival was 100%. They found that kidney transplant in properly selected patients with ID provided excellent patient and graft survival rates and that patient quality of life and health, as judged by the primary support people, was highly improved after kidney transplant in comparison with dialysis or advanced chronic renal failure. The authors concluded that the presence of ID should not be considered a contraindication to kidney transplant.<sup>19</sup>

Ohta et al<sup>20</sup> reported data from 8 Japanese institutions from 1988 to 2004; 522 pediatric kidney transplants were performed, including 25 (4.8%) in recipients ID. Follow-up data revealed all 25 grafts were functioning during a mean observation period of 41.1 months. All people providing primary support for these children were satisfied with the transplant and believed that quality of life was improved for both the transplant recipients and themselves.<sup>20</sup>

Galante et al<sup>21</sup> reported results of renal transplant in recipients with ID; graft survival and long-term renal function was equivalent to recipients without ID. They also concluded that renal transplant may offer significant advantages when compared to the need for dialysis in patients with ID.<sup>21</sup>

## TRANSPLANT ETHICS

In transplant ethics, the ethical principles directly applicable to the allocation of organs for transplant are respect for persons, utility, and justice.<sup>22</sup> Respect for persons embraces respect for autonomy; this necessitates transparency of processes and allocation rules to enable stakeholders to make informed decisions. Utility describes the effort to maximize the greatest benefit for the greatest number of

patients.<sup>23</sup> Utility applied to the allocation of organs should maximize the net overall good, balancing benefits and harms, thereby incorporating beneficence and nonmaleficence. For example, commonly accepted medical contraindications to transplant incorporate utility by excluding individuals whose diseases can be expected to recur after transplant, diseases that may be worsened by posttransplant immunosuppression, or diseases that make surgery unsafe for the patient.<sup>24</sup> In public policies related to allocation of organs, there is consensus that the social worth or value of individuals should not be considered. IDD as a social value criterion results in implicit and explicit bias that may reflect the values of the decision-makers and affect rationing decisions. For children with IDDs, a social value criterion focuses on their limitations and discounts the contributions that these children make to their families and society.<sup>12</sup> Justice refers to fairness in the pattern of distribution of the benefits and burdens of an organ procurement and allocation program. Equitable access to the transplant waiting list is the basis of equitable organ allocation. Justice requires that criteria for candidacy are applied in an equal manner. Equitable allocation incorporates efficiency and equity, as specified in the Final Rule implemented in 2000, "distributing organs over as broad a geographic area as feasible...and in order of decreasing medical urgency."<sup>24</sup>

Excluding children with disabilities from the qualifying pool of potential recipients violates these ethical principles. Children with disabilities can be deceased organ donors and contribute to the supply of solid organs, so it would be unfair to categorically exclude them as recipients of organ transplants.

Beneficence and nonmaleficence apply not only to the pediatric patient

being referred, accepted, or listed for transplant but also to the family construct. The family, in addition to the patient, is a stakeholder and must be educated in the benefits, risks, and harms of transplant and collaborate with the transplant team in the decision-making process. Evaluation for transplant includes determining if there are significant medical comorbidities that unduly limit transplant survival; transplant is not offered to any patient who will be harmed by the procedure.

One pediatric transplant center stated that developmental disability alone should not preclude transplant; however, "biological survival is not a sufficient goal for transplantation. Survival for the purpose of having continued conscious experience is a minimum goal of transplantation."<sup>25</sup> The center's neurodevelopmental task force, drawing on federal and expert consensus guidelines, defined terms including minimally conscious state and persistent vegetative state. As such, the center's policy is to not offer transplants to patients in persistent vegetative states. The task force concluded that a scarce resource should not be used to prolong the survival of people who very likely have no conscious experience. The task force sought assistance from a community ethics committee that used an absolute lack of benefit argument, claiming that it is ethically justifiable to exclude patients in persistent vegetative state from receiving transplants.<sup>25</sup>

In balancing beneficence and nonmaleficence, the benefits, risks, and harms of transplant to pediatric patients with developmental disabilities, it is necessary to acknowledge that the transplant can add to or reduce the burden of treatment. The pediatric patient with disabilities may have the burden of other organ system disease in addition to the failed organ. Many children are already dependent on technology for survival, such as

a feeding tube or tracheostomy. For these children with medical complexity, certain inherent aspects of the disability, such as recurrent tracheitis or pneumonia, may pose a more significant risk after transplant because of the required immunosuppression.<sup>26</sup>

Transplant teams have the responsibility of educating families about the benefits, risks, and possible harms of organ transplant and collaboratively making the best decision possible. Although many parents will naturally subordinate their own interests and the interests of siblings when dealing with the interests of their child with organ failure being evaluated for transplant, it is helpful to remind parents that it is acceptable to directly consider their own interests and the interests of other children when making decisions for and about their sick child. It is beneficial to have parents openly acknowledge the sacrifices associated with various treatment options and the effect on their own lives and the lives of their other children.<sup>27</sup> It is ethically permissible for some families to decide that because of the degree of IDD, their children may not attain enough benefit to warrant the immediate and lifelong burdens of transplant.

## QUALITY OF LIFE

A core issue in the discussion of organ transplant for children has to do with the concept of quality of life. The World Health Organization defines quality of life as an "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."<sup>28</sup> By its very nature, quality of life is individualistic, and although many attempts have been made to measure and monitor quality of life for groups of people, one must not lose sight of the individual's



understanding of his or her own quality of life.

As commonly defined, quality of life goes well beyond health-related matters and includes physiologic, psychological, and social factors.<sup>29</sup> Likewise, disability is commonly understood to cross multiple domains, including body functions, body structures, activity and participation, and environmental factors,<sup>30</sup> all of which affect an individual's assessment of his or her quality of life. This complicated interplay of medical and nonmedical factors is challenging to families and physicians who must decide whether to proceed with transplant for a child with a disability.

It is well known that many individuals with disabilities rate their own quality of life similarly to individuals without disabilities<sup>31-33</sup> and higher than their families or physicians do when using proxy measurements.<sup>31,34,35</sup> This has been called the "disability paradox"<sup>34</sup>; individuals with disabilities tend to base their assessment of quality of life on factors beyond their physical and mental functioning, whereas proxy reporters tend to focus on the disability.<sup>29</sup> Clinicians' bias as a result of their own perception of the disability may undervalue the actual quality of life of the patient. As stated by Graham and Robinson,<sup>36</sup> "while quality of life considerations should be considered when assessing the benefits and burdens of medical care, there is the concern that many clinicians may unconsciously use the phrase 'quality of life' to mask a set of more complicated, unspoken assumptions about the lives of the disabled." Many clinicians working in an inpatient setting may not recognize that their assessments of quality of life are based on an incomplete clinical picture and are, therefore, limited. The child's condition and function during a hospitalization provides limited insight into a patient's overall quality

of life and the family's experiences, which may contribute to bias on the part of clinicians. Professional attitudes then conflict with parental assertions about the appropriateness of an intervention, not because of ethical or moral differences, but because of different perceptions about the baseline quality of life of the child.<sup>36</sup>

## EVALUATION FOR TRANSPLANT

The evaluation for solid organ transplant is a multidisciplinary assessment that includes a psychosocial evaluation, the goal of which is to identify patient and family strengths and risk factors that may affect posttransplant outcomes. Transplant evaluations for all individuals also include an assessment of the psychosocial milieu in which the individual exists.<sup>1</sup> The degree of psychosocial support available to the individual is part of this determination. In transplant evaluations for all young children and for older children with disabilities, the presence of caring, able, and committed caregivers is of paramount importance. These caregivers must be committed to the immediate and long-term care of the individual and his or her medical and psychosocial needs. The American Academy of Pediatrics policy statement emphasized the goal of keeping the family unit intact during and after the transplant process.<sup>1</sup> For patients with disabilities, caregivers often include a number of people outside the immediate family and may include the extended family, home nurses, therapists, clergy, and educators. Developmental specialists may be of particular importance for making the individual "come alive" for the transplant committee, demonstrating how the individual functions within his or her psychosocial setting.<sup>37</sup> The commitment of this extended caregiving team should be taken into account when considering an individual for transplant.

The OPTN encourages individual transplant centers to develop their own criteria for these "nonmedical" evaluations, although some guidance is given.<sup>38</sup> For instance, they suggest addressing problems with adherence, such as for an organ failure caused by behaviors such as smoking and alcohol use, but do not give strict criteria for exclusion from transplant consideration.

The likelihood of nonadherence to posttransplant regimens and medical care is commonly cited as a disqualifying barrier for patients with disabilities. However, nonadherence is highly prevalent in other populations, particularly adolescents.<sup>39</sup> Patients with disabilities often require assistance with their medication regimen and, thus, have a high degree of oversight, which may improve the likelihood of adherence.<sup>40</sup>

The presence of behavioral and emotional problems seems to be a more important predictor of low quality of life among children with disabilities than the extent of the physical disability.<sup>41</sup> In typically developing children, behavioral and emotional problems would be an important determinant of eligibility for organ transplant<sup>42</sup> because such problems can affect the ability to adhere to complex posttransplant medical recommendations and should likewise be considered a factor for individuals with disability. Many children with chronic illnesses, particularly those with IDD, have distress with medical visits or phlebotomy, often because of past painful interactions with the medical system.<sup>43</sup> Patients with these issues often respond to child life and other therapies to allow for medical tasks to take place.<sup>44</sup> However, if children cannot be accustomed to simple medical procedures such as phlebotomy, they would be poor transplant candidates because of the chronic and continuing need for blood tests. For such patients,

posttransplant care is not likely to be practical, regardless of the presence or absence of a developmental disability.

Although patients with disabilities commonly report good quality of life, their caregivers often report poorer quality of life, which may be related to the intensity of the care that is necessary.<sup>45,46</sup> The caregiving burden is often more closely related to the extent of behavioral and emotional problems than the severity of the motor or cognitive impairment.<sup>47</sup> The psychosocial evaluation in these circumstances should include the functioning of the broadly defined family unit rather than only the individual to receive the transplant. The family of a child with disabilities might experience an increase or decrease in the caregiving burden, and this should be explored individually.

The lack of standardized mechanisms for transplant centers to assess cognitive development and adaptive functioning was noted by Wightman et al.<sup>48</sup> In a large ( $N = 2076$ ) retrospective cohort analysis of children receiving a first kidney-alone transplant in the UNOS data set from 2008 to 2011, they reported 16% of the recipients were children identified as having definite or probable ID. For the purpose of the study, the authors created a definition of ID on the basis of information in the UNOS data set because of the lack of standardized mechanisms for transplant centers to assess cognitive development, academic level, or academic activity. Short-term (3-year) graft and patient survival were similar between children with definite or probable ID and without ID. The authors acknowledged that their study did not assess children listed for transplant who remain on the list, patients with end-stage kidney disease not referred to a transplant center, or those refused listing by a transplant center, thereby underestimating the number of

children with disabilities eligible for consideration for kidney transplant.<sup>48</sup> The standardization of the definition of disability including both intellectual functioning and adaptive behavior may be helpful in predicting the outcome after transplant.

## SUMMARY

When transplant is likely to provide significant health benefits, denying transplant to people with disabilities on the basis of their supposed lower quality of life may constitute illegal and unjustified discrimination.<sup>8</sup> The decision to initiate transplant must include consideration of both the individual patient's current quality of life with the diseased organ and the potentially improved quality of life with the transplanted organ, albeit with the burdens of surgery, immunosuppression, and other posttransplant therapies.<sup>49,50</sup>

The notion that children with disabilities have a lower quality of life than children with typical development is both incorrect and ethically problematic in decisions regarding organ transplant. Care must be taken to ensure that medical and psychosocial factors that may affect the transplant outcome are not confused with judgments of an individual's social worth. Children without disabilities have no more claims to scarce resources, such as organ transplants, than do children with disabilities.

To address concerns regarding the fairness of transplant evaluations for patients with IDD, a framework for transplant centers is necessary to ensure procedural consistency and transparency. The definition and assessment of ID, including the evaluation of cognitive development and adaptive functioning, and the criteria for recipient candidacy and selection require standardization and transparency, making transplant centers accountable for their decisions. One pediatric transplant

center used a multidisciplinary approach to develop a center-wide transplant policy. To increase transparency and accountability with respect to candidacy decisions for patients with developmental disabilities, the task force recommended the formation of a transplant listing advisory committee. The purpose of such a committee is to ensure that institutional transplant selection criteria are fair and nondiscriminatory and that patients declined for evaluation or listing were granted a fair and unbiased review, particularly with respect to characteristics that identify vulnerable or protected classes of people, such as those with disabilities, who may be protected under the ADA.<sup>25</sup>

In adhering to the ethical principles of respect for persons, utility, and justice, children with IDDs should not be excluded from the potential pool of recipients and should be referred for evaluation as recipients of organ transplants. IDD alone should not be a contraindication to the referral, acceptance, or listing for solid organ transplant. The presence of an IDD is relevant but should not be the determinative factor.

## RECOMMENDATIONS

1. Patients should not be excluded from consideration for solid organ transplant solely on the basis of an intellectual or developmental disability. When transplant is likely to provide significant health benefits, denying transplant to people with disabilities on the basis of their supposed lower quality of life may constitute illegal and unjustified discrimination.
2. Transplant programs should standardize the definition and assessment of ID so that transplant decisions can be individualized, equitable, and transparent. The transplant team

should consider both the cognitive and adaptive skills of the individual. Consistency in defining IDD allows the use of IDD as a medical criterion to prevent unjustified exclusion of children from access to solid organ transplant. There should be concordance among the respective solid organ transplant programs within an institution in defining IDD to avoid individual programmatic biases. The transplant team should consider both the cognitive and adaptive skills of the individual. Cognitive testing alone is inadequate to characterize a person's level of disability. The individual's level of adaptive functioning must be taken into account; specifically, the skills with which an individual lives within his or her environment (eg, the social, conceptual, and practical skills needed for self-care, self-direction, communication, home living, use of community resources, and functional academic skills) must be considered. Failure to consider adaptive functioning as part of the transplant evaluation results in an inaccurate assessment of ID.

- The transplant evaluation is a collaborative process that should occur in person rather than by medical record review and should include caregivers such as therapists and developmental specialists who can illustrate the patient's degree of function. Evaluations for transplant to an

individual with ID should include professionals with expertise in the evaluation and management of individuals with ID.<sup>51</sup>

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#### ABBREVIATIONS

ADA: Americans with Disabilities Act  
HHS: US Department of Health and Human Services  
ID: intellectual disability  
IDD: intellectual and developmental disability  
OPTN: Organ Procurement and Transplantation Network  
UNOS: United Network for Organ Sharing

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