House Committee on Health Care
Paul Terdal, Portland, OR
Support House Bill 2839
February 14, 2017

Chair Greenlick and members of the Committee,

I’m writing in support of House Bill 2839, which prohibits discrimination against individuals with disabilities in the provision of organ transplants.

Individuals with mental or physical disabilities have been denied access to life-saving organ transplants on the basis of their disability – in Oregon and elsewhere. In some cases, this has actually been driven by beliefs that the lives of disabled individuals are less worthy; in others, it has been based on generalized assumptions that individuals with disabilities are incapable of participating in a transplant operation without considering evidence that the person will have sufficient support and assistance to compensate for their disability.

In California and New Jersey, historic issues over provision of transplants for disabled patients led to legislation specifically prohibiting such discrimination and requiring consideration of the patient’s support systems.

In 2012, Lief O'Neill, a 9-year old boy with autism from Eugene, Oregon, had great difficulty accessing a heart transplant in Oregon due to his disability. Fortunately, he was able to travel to California for treatment at Stanford’s Lucille Packard Children’s Hospital, which was very successful, and today Lief is thriving with his new heart.

HB2839:

- Provides a specific and straightforward rule prohibiting discrimination on the basis of disability – unless the disability is determined to be medically significant.
- Establishes an expedited judicial review process to quickly resolve claims of discrimination.

In addition, I propose an amendment with two provisions (see Exhibit A) to:

- Require consideration of the patient’s support system in determining the patient’s ability to comply with post-transplant medical requirements.
- Prohibit discrimination on the basis of age in addition to disability.

Sincerely,

Terdal

Paul Terdal

Attachments:

- <u>Exhibit A</u>: Proposed Amendments to HB2839:
    - Require consideration of patient's support systems in determining ability to comply with requirements;
    - Add prohibition against age discrimination.
- <u>Exhibit B</u>: Ar Ne'eman, Steven Kapp, Caroline Narby. Organ Transplantation and People with I/DD: A Review of Research, Policy, and Next Steps. Autistic Self Advocacy Network, March 2013
- <u>Exhibit C</u>: Bailey DB, Schneider LM, Maeda K, Hollander SA, Shaw RJ, Rosenthal D, et al. Orthotopic Heart Transplant in a Child with Nonverbal Autism. Austin J Autism & Relat Disabil. 2016; 2(2): 1017.
- <u>Exhibit D</u>: California Health and Safety Code, Section 7151.35
- <u>Exhibit E</u>: New Jersey C.26:6-86.1 to C.26:6-86.3

79th OREGON LEGISLATIVE ASSEMBLY--2017 Regular Session

House Bill 2839

Sponsored by COMMITTEE ON HEALTH CARE

SUMMARY

The following summary is not prepared by the sponsors of the measure and is not a part of the body thereof subject to consideration by the Legislative Assembly. It is an editor's brief statement of the essential features of the measure **as introduced.**

Prohibits eye bank, tissue bank, procurement organization, hospital or physician from considering any disability of potential recipient of anatomical gift and from requiring individual with disability to demonstrate ability to perform major life activity substantially limited by disability upon receiving anatomical gift.

Declares emergency, effective on passage.

Comment [PT1]: Add a prohibition on age discrimination in addition to the prohibition on disability discrimination

A BILL FOR AN ACT

Relating to anatomical gifts; and declaring an emergency.

Be It Enacted by the People of the State of Oregon:

SECTION 1. Section 2 of this 2017 Act is added to and made a part of ORS 97.951 to 97.982.

SECTION 2. (1) In procuring and using anatomical gifts under ORS 97.951 to 97.982 for purposes related to transplant and therapy, if a document of gift does not name the recipient of the anatomical gift as described in ORS 97.969 (1), an eye bank, tissue bank, procurement organization, hospital or physician may not:

(a) Consider any disability, as described in ORS 659A.104, of a potential recipient of the anatomical gift, unless a physician, upon examining the potential recipient, determines that the disability is medically significant to the provision of the anatomical gift. If an individual has the necessary support system to assist the individual in complying with post-transplant medical requirements, an individual's inability to independently comply with those requirements shall not be deemed to be medically significant~~relevant~~; or

Comment [PT2]: This language is taken from New Jersey C.26:6-81.2(a).

(b) Require a potential recipient with a disability, as described in ORS 659A.104, to demonstrate an ability to perform a major life activity substantially limited by the potential recipient's disability upon receiving the anatomical gift.

(2) This section applies to:

(a) Any referral by a physician;

(b) Any evaluation of a potential recipient of an anatomical gift; and

(c) The establishment of any list prioritizing the order in which potential recipients of anatomical gifts may receive an anatomical gift.

(3) Judicial review of a claim brought under this section may be sought from the Circuit Court for Marion County or from the circuit court for the county in which the potential recipient of the anatomical gift resides or resided or was denied the anatomical gift. The circuit court shall give priority on its docket and expedited review to a claim brought under this section.

SECTION 3. Section 2 of this 2017 Act applies to anatomical gifts that are the subject of a referral made pursuant to ORS 97.972 on or after the effective date of this 2017 Act.

SECTION 4. This 2017 Act being necessary for the immediate preservation of the public peace, health and safety, an emergency is declared to exist, and this 2017 Act takes effect on its passage.

NOTE: Matter in **boldfaced** type in an amended section is new; matter [*italic and bracketed*] is existing law to be omitted. New sections are in **boldfaced** type.

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

Ari Ne'eman, *Autistic Self Advocacy Network*
Steven Kapp, *University of California, Los Angeles*
Caroline Narby, *Autistic Self Advocacy Network*

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.

> *... it has historically been difficult to enforce federal civil rights law within the area of medical decision-making.*

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[1]. 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[2]. 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[3].

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

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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?[4]" 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[5]." 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.

...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.

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[6]. When the same question was asked for patients with IQs under 50, almost 3 in every 4 transplant centers indicated an absolute contraindication[7]. More recent data supports these concerns as well, while suggesting that some progress has been made since the Levenson and Olbrisch's 1992 survey.

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[8]. 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[9]."

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"[10]. 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[11]. 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[12].

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[13].

There are over fifty published cases of kidney transplants for people with intellectual disabilities[14]. Success and medical adherence rates are comparable to that of the general population[15], though access to sufficient support from a family member or caregiver is a factor in medical adherence[16]. 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[17]. 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[18]."

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

> *...46% of heart programs indicated that even mild or moderate cognitive impairment would be a relative contraindication ... 71% of heart programs surveyed always or usually utilized neurodevelopmental status in determinations of eligibility for transplantation...*

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[19]. 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[20,21]." That successful compliance with a postoperative medical regimen can be included within this scope of "supportable" activities should elicit no surprise whatsoever[22]. 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.

> *... 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.*

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[23]. 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[24]. 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.[25]

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.

Consideration should be given to issuing ... clear guidance to the field outlining the requirements of the ADA/504 as applied to the topic of organ transplantation.

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[26,27]. 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 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[28]. 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[29]."

Many concepts in applied and academic bioethics explicitly discriminate against people with disabilities by design.

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 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[30]. 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[31]. 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[32]. 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[33]. 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.

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.

Summary of Recommendations

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. Sugh 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.

… states should follow California's example and pass legislation explicitly clarifying legal protections against discrimination for people with disabilities seeking organ transplants.

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.

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.

Endnotes

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Case Report

Orthotopic Heart Transplant in a Child with Nonverbal Autism

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Abstract

Improved outcomes for heart transplantation for end-stage heart failure in pediatric patients, and a critical shortage of donor organs, makes it imperative to reserve heart transplantation for those who are most disabled by heart failure and most likely to derive the maximum benefit from transplantation. Careful consideration is required in the selection and training of candidates for the rigorous care required after transplantation. In addition to medical appropriateness, factors such as psychosocial stability and the presence of other severe chronic illness that could interfere with treatment adherence are considered in evaluating a candidate's suitability for transplant. This report illustrates the case of a child with nonverbal autism and dilated cardiomyopathy who received a successful orthotopic heart transplant following prolonged support with a Left Ventricular Assist Device (LVAD). The Success of the transplant and bridging medical interventions was supported by family involvement and clinical expertise of multiple specialties. This case provides evidence that children with Autism Spectrum Disorders (ASDs) should be considered for cardiac or other solid organ transplants. Although children with ASDs present unique challenges for medical interventions, like all patients, children with ASDs should be evaluated on a case-by-case basis. The presence of ASD (including nonverbal ASD) should not be an absolute contraindication for transplant.

Keywords: Autism; Heart; Transplant; Cardiac; Pediatric

Abbreviations

ASDs-Autism Spectrum Disorders; LVAD-Left Ventricular Assist Device; P-TRI-Pediatric Transplant Rating System

Introduction

According to recent registry reports from the International Society for Heart and Lung Transplantation, approximately 400 pediatric heart transplantation procedures are performed worldwide each year.The most common indication for heart transplantation in older children and adolescents is cardiomyopathy [1]. Autism is a neurodevelopmental disorder caused by abnormal brain development, manifesting in persistent deficits in social communication and restricted, repetitive patterns of behavior, interests or activities. ASDs tend to occur more often in people with certain genetic conditions, which may lead to greater risk for congenital conditions including cardiomyopathy [2]. Management of children with severe autism in the hospital setting and post-transplant can be challenging. Direct communication between the patient and team may be limited due to deficits in communication or lack of social motivation. Routines may be difficult to establish in the setting of emergent medical needs. Adverse responses to sensory stimuli may create significant challenges to utilizing medical devices. Furthermore, sensory seeking behaviors may further threaten the maintenance of such interventions. Individuals with ASDs may require greater assistance with daily activities, both during hospitalization and post-transplant.

Case Presentation

A nine-year-old male with autism (weight: 47kg, height: 148cm, and BSA: 1.39 m^2) presented to an outside hospital with a two week history of malaise and shortness of breath. An echocardiogram confirmed dilated cardiomyopathy with severely depressed ventricular function. Despite medical management, the patient progressed to cardiogenic shock, was transferred to an out-of-state facility capable of offering cardiac transplantation, and was immediately placed on ventricular assist extracorporeal membrane oxygenation.Given the patient's poor prognosis for recovery, it was decided that heart transplantation was the most appropriate treatment.

During pre-transplant evaluation, appropriate concerns arose regarding biopsychosocial factors, from both the medical team and family. The patient possessed no spoken language, though he had recently developed the ability to communicate short sentences through the use of a keyboard and demonstrated the ability to understand concepts appropriate to his age. He experienced particular difficulty with motor control, requiring assistance for many daily activities. Additionally, he possessed significant sensory sensitivities and had poor reactions to restrictive environments. He had in the past struggled with impulsivity including development. With these challenges, the team and family faced was maintaining an LVAD in the setting of a cardiovascular intensive care unit where distressing stimuli and a restricted environment were essential.Balancing these concerns, the patient had a supportive family who was involved in the medical management, committed to working with a large team of caregivers, and communicated effectively with providers. After presentation to the multidisciplinary selection committee, the patient was accepted for heart transplantation and underwent implantation of a Heartmate® II LVAD as a bridge to transplantation.

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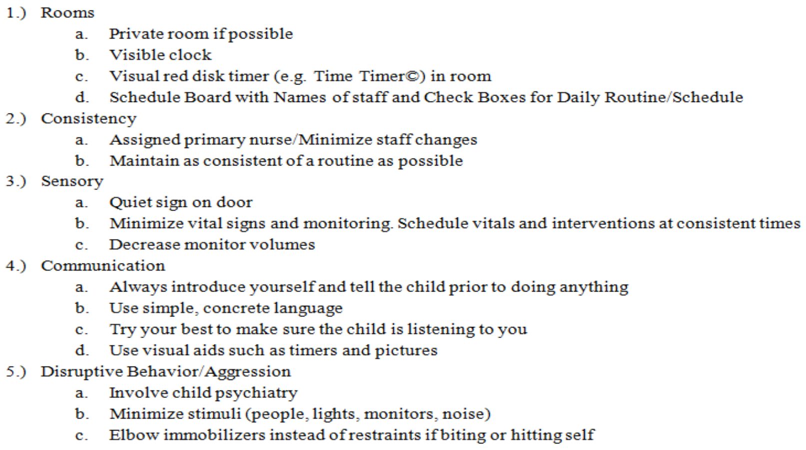

1.) Rooms
    a. Private room if possible
    b. Visible clock
    c. Visual red disk timer (e.g. Time Timer©) in room
    d. Schedule Board with Names of staff and Check Boxes for Daily Routine/Schedule
2.) Consistency
    a. Assigned primary nurse/Minimize staff changes
    b. Maintain as consistent of a routine as possible
3.) Sensory
    a. Quiet sign on door
    b. Minimize vital signs and monitoring. Schedule vitals and interventions at consistent times
    c. Decrease monitor volumes
4.) Communication
    a. Always introduce yourself and tell the child prior to doing anything
    b. Use simple, concrete language
    c. Try your best to make sure the child is listening to you
    d. Use visual aids such as timers and pictures
5.) Disruptive Behavior/Aggression
    a. Involve child psychiatry
    b. Minimize stimuli (people, lights, monitors, noise)
    c. Elbow immobilizers instead of restraints if biting or hitting self

Figure 1: In-Patient Hospital Protocol for Children with ASDs (Froehlich, Hoffman, and Lotspeich, unpublished).

Given the sensitive LVAD equipment, one critical step was to establish the safety and physical supervision. The family played an essential role in educating the medical staff about optimal ways to support the patient. Although a parent was always at the bedside, this patient was also provided with one-to-one aides to assist with mobility and transfer, and to provide respite as needed. Due to difficulties the patient experienced with transitions between unfamiliar staff members, the pool of the hospital staff was limited to provide greater consistency.

Social work was vital in providing support for the family. The child psychiatry team, aided with pretransplant psychological evaluation and provided support throughout the hospitalization. Individual therapy was conducted via typing and secure e-mails with the therapist in the room. This unique intervention helped the patient to communicate with the medical team, practice skills, and manage anxiety around procedures and transitions. Through typing, he was able to express his thoughts including fears about death, and to explore these feelings with his psychiatrist. Individualized interventions such as leaving the room door closed, scheduling quiet times, and allowing the patient to sit outside clinic rather than in busy waiting rooms were useful in minimizing stress reactions. The hospital, school, occupational therapy, physical therapy, and child life teams ensured continued education and maintenance of a regular schedule as was possible.

After eight months of hospitalization and maintenance with LVAD pump, the patient underwent orthotopic heart transplantation. The heart was implanted with a standard bicavalanastamosis. The patient completed outpatient management with limited complications, no significant rejection and was cleared for return home one year after the first presentation. Adherence with immune suppressant drug therapies has been excellent, with levels being at or near goal throughout the post-transplant course. This successful outcome can be credited to in part to an adaptive, and knowledgeable family that allowed for effective coordination between patient, family and specialty teams.

Discussion

Recent advances have led to the prolongation and quality of life for pediatric patients after heart transplant. However, the process including preoperative, perioperative, and long-term postoperative stages, can present major psychosocial obstacles for families [3]. For children with ASDs, the process of transplantation and aftercare presents additional challenges. Success in the transplant treatment process requires resilience and ability to tolerate daily physically invasive procedures, unpredictable changes in routine, as well as the patient and family's ability to adhere to treatment regimens. Due to the limited availability of donor organs, transplant centers are faced with the challenging task of deciding which patients will benefit most from receiving a donor organ. Selection committees incorporate a range of biopsychosocial factors into their candidacy decisions. Teams utilize instruments such as the Pediatric Transplant Rating Instrument (P-TRI) [4]. The P-TRI identifies areas of psychosocial vulnerability or strength that help determine ability to complete the transplant process and maintain treatment adherence. Among the criteria evaluated in the P-TRI are factors related to illness such as knowledge about and motivation for transplant, treatment adherence, psychiatric history, family environment and psychosocial support. For children with ASDs, it is important to consider how social-communication and other challenges may affect these areas, and what mechanisms can be employed to overcome barriers. Children with ASDs may require special accommodations and multi-disciplinary care during hospitalizations. Hospitals may establish protocols for managing children admitted with ASDs. In the case described, a general in-patient protocol for children with ASDs was employed (Figure 1). It is a vital part of the transplant process to involve a multidisciplinary team including physicians, nurses, mental health professionals, social workers and rehabilitation specialists. Care conferences involving all disciplines should be held regularly and include the patient and family to discuss treatment plans. Teams and caregivers must remember the physical and psychological toll prolonged hospitalization takes on patients and families. Reciprocally, families must be willing to accept imperfections in systems of care. Flexibility and willingness to employ innovative measures tailored to the individual needs of each child are imperative. Although ASDs may present challenges to transplant, it is important to note that autism may uniquely prepare patients and families for the challenges involved in the organ transplant process. Families often already have experience managing complex systems of care and time intensive treatment practices. They may already maintain strict healthcare routines and have an established support network to assist with care needs, and are often well-versed in daily sacrifice to accommodate the special needs of their children. In the evaluation of candidates for heart transplant, medical urgency and ability to maintain transplant care are important factors. While ASDs and other developmental delays may pose challenges in medical management, these disabilities should not be considered absolute contraindications to transplant. Many of the possible associated challenges may be overcome with strong support, including close family involvement and a dedicated interdisciplinary transplant team.

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California Health and Safety Code, Section 7151.35

7151.35. (a) No hospital, physician and surgeon, procurement organization, or other person shall determine the ultimate recipient of an anatomical gift based upon a potential recipient's physical or mental disability, except to the extent that the physical or mental disability has been found by a physician and surgeon, following a case-by-case evaluation of the potential recipient, to be medically significant to the provision of the anatomical gift.

(b) Subdivision (a) shall apply to each part of the organ transplant process. The organ transplant process includes, but is not limited to, all of the following:

(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.

(c) A person with a physical or mental disability shall not be required to demonstrate postoperative independent living abilities in order to have access to a transplant if there is evidence that the person will have sufficient, compensatory support and assistance.

(d) The court shall accord priority on its calendar and handle expeditiously any action brought to seek any remedy authorized by law for purposes of enforcing compliance with this section.

(e) This section shall not be deemed to require referrals or recommendations for, or the performance of, medically inappropriate organ transplants.

(f) As used in this section "disabilities" has the same meaning as used in the federal Americans with Disabilities Act of 1990 (42 U.S.C. Sec. 12101 et seq., P.L. 101-336).

New Jersey C.26:6-86.1 to C.26:6-86.3

CHAPTER 80

AN ACT concerning anatomical gifts and supplementing P.L.2008, c.50 (C.26:6-77 et seq.).

BE IT ENACTED by the Senate and General Assembly of the State of New Jersey:

C.26:6-86.1 Findings, declarations relative to anatomical gifts.

1. The Legislature finds and declares that:

a. A mental or physical disability does not diminish a person's right to health care;

b. The "Americans with Disabilities Act of 1990" prohibits discrimination against persons with disabilities, yet many individuals with disabilities still experience discrimination in accessing critical health care services;

c. Individuals with mental and physical disabilities have been denied life-saving organ transplants based on assumptions that their lives are less worthy, that they are incapable of complying with complex post-transplant medical regimens, or that they lack adequate support systems to ensure such compliance;

d. Although organ transplant centers must consider medical and psychosocial criteria when determining if a patient is suitable to receive an organ transplant, transplant centers that participate in the Medicare and Medicaid programs are required to use patient selection criteria that result in a fair and non-discriminatory distribution of organs; and

e. New Jersey residents in need of organ transplants are entitled to assurances that they will not encounter discrimination on the basis of a disability.

C.26:6-86.2 Eligibility to receive anatomical gift.

2. a. An individual who is a candidate to receive an anatomical gift shall not be deemed ineligible to receive an anatomical gift solely because of the individual's physical or mental disability, except to the extent that the physical or mental disability has been found by a physician or surgeon, following an individualized evaluation of the potential recipient, to be medically significant to the provision of the anatomical gift. If an individual has the necessary support system to assist the individual in complying with post-transplant medical requirements, an individual's inability to independently comply with those requirements shall not be deemed to be medically significant. The provisions of this subsection shall apply to each part of the organ transplant process.

b. The court shall accord priority on its calendar and expeditiously proceed with an action brought to seek any remedy authorized by law for purposes of enforcing compliance with the provisions of this section.

c. The provisions of this section shall not be deemed to require referrals or recommendations for, or the performance of, medically inappropriate organ transplants.

d. As used in this section, "disability" has the same meaning as in the federal "Americans with Disabilities Act of 1990," Pub. L.101-336 (42 U.S.C. 12101 et seq.).

3. This act shall take effect immediately.