

# Organ transplantation, organ donation and mental retardation

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**Abstract:** We reviewed the literature on accessibility and outcomes of organ transplantation in individuals with mental retardation (MR) and on the prevalence of organ donation in this population. Six centers have published outcome data on renal transplantation in 34 individuals with MR. The one- and three-yr patient survival rates were 100% and 90%, respectively. The studies reported good compliance with post-transplant medications due to consistent support from family members or caregivers. The outcome studies for liver and heart transplantation among these individuals are limited. The literature on organ donation in individuals with MR is mostly concerned with legal issues. The courts generally permit organ donations when such is in the best interests of the donor.

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Prior to the 1990s, MR was regarded as a contraindication for solid organ transplant operations (1, 2). The main concern was that people with MR, especially those with severe or profound MR, lacked the necessary cognitive skills to comply with complex post-transplant, anti-rejection medication regimens. As the number of organs available has been insufficient to transplant everyone with a medical need, some authorities felt ethically obligated to allocate organs based on the individual's quality of life. People with MR were disadvantaged or not considered altogether for transplant operations because they were presumed to have a poor quality of life.

In 1995, Sandra Jensen, a 32-yr-old woman with Down syndrome, was initially denied a heart–lung transplant at Stanford University Medical Center and also at the University of California at San Diego (3). Hospital authorities rejected Jensen's application because of her MR. Jensen's advocates, however, obtained sufficient

publicity and political support to persuade the Stanford Medical Center to reconsider. Jensen was transplanted in January, 1996 and died 18 months later from complications from immunosuppressive (anti-rejection) medication.

William Bronston, the physician who had advocated for Sandra Jensen, formed a group of MR advocates, professionals and scholars in 2004 called the National Work Group on Disability and Transplantation. This group posted an online questionnaire concerning access to transplant centers at the website of the nation's largest MR family organization, the Arc of the United States. Of the 205 people who responded to the transplant questionnaire, 80% believed that people with MR are discriminated against regarding access to organ transplant operations. When shown the results of the survey in the summer of 2004, the Joint Commission on Accreditation of Healthcare (4) expressed concern that many people with disabilities are 'denied evaluation and referral for transplantation'.

Although many people with disabilities and their advocates remain concerned about equal access to transplantation, the prevalence of organ transplantation in individuals with MR has yet to be examined. Information on the extent of any possible discrimination and outcomes of organ

Abbreviations: ADA, Americans with Disabilities Act; COACH Syndrome, Association of anomalies composed of cerebellar vermis hypoplasia, oligophrenia, congenital ataxia, coloboma and hepatic fibrosis; MR, mental retardation; OPTN, Organ Procurement and Transplantation Network; UNOS, United Network for Organ Sharing.

transplantation in these individuals is limited. Dobbels et al. (5) noted the need for research on MR and organ transplantation, especially the need for studies to determine outcomes such as post-transplant non-compliance and mortality in MR organ transplant recipients.

This article is intended as a scholarly review of what is currently known about these issues. We were especially interested in the following questions: Do people with MR have equal access to organ transplantation and is there a process in place to monitor such accessibility? What is the outcome of transplantation in individuals with MR? What effect does the rigorous post-transplant regimen have on MR individuals and/or their caregivers? What specific issues may influence the likelihood of compliance with the medical requirements of post-transplant care? Are individuals with MR allowed to donate their organs? What are the ethical and legal issues that would impact the decision to allow organ donation from an individual with MR?

### Access to organ transplantation

Twenty published studies addressed the issue of accessibility of people with MR to transplant operations (1, 2, 6–23). In the 1992 Levenson and Olbrisch survey (6), a total of 411 transplant centers reported whether or not people with IQs between 50 and 70, and those with IQs less than 50, were eligible for cardiac, liver or renal transplant operations. As shown in Table 1, the results indicated a significant limitation of access as a function of IQ. Individuals with IQs between 50 and 70 were significantly disadvantaged in seeking heart and liver transplants and they were moderately disadvantaged in seeking kidney transplants, while those with lower IQs were even more disadvantaged. Other investigators have documented wide discrepancies among centers in the psychosocial criteria that are used to make transplantation decisions (7–9).

Table 1. Percent of transplant centers saying subaverage IQ is an absolute, relative or no contraindication for transplant operations (6)

	Cardiac (n = 122)	Liver (n = 72)	Renal (n = 217)
IQ 50–70			
Absolute contraindication	25.6	10.9	2.6
Relative contraindication	59.0	69.6	51.3
No contraindication	15.4	19.6	46.1
IQ <50			
Absolute contraindication	74.4	45.7	24.0
Relative contraindication	19.2	41.3	51.9
No contraindication	6.4	13.0	24.0

Phipps (10) summarized the data for 706 patients referred for heart transplantation at a Montreal hospital over a period of 11 yr. Only two of the 706 patients had MR and both were denied wait listing for a heart transplant. No further details were reported on these cases. The fact that so few people with MR showed for heart transplantation is consistent with the possibility of access limitations in the referral process.

In 1995, over 65% of second-year medical students at a university in California rated Down syndrome as a contraindication to heart transplantation, while 31% rated it as irrelevant in the transplantation decision (11). In comparison, 'Low IQ' was rated as a contraindication to heart transplantation by 35% of these medical students, while 60% rated it as irrelevant.

Collins et al. (1) reported a case study of a 20-yr-old woman with an IQ of 55 who needed a heart–lung transplant. The hospital's evaluation team denied the woman an opportunity to be listed for transplantation because of her cognitive limitations and concern about her potential to learn to comply with post-transplant medication regimens.

In their summary of indications and contraindications for heart transplants, Copeland and Solomon (2) stated that, 'any mental or psychological condition which would make the patient unable to comply with a difficult medical regimen over the long term is an absolute contraindication to heart transplantation. Included in this category would be patients with psychosis or mental deficiency and also patients addicted to drugs'.

House and Thompson's (12) review of the psychiatric aspects of organ transplantation asserted that patients with significant MR are poor candidates for organ transplantation. They did not explain this opinion other than to suggest likely problems with compliance.

Savulescu (13) questioned the public policy of equal access to donor hearts for people with Down syndrome. 'We should face reality,' he urged, 'quality and length of life and probability of benefit (and cost of treatment) are relevant in determining who should receive treatment [heart transplantation]. Severe disability in some circumstances should disqualify a person from access to scarce resources'.

Santiago-Delpin (14) expressed a somewhat positive attitude toward transplantation and MR. He proposed that individuals with MR should be excluded for transplantation only when they are totally dependent on others for care and/or have medical conditions that would

complicate the outcome. Santiago-Delpin also noted that transplantation should improve the quality of life of cardiac patients with MR.

Arciniegas and Filley (15) suggested that MR should not be considered an absolute contraindication to transplantation. Rather, consideration should be given to level of support and functional abilities when determining whether a person with MR is an appropriate candidate for transplantation.

Ehrich and Wolff (16) also opposed using MR as an absolute contraindication for these life-saving operations. They suggested that renal transplantation decisions in children with Down syndrome should be made on an individual basis. They stressed the need for outcome research on renal transplantation and Down syndrome.

In 1995, the Patient Care and Education Committee of The American Society of Transplant Physicians (17) developed clinical practice guidelines on renal transplant candidates. These guidelines stated that MR should only be considered a contraindication to transplantation when the cognitive impairment is so severe that it impairs compliance with essential medical regimens. The guidelines also stated that support from family and/or caregivers can compensate for an individual's inability to comply with medical regimens on his/her own.

In a national survey of 559 transplant centers, Corley et al. (18) identified six factors from the Criteria for Selection of Transplant Recipients Scale, which described the opinions of transplant coordinators about which psychosocial ≠ life-style criteria should be used to determine whether or not transplantation was appropriate. MR was listed in the Family/Socioeconomic factor, and this factor had the highest likelihood to be considered for transplantation.

Leonard et al. (19) noted in an editorial that there were no scientific reports on the outcomes of heart or heart-lung transplantation in individuals with Down syndrome. They reported that over a 14-yr period in the United Kingdom, only three cardiac transplant centers received referrals for patients with Down syndrome and all three were denied for reasons other than Down syndrome. Nine experts who responded to a questionnaire all reported that, at their hospital, heart transplant access decisions for people with Down syndrome depend partially on the patient's ability to understand the transplant process.

In an editorial on health care for Down syndrome individuals, Scott (20) questioned why only one individual with Down syndrome

had ever been placed on Great Britain's National Health System waiting list for a heart and lung transplant, despite these individuals having an increased risk of cardiac complications. Silber and Batshaw (21) expressed the opinion that although individuals with MR have had increased access to organ transplantation since the 1990s, they are still prone to discrimination based on issues of quality of life and post-transplant compliance.

In a commentary on whether or not the use of psychosocial criteria for determining access to organ transplantation violates ADA, Orentlicher (22) concluded that MR could be used as an exclusionary criterion when it increases the likelihood of medical complications or decreases the likelihood of a favorable outcome. Presently, there is little scientific data demonstrating poor outcomes or medical complications following organ transplantation in individuals with MR. Orenlichter suggested that ADA's requirement of 'reasonable accommodations' implies that patients with MR be given support services and that transplantation decisions be made on an individual basis and not influenced by whether or not a person is part of a specific MR category or group.

Whitehead (23) wrote a law commentary on ADA and the organ allocation guidelines of the UNOS. She suggested that the guidelines should establish a protocol for making reasonable accommodations when evaluating the risk of organ transplantation in individuals with disabilities. Whitehead also proposed that UNOS should encourage that access decisions be based on the assessment of each individual and not based on a group characteristic, such as MR.

### **Outcome of organ transplantation**

Table 2 shows the results of renal transplantations in individuals with MR based on case reports and information obtained from transplant centers (24–29). In addition to published information, Table 2 includes information we obtained by directly contacting the investigators. Some investigators updated information about their published cases and others reported new patients who had been transplanted since their studies were published. The causes of renal failure across cases included nephrotic syndrome, congenital dysplastic kidneys, chronic glomerulonephritis, IgA nephropathy, pyelonephritis, hypertension, hemolytic uremic syndrome, nephronophthisis, polycystic disease, Prune-Belly syndrome, anoxic renal damage, focal segmental glomerulosclerosis, urethral valve and

Table 2. One- and three-yr patient survival rates following renal transplantation in individuals with mental retardation

Transplant center	Age at transplant (yr)	1-yr patient survival*	3-yr patient survival <sup>†,‡</sup>
University of Illinois, Chicago, IL (24); E. Benedetti (personal communication, October 10, 2005)	16, 17, 17, 22, 23, 26, 31, 45	8/8	8/8
Children's Hospital, Stockholm, Sweden (25); M. Englund (personal communication, October 18, 2005; January 30, 2006)	1, 1, 5, 5, 7, 7, 9, 11, 12, 15 (three cases unknown)	13/13	12/12
North American Pediatric Renal Transplant Cooperative Study (26)	6–12 (8 cases), 13–17 (5 cases) >17 (1 case)	Information not available	11/14
The Hospital for Sick Children, Toronto, Canada (27)	7, 10	2/2	1/1
Massachusetts General Hospital, Boston, MA (28); O.S. Surman (personal communication, September 6, 2005)	36, adult (age not specified)	2/2	2/2
St Christopher's Hospital for Children, Philadelphia, PA (29); J.H. Baluarte (personal communication, September 6, 2005; January 12, 2006)	14, 20	2/2	0/1
Children's Hospital of Philadelphia, Philadelphia, PA; J.H. Baluarte (personal communication, September 6, 2005)	10, 11, 13, 17, 19, 34	6/6	4/4
Total across all studies		33/33	38/42

\*Numerator = number of patients who survived 1 yr; denominator = number of patients transplanted.

<sup>†</sup>Numerator = number of patients who survived 3 yr; denominator = number of patients transplanted.

<sup>‡</sup>The number in the denominator may differ from the denominator in the 1-yr patient survival column because 3 yr have not elapsed since all cases were transplanted.

cystic kidney, congenital lesions, membranous nephropathy, chronic renal failure secondary to reflux nephropathy, multicystic dysplastic kidney, tubulointerstitial fibrosis and global glomerulosclerosis.

The patient survival rates for all MR renal transplant patients presented in Table 2 were 33 of 33 (100%) at one-yr follow up and 38 of 42 (90%) at three-yr follow up. OPTN has reported national patient survival rates for renal transplantation of 95% at one-yr follow up and 90% at three-yr follow up (based on OPTN data as of Jan 27, 2006). Thus, the data currently available provide some evidence that rates of success of renal transplantations in people with MR may be comparable to nationally reported rates for the general population as a whole.

The results presented in Table 2 should be interpreted cautiously. The sample sizes are small and there may be some bias in favor of positive outcomes. Such sample bias might occur, for example, if surgeons were more likely to report successful cases than unsuccessful cases. Another possible biasing factor is that some investigators included only those patients who were healthy except for their failing organ (24). On the other hand, those studies that reported outcomes for all MR patients transplanted over a period of years may have been less susceptible to biasing factors (25, 26).

Some studies reported good post-transplant medication compliance when patients had support from family members or concerned caregivers. Benedetti et al. (24) reported that post-transplant compliance in their study was excellent. Baqi et al. (26) suggested that renal

transplantation is a reasonable option for patients with Down syndrome.

Individuals with Down syndrome have a weakened immune system (30) and demonstrate an increased incidence of heart disease (31), infections (32) and malignancies (33, 34). Some transplant experts have expressed concern that post-transplant immunosuppressant medications might increase the risk of mortality significantly more in post-transplant patients with Down syndrome than in post-transplant patients generally. In a study relevant to this concern, Baqi et al. (26) reported 14 post-transplant patients with Down syndrome who were administered standard immunosuppressive medication. Nine of these 14 patients, moreover, were given induction therapy. Eleven of the 14 patients had survived at three-yr post-transplant follow up; of the three who were not alive at three-yr follow up, one died from a viral infection and two died from cardiopulmonary complications. Baqi et al. were concerned about the three deaths and suggested that patients with Down syndrome may require less aggressive anti-rejection therapy because their immune systems may already be weakened.

Renal transplantation is by far the most common transplant operation in the general population. Not surprisingly, therefore, the MR literature shows mostly renal transplantations with this population. Much less information has been reported regarding the outcomes of liver and heart transplantation for individuals with MR. Transplant centers need to be surveyed to determine the prevalence and outcomes of such transplant operations.

Two articles have been published on liver transplantation in individuals with MR (35, 36). A child with COACH syndrome, which leads to mild MR, received a liver transplant and was in good health six yr post-transplant (35). Ewart-Toland et al. (36) described an infant with Kabuki syndrome who underwent a living-related liver transplant at eight months of age and showed no signs of rejection three months post-transplant.

With the exception of the previously mentioned publicized case of Sandra Jensen, investigators have reported only one case of an individual with MR receiving a heart transplant. Orr et al. (37) discussed a child who had an 8p- chromosome deletion disorder associated with moderate to severe MR. The child underwent a heart transplant at age three months and at age 15 yr was responding well to immunosuppressive therapy.

#### **Effect of transplantation on caregivers**

Family members or caregivers are especially important for MR patients who undergo transplant operations. They may be needed to make medical appointments and to insure compliance with post-transplant medication regimens. Very little information has been reported on the caregiver experience with transplant patients who have MR. Studies are needed on what can be done to assist caregivers and to help them support patients. We need to know more about educating caregivers in how they can help post-transplant patients and how to help themselves cope with the stress of providing such care. As far as we could determine, little or no information has been published directly pertaining to these issues.

#### **Organ donation**

The largest body of literature on organ donation in individuals with MR pertains to legal issues regarding consent. In 1969, the Kentucky Court of Appeals upheld a lower court ruling that a 27-yr-old man with MR could donate a kidney to his 28-yr-old brother who was dying of renal disease (38). The court's decision was based on the 'substituted judgment standard' which permits guardians to judge what the individual would want if he or she was legally competent to make a decision regarding organ donation. The substituted judgment standard also requires that the guardian take into consideration the best interests of the donor. The judge also applied the 'avoidance of detriment' test based on testimony that the death of the donor's brother would be psychologically traumatic for the donor (39).

In 1979, a Texas court ruled that a 14-yr-old girl with Down syndrome could donate a kidney to her younger brother who had end-stage renal disease (40). The court based its decision partially on the close relationship between the 14-yr-old and her brother and concluded that she would suffer psychologically if he died. In 1984, a New York court applied the avoidance of detriment standard to permit a 43-yr-old man with MR to donate bone marrow to his 36-yr-old brother. The Court decided that the benefits of donation to the donor outweighed the risks (41).

In 1973, a Georgia court ruled that a 15-yr-old girl with MR could donate a kidney to her mother. The court based its decision on the doctrine of substituted judgment and the psychological benefit to the daughter, the close bond between the mother and daughter, and the lack of medical alternatives for the mother's kidney disease (42).

In 1973, a Louisiana court did not allow a 17-yr-old man with MR to donate a kidney to his 32-yr-old sister who had renal disease (43). The court ruled that a kidney transplant was not an absolute necessity in order to preserve the sister's life and that the donation was not in the best interest of the brother, despite the parents' argument that the sister would be his ultimate caregiver.

Ethicists have commented on organ donation in individuals with MR. Klepper (44) suggested that individuals with MR should be allowed to donate organs based on an evaluation of the following criteria: (i) What is the risk of possible harm to the donor? (ii) What are the expected benefits? (Will the organ donation save someone's life?) and (iii) Is there a close relationship between the donor and recipient, such as that between family members or life-long friends? Steinberg (45) argued that kidney donation by individuals with MR should only be allowed when the recipient is a first-order relative with a close relationship with the donor and in which transplantation is the only option over death. Morris (46) suggested that individuals with MR should only be considered possible organ donors when it can be demonstrated that they will psychologically benefit from the donation.

Lebit (47) urged caution and stated that the courts have inappropriately interpreted and applied the standard of substituted doctrine in organ donation cases involving donors with MR. In the context of determining whether an individual with MR will benefit from organ donation, Lebit argued that there were no criteria for determining the degree to which someone might benefit. Cheyette (48) argued even more strongly

Table 3. Guidelines to report case studies on individuals with mental retardation who receive an organ transplant

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Cause of mental retardation (if known)
Cognitive evaluation
IQ score
Adaptive behavior score
Co-existing conditions
Physical disabilities
Sensory disabilities (hearing, vision)
Other health problems
Psychiatric diagnosis (if any)
Primary diagnosis of organ failure
Type and duration of pretransplant therapy
Availability and nature of support for post-transplant care
HLA-ABDR matches, if applicable
Age at transplant
Donor source (living related ≠ non-related or deceased donor)
Incidence of acute/chronic graft rejection episodes; treatment and reversal outcome
Number of prior transplants
Type and dosage of immunosuppressive medications (initial and current)
Compliance with immunosuppressive medication and clinical follow up
Incidence of post-transplant medical complications
Quality of life and health following transplant
Age at follow up
Length of graft survival
Length of patient survival
Return to dialysis or retransplantation
Age at death and reason (if applicable)
Type of physician follow up
National clinical data requirements

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against organ donation and proposed that organs should never be recovered from individuals with MR out of concern for the autonomy and well being of the donor.

The published literature on the legal aspects of organ donation is based almost entirely on United States law. Additional cases from countries outside the United States need to be published to gain a more global perspective on legal issues.

### Future research

Readers are encouraged to publish their cases so we can build a stronger database and address outcomes with liver transplants, heart transplants and other organs. Table 3 lists the information that should be included in future case study publications. By reporting the comprehensive data listed in Table 3, future reviewers should be able to compare the variables and compile them into a consolidated report on outcomes.

A number of issues merit attention from future investigators. These includes outcome by organ, age and co-occurring disabilities; legal issues in various countries; and factors affecting rates of organ donation.

### Conclusions

The relevant literature suggests that individuals with MR have some access to organ transplantation, but it is unclear if they have equal access. The preliminary outcomes of renal transplantation among individuals with MR are positive, but few results are available for liver and heart transplantations. Ethicists and courts have developed a number of criteria that permit organ donations, but no information has been reported on the extent of organ donations by individuals with MR.

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