

Lives Worth Saving: Organ Transplantation and People with Disabilities

In 1995, Sandra Jensen was denied a heart/lung transplant. The transplant had been recommended by her attending physician. It was the only way to save her life. The transplant had even been approved by her insurer, MediCal. The problem – two California transplant centers refused to save Sandra's life. The reason – a categorical decision that people with Down Syndrome were not appropriate candidates for heart/lung transplants. This had nothing to do with Sandra personally. One of the hospitals never even met or examined her. The other hospital found no medical basis for denying her. They just did not think she could understand the operation and follow the complicated procedures after the operation.

The good news – Sandra got her heart and lung transplant. She was the first person with Down Syndrome in the world to do so. With the help of friends and supporters¹, Sandra attracted national attention, and one of the hospitals relented. Sadly, Sandra died 16 months later. She did not die because she did not understand or could not follow the procedures. She died because of the side effects of one of the drugs she took to prevent rejection.

The bad news – many people with disabilities still face discrimination in terms of referral and evaluation for transplantation, and actually receiving a transplant once referred. In this article, we talk about some of the issues individuals and families face, what is being done to overcome them, and what you can do.

And more bad news – if discrimination were removed from the scene, people with disabilities would still have a problem getting life saving transplants because there are not enough organs. SO, STOP READING FOR A MOMENT, AND MAKE A NOTE TO SIGN UP TO BE AN ORGAN DONOR RIGHT AFTER YOU FINISH THIS ARTICLE.

Two Focal Points of Action

It is almost a decade after the struggle to get a transplant for Sandra Jensen. Two different groups have renewed the effort to address the issues. Their work may well open the door much wider so that people with disabilities have access to the life saving and life improving benefits of organ transplants.

The National Working Group on Disability and Transplantation is an all-volunteer group of leaders and advocates representing people with disabilities, families, professional and consumer organizations who have joined with leaders in the medical community to address the issues of discrimination and organ transplants. Formed in 2003, the National Working Group is trying to get better information about the experiences of people with disabilities, promote better understanding in the transplant

¹ One of Sandra's active supporters was William Bronston, M.D. who is the coordinator of the National Working Group on Disability and Transplantation.

medical community, and promote organ donation among people with disabilities and their families.

In 2004, the National Working Group developed a nation-wide survey to get some facts about what individuals and families are experiencing.

As the National Working Group was meeting, the **Joint Commission on the Accreditation of Health Organizations (JCAHO)** began its examination of the need for more organ donors and to take a hard look at its policies and standards about organ transplantation. JCAHO is looking at the much broader landscape of access to organ transplantation medicine, and has identified systemic discrimination involving many groups.

Sidebar

Since the passage of the Americans with Disabilities Act and the establishment of related federal regulations, discrimination against persons with disabilities in medical treatment is prohibited. But, despite the legal protections offered to persons with disabilities, many still face significant hurdles to being assessed for, wait-listed, and eventually receiving donor organs.

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Both groups have issued reports that tell us much about organ transplantation and people with disabilities.

Moving Down the Road -- Roadblocks and Detours

There is a very great deal we do not know about the experience of people with disabilities in terms of organ transplants. The National Working Group's survey gives a first glimpse at how things have improved, but also how many barriers there are.

There are many steps along the way to a transplant:

- Someone – the individual, a family member, or a medical professional – has to think that the individual's condition is severe enough that a transplant is needed.
- Then, the person might be referred to a specialist such as a cardiologist or a specialist in internal medicine. The specialist must decide whether or not a transplant is a good idea. If so, there would then be a referral to a transplant center specialist.
- The transplant center specialist must then decide if a transplant is possible and a good idea.
- If the transplant center specialist agrees, then the person is put on a wait list for an organ.
- Once on the wait list, an organ must become available.

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The National Working Group's survey captured the experiences of just over 200 individuals who were involved with one or all of these steps². The survey was distributed widely through a network of national organizations. The survey was intended for people with a disability who have a severe health condition that might be helped by organ transplantation. The responses were from people with disabilities, family members, friends and advocates, each speaking on behalf of an individual situation. They were connected to dozens of local, state and national organizations and networks.

We do not know how representative the respondents are of all people with a disability who have severe health conditions that might be helped by organ transplantation. So far, there has been very little research about this important issue. As a result, we do not know how much the survey represents what is going on nationally. It does give us a picture of what is happening for 205 people over the course of their lives³. If we had go information about what has happened in the past, we could talk about whether the situation is improving or not. Comparisons over time are further complicated by the fact that the experiences the respondents describe in the survey have taken place over a span of years, decades in some cases.

What the survey reveals is that significant numbers of people do manage to move through the system, but many face barriers at each step of the way. While people with disabilities are still categorically excluded from transplantation opportunities, this is no longer the universal rule. People with disabilities are no longer routinely and reliably seen as people not worth saving.

[NOTE: the information in italics in the following sections is to explain where the numbers and percentages came from. In some cases the actuals were not given in the April 16th final results report, so they were "eyeballed" on the graphs.]

The survey responses show that people with disabilities are being recommended for and are receiving transplants. They are often referred for evaluation and a transplant is then suggested.

- 20% [*eyeball estimate of 41 individuals in Q18 chart out of 205*] of the individuals had either received an organ transplant or were on a waiting list to receive one. That means that they had completed all the steps, been evaluated for a transplant, and considered appropriate for a transplant. Another 9% [*eyeball estimate of 18 in Q18 chart*] have been evaluated and their condition is being monitored to see if a transplant becomes needed.
- Just over two thirds (68%) [*Q16, total of 139 seem to have been referred*] of the individuals described in the survey had been referred to a specialist or a transplant center for evaluation. When the specialists saw those individuals, a transplant was suggested for just over half of them (54%) [*Q 16, 76 of 139*]

² For a full description of the respondents, see *Individual and Family Disability Survey – Final Results*. Conducted by The National Work Group on Disability & Transplantation. Published April 16, 2004 The full report is available at <http://www.govoter.org/transplant/TransplantationandDisabilityNationalSurveyResultsFINAL.pdf>

Historically, this is a tremendous improvement. **We have moved from automatic exclusion, to selective inclusion.** As the Joint Commission on the Accreditation of Health Organizations points out,

The world of organ transplantation is also a harsh environment for people with mental and physical disabilities. When this new treatment option was first introduced, individuals with disabilities were automatically excluded from consideration for transplantation.

There are still patterns of exclusion, however. Many of the stories from the survey tell of people with health problems which others do not agree is severe enough to consider a transplant or even a referral to a specialist for evaluation. And, for those for whom a transplant is suggested, many do not receive an evaluation.

- Only half (52%) [77 of 147 Q14] of the people who asked the primary care physician for a referral to a specialist actually got a referral.
- Over a third (35%) [eyeball estimate of 48 of 139 referred, top line of Q18 graph] for whom a transplant had been suggested were never evaluated.

So what stands in the way of people receiving organ transplants for their severe health conditions? The blatant and sometimes subtle dynamics of exclusion include powerfully negative attitudes, perceptions of need for and benefit of an organ transplant, perceptions about the ability of the person to cope, financial need, and all the “regular” barriers to quality health care.

> Powerful and Deadly Negative Attitudes. High on the list of barriers is negative attitudes towards persons with physical, mental or intellectual disabilities. A full 80% of the people responding to the survey think there is a problem in accessing or getting an organ transplant because of negative attitudes.

These negative attitudes often involve the assumption or belief that some lives are not worth saving. Others make generalized assumptions about the capabilities of people with disabilities. Individuals are not seen as capable. Their support networks are ignored or discounted.

For some people, these negative attitudes have a long history and dramatically increase over time. They result in people not getting treatment and their conditions deteriorating. Sandra Jensen’s mother describes how Sandra’s heart condition could have been easily repaired in her youth. Because it was not, her situation became more and more serious over the years.

My daughter, Sandra Jensen, was born with Down Syndrome and a congenital heart defect. At that time, 1960, we were told that the heart condition could not be corrected and that she would die by the time she was in her teens. When she was 25, well past the time she was predicted to die, she went to a new primary care physician. The physician wanted to know why Sandra was not under the

care of a cardiologist. I told her that we had been told not to bother. She referred my daughter to a cardiologist who did extensive testing for the first time in her life. As a result of the testing, he told us that if she were born then that it would be relatively simple to correct the heart defect. However, in 25 years, the heart defect had caused damage to the lungs. At that time he said that the only treatment would be a heart and lung transplant. (Final Survey report, page 41)

Sidebar

Given what medicine can do today, it is important that individuals and families re-evaluate advice to “do nothing” that was given in the past. That advice may have been based on what was possible in the past. It may also have been based on profound prejudice that routinely threatened the lives and safety of people with disabilities.

There is certainly a sense in the stories from the survey that these negative attitudes often have as much to do with not being as energetic in treating people with disabilities as it does with being actively resistant to treating them. People have been and are the victims of both benign neglect and active denial of treatment. Many respondents have been told that surgery or transplantation was just not offered to people with disabilities. Many of the people who responded to the survey have experience with people with Down Syndrome, and there are many references to “denial of treatment because of Down Syndrome”. The following story suggests that even when treatment is offered, it might not be as aggressive as it should be.

My child was to have extensive open heart at age 7 weeks. I was told it was her only hope. She also as it turns out has other medical complications. Because of her need for Heart surgery all other problems were blamed on her heart or considered behavioral This situation is still a problem today. Most of her other diagnosis were found by accident. She was Failure to thrive for years before they found the glandular and stomach problems were not being caused by the Heart. The Heart doctors kept saying it was not her heart and the other specialist kept blaming everything on her heart and Mom is still trying to get her help and being blamed for making stuff up even when blood and other tests show proof of other problems. Each specialist wants to blame her problems on some other specialist and when that does not work it must be mom or behaviors. Doctors don't really listen. If they don't see a child turn blue, sweat, and become non-responsive it just does not happen. She kept "passing out" at school. After two 24 hour halter monitors were normal, it was decided it was behavioral the third halter showed she arrested 24 times in 8 hours for more than 3 seconds. Then they put in a pacemaker. I WISH I COULD FIND A DOCTOR WHO WOULD LOOK BEYOND THE DOWN'S AND TREAT HER LIKE A FULL WHOLE REAL CHILD. (page 40)

Sidebar

The basis for this exclusion was the perception of worthiness against the reality of scarcity – “a valuable organ for an unvalued life”.

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> **Perceived Health Condition and Need.** A related dynamic is the extent to which people think the individual's health condition warrants an organ transplant. On the face of it, a fair number of the respondents to the Working Group survey did not think the individual's health condition was severe enough to consider and seek an organ transplant.

- 40% of respondents themselves did not consider the health problem health condition is severe enough to consider and seek an organ transplant
- 39% (not necessarily the same people) did not ask the primary care physician for a referral to a specialist.

At least three dynamics are involved. In some cases, primary care physician appear to refer individuals to a specialist even if the individual or family does not see the need. In other cases, when some individuals and families see the need, the primary care physician may still not make a referral. And for some people, they did not have to ask -- the physician automatically made the referral. **Moving automatically toward inclusion is a far cry from being categorically excluded.**

It is also encouraging to see that many do not see the need for a transplant, at least not yet, because other interventions are being tried or have been successfully used – chemotherapy, open heart surgery, heart valve replacement, closely monitoring to see if the effects of the disease emerge, and so on. This is clear improvement from the “radical non intervention” in Sandra Jensen’s early life that caused much more serious problems later on. On the other hand, we do not know if some of these pre-transplant alternatives are because the individual is seen as not worthy of a transplant.

For some, the reasons they did not think a referral or organ transplant was necessary indicate both blatant and subtle forms of discrimination and exclusion. Subtly, the idea of a transplant may just not be raised. More blatantly and illegally, the fact of a person’s disability is given as a reason for exclusion.

I ask the case manager of the health services, but [they] never mention about organ transplantation.

Not required in my health plan.

It never comes up when I talk to my doctor.

At this time the impairment to the liver is stable, although failure is a great possibility in the near future. GI and special needs pediatrician as well as surgeons have advised me that the chances of securing a liver due to his disability will be slim to none as the disability will affect his spot on the donor list and that if a liver were to be available for him most likely the insurance company would not pay because of his estimated decreased life expectancy due to medical problems related to damage causing his disabilities.

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I have been told by her cardiologists that she is not eligible for a transplant because of her Down Syndrome.

We were told that if he was "normal" like us, he would be a great candidate for a corneal transplant.

Patient's VA doctor believes he is a good candidate for transplant but is being denied transplant because of his HIV status... The HIV doctor says his HIV status is stable, and not a barrier to transplant.

The first doctor we saw, they told us that no transplant could be done because our son was "retarded". That alcoholics and drug addicts make better candidates since our son could not handle his own medication.

My daughter was diagnosed with severe pulmonary hypertension with Eisenmengerat 18 months.... she is now 20 yrs. old.... Every doc says her odds for life are worse with transplant... No one would really discuss this with us and then when she has hemoptysis or something she is too severe for one.. she needs a heart and lung.

The battles that I have seen...have almost nothing to do with medical care, and almost everything to do with discrimination. Many of these doctors are old and think individuals with ID/MR should be in institutions and certainly shouldn't get a good kidney... This attitude is told to families over and over and over until they accept it. My friend's story has a really happy ending - but how many don't?

> Perceived Ability to Cope. Many of the stories of exclusion point to the categorical decisions and perceptions of health care professionals

My friend was not put on a waiting list as he was told that he must have a "family friend, or relative" for a caregiver for the 3 month recuperation period after transplant. Unfortunately he has not been able to find someone who is willing to not get paid & take off work in order to help him through this time. We are in the process of appealing this. My friend has concerns as he signed a paper indicating his understanding of the rules which were related to personal behavior toward staff in the liver transplant area. He is worried that if he questions decisions or has questions pertaining to process that it may be misunderstood. We will be working with an agency in the local area to assist us with this current dilemma.

The nurse in charge indicated that the team felt that he would not be able to "handle" all the medicine taken (even though he takes over 10 pills a day now)

[He was not referred] because his disability affects his normal daily activities to the extent that he requires help with daily hygiene.

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Due to his mental illness, the patient must be closely followed to monitor behaviors and medication compliance.

I was told that my quality of life was questionable since I was in a wheelchair and totally blind. I was not a good candidate because the process was "too involved for me."

All of this indicates a lack of understanding among health professionals about the capacities of individuals, their families and networks of support.

> Insurance and Financial Need. Financial need is a major barrier and basis of exclusion. Among the survey respondents, only one in three (36%) think their insurance would cover all of the costs of a transplant. In one in four (27%) of the situations described in the survey, none of the costs of organ transplant are covered by insurance. [176 people answered Q8 in terms of what insurance covered. The percentages here are based on 205 respondents.]

A large percentage of the respondents are covered by Medicaid. Because Medicaid has such low reimbursement rates, it is quite likely that the profitability level for transplant operations is not met from the point of view of health care providers. While people may see Medicaid as providing "full coverage", the reimbursement rate within that coverage would, in fact, limit the number of people accepted for surgery.

All of this, of course, has two consequences. Individuals and families do not move ahead with treatment because the costs are too high. Or, medical facilities refuse treatment because the costs are not covered. The survey indicates that about one third of the respondents have insurance that provides full coverage for organ transplantation. This is their belief, but we can not be sure that this would, in fact, mean that all the costs of transplantation would be covered to the degree acceptable to providers.

At this point, the condition is not serious enough to justify the expense. If it continues to worsen, insurance will pick up more of the costs, and I will see a specialist.

The person was told that his condition was not as severe as others, and that the cost may outweigh the condition.

With the new system, my mother up 'til now was on the bottom of the list, in this region. Due to her limited income we could not put her on a list in another region.

My husband is self-employed. As such we were not able to get insurance coverage on our private policy for our daughter with Down syndrome. We have had to jump through various and seemingly endless hoops to come up with a viable, affordable solution. In the end I have had to go to work for my husband so he could create a "group" plan for his assistant and me. Only in the group plan would our daughter be covered.

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Negative experiences are finding a health insurance that will cover my pre-existing condition and paying for most of the cost. As my graduate student insurance only covers 60-70% I am still left to pay the other cost. I feel that we need desperately national health coverage.

The condition I have may or may not make me a good candidate for transplantation, but because of limits placed by my health insurance company. I'll have to wait until I'm critically ill to find out. My doctor shares this frustration, because he's seen this type of situation evolve into a "lose-lose-lose" scenario: the patient loses because he is forced to wait for months (or even years) to get the treatment they need; the doctor loses, because his patient is sicker and may seek treatment elsewhere, and the insurance company potentially loses because care for the patient becomes more complicated and expensive as the patient gets sicker. I don't like the prospect of possibly dying before I can get the care I need, so my insurance company can make larger profits.

"I assessed the financial picture. I was 53. If I got a transplant, I would be dropped off of Medicare after 3 years. If I didn't have health insurance, which has happened before in my life, I couldn't afford the anti-rejection drugs and would lose the organ. I would be too young for Medicare until 62-65. I get along with home hemodialysis very well. Even in unit dialysis isn't so bad as a lifestyle."

> Non-transplant Related Barriers. Many of the issues already mentioned – attitudes, discrimination, money – are not unique to the transplant experience. The respondents to the Working Group's survey also commented on other barriers to good health care.

"Access to some medical and legal facilities (Doctor's office or court house) is still sometimes limited...Public transportation is often lacking..."

"Arranging for sign-language interpreter for medial appointments and training...is essential"

"Lack of education for nurses and technicians who care for dialysis clients and the need they have to treat clients poorly, lack of sterile protocol, lack of information due to clients."

Rural locations (money for trips) are concentration camps of ill prepared doctors for those with head/cognitive injuries.

"I was told that at the (university) hospital, they will transplant a kidney but not even consider a heart transplant for someone with Down Syndrome. I suppose it could be a departmental decision. It is confusing that they will do repeated surgeries up to, but not including, a (heart) transplant."

"It has often been difficult for the family to have appropriate education and therapies provided for the child without great emotional and financial expense."

Sidebar

The systemic barriers involved in organ transplantation medicine are far from trivial. One in four of the respondents to the Working Group's survey said they know someone who might or did die as a result of lack of access to transplantation medicine. Some of the dynamics included -- having to wait too long, people who appealed or litigated and did not survive their struggles for surgery, lots of close calls where transplantation arrived in the nick of time, misdiagnoses, less definitive interventions that didn't work, consequences of the general lack of good preventive and early intervention medicine in the system, and of course those who were deemed "medically" inappropriate for transplantation.

What's To Be Done?

The people who responded to the National Working Group on Disability and Transplantation survey have a number of stories about strategies that have worked for them. The Joint Commission on the Accreditation of Health Organizations argues for increasing the supply of organ donations and systematically examining ways to remove the barriers faced by people with disabilities. The Working Group has developed a series of recommendations to focus advocacy and research, and improve system wide access to transplantation medicine.

> Advocacy and Allies. The Working Group survey collected lots of stories about successful efforts to reverse decisions, help professionals and institutions see the light, and find people more willing than the barrier creators to help. These stories suggest a list of actions that individuals, families and their allies can take.

- **Put on the pressure.**

My daughter was refused a heart-lung transplant because as the doctor said "We do not consider a person with Down Syndrome a candidate for transplantation." Later, with much pressure, the decision was reversed.

- **Use the law. Discrimination is illegal.**

Both the physician and myself are extremely upset about his not being a candidate for the transplant and plan on appealing the decision... and if need be, press discrimination charges against the hospital.

At that point, we contacted the National Downs Syndrome Congress who gave us the contact in the US Justice Dept. The lawyers there were highly interested in this case and flatly stated they would come to Denver to pursue this if necessary. However, their letter to University Hospital did the trick in changing the attitude of the doctors. The letter asked what the hospital procedures were to qualify someone for transplant without revealing our son's name. They didn't have to.

Their letter head spoke volumes and we were then told by a member of the transplantation team that they could not discriminate.

- **Identify and marshal your allies.**

Again, this was only given as an option after many, many meetings and many hours of advocacy on the part of his family, friends, and finally an Arc advocate. The "funny" part of his story is that in the end all the Arc advocate had to do was introduce himself, state what Arc's mission is, and suddenly my friend would be on the list at the end of the day.

One of our legislators got involved and told the hospital I had an ADA complaint that I would probably win. The hospital quickly re-evaluated Reagan. She was on the heart transplant list as a 2. She was on the list 13 DAYS when we got the call.

- **Learn what you need to know. Take a second look at what you were told in the past.**

Too few families have the time, knowledge, and skills to do the work we did to make this happen for him. I have to say again - thank you for collecting this information! It is so important. If I hadn't had a fit about this, and more importantly if Arc hadn't been sitting in that meeting, my friend would probably be dead today. He should have been on that list 5-10 years earlier.

We feel that more information should be given to the parents and/or patient. Our family was given a sugar coated version of what goes on in transplant. Now we have lived the extreme and seen the extreme that multi-visceral transplantation is. We have been in the hospital more than home since transplant. One thing or another happens. I feel that more knowledge for the families is essential. If I had not researched many of the treatments and options on my own, I would be lost. Many of the families I have encountered here at the transplant center are oblivious to what is going on medically with their child.

- **Get another opinion. Shop Around. Get on Multiple Lists. Play the Game.**

Initially, the first eye specialist stated because our child was Down syndrome, she may not be eligible to receive the corneal transplant. We questioned this statement and were referred to another eye specialist. The situation has not been resolved since we are new patients (only one visit) to the new doctor.

These are steps that individuals and families have taken, often in cahoots with advocacy organizations. It would be much easier, of course, if the system changed so that all this energy did not have to be devoted to playing the system.

> System Change. Both the Joint Commission on the Accreditation of Health Organizations (JCAHO) and the National Working Group on Disability and Transplantation have a series of recommendations to begin to address the inequities and life threatening issues facing people with disabilities who could benefit from organ transplantation.

Some of the JCAHO recommendations are:

- Employ grassroots efforts such as those used by MOTTEP [The National Minority Organ Tissue Transplant Education Program] to raise awareness, change behavior and increase the rate of donation among ethnic and minority groups, and among persons with disabilities and their families.
- Periodically re-evaluate the priorities for organ allocation to identify opportunities to equalize access to transplantation.
- Conduct further studies to enhance knowledge about the underlying causes of transplantation disparities and to create a basis for problem solving.
- Develop American with Disabilities Act compliance and clinical training materials and certification mechanisms to enhance health care professional knowledge and abilities to serve persons with disabilities.
- Establish protocols for assessing the ability of disabled patients to comply with post-transplant regimens.

The Working Group's recommendations call for action on several fronts:

- Recognize the serious lack of national and local data regarding the experience of persons with disabilities and the transplantation system. Immediately fund and mount a proper, scientific study, appropriately sampled using multiple methodologies. In other words – find out what is going on.
- Give priority to and take action in those areas where corrective intervention would have the most immediate effect of upgrading and expanding services to persons with disabilities. Mount a training initiative to initially target the gatekeepers and decision makers of this system. The training initiative should be inserted into JCAHO accreditation standards
- Establish a “Center for Leadership, Research and Training Center on Disability Transplantation”. The Center would be a focus for advocacy, consultation, oversight and coordination to systemically ensure equal and quality access to organ transplantation medicine.

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- JCAHO must continue to exercise its pioneering leadership in examining and shaping national health organization accreditation and quality services to bring competence, parity and equity to the broad disability community.
- Intensify the campaign to reform the state and federal financing system to remove the myriad barriers to affordable, universal health coverage and service. That system largely defines the American health care experience for all of us.

Sidebar

It is the fundamental reiteration of wholly illegal, explicit and de facto discrimination, ignorance, and the lack of systematic professional training, scientific and objective information exchange, that require bold action by all parties.

The National Working Group on Disability and Transplantation

> Sign Up to be a Donor. The people who responded to the Working Group survey often had two types of stories – the importance of finding your own donor, and the tragic consequences of waiting too long for a suitable organ.

Over half of the people who responded to the survey said they would donate organs as a live donor, though most preferred donating only to a family member or friends. Almost three quarters said they would donate organs upon their death. [*These are eyeball estimates based on the graph Q22*]. Over 20% said they were already donors. And another 38% said they would be more likely to become donors if there were equal access to transplantation medicine for people with disabilities.

Her brother was an acceptable donor. We were on the waiting list for about a month for a space in the facility to open up.

His younger brother donated a kidney.

After being followed and having surgery, at age 3 he received the first (my kidney) transplant.

I had a transplant nearly 7 years ago; my brother gave me one of his "pre-owned" kidneys

Transplantation was done through relative living donor. Waiting list option was deemed too long (by myself) when I learned the average wait was 4.5 years for a kidney

With the proper recognition and support of the health care community, people with disabilities, as well as their families and advocates, can improve access to transplantation by becoming organ donors themselves. Increasing organ donation ultimately means there will be more organs available for everyone.

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[Note: Can we refer folks to a place where they can find out how to become a donor in their state?]

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