

SUMMARY REPORT

of

INDIVIDUAL AND FAMILY DISABILITY SURVEY

from

The National Work Group On Disability & Transplantation

March 11, 2004

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The National Work Group on Disability & Transplantation (NWGDT) is an all-volunteer group of disability family, professional and consumer organization leaders and senior advocates, teamed with representatives from the medical, surgical and administrative top echelons of the America's organ transplant system.

Our purposes are to:

- Remedy the unacceptable dearth of data regarding access to, and the experience of, persons with disabilities in seeking transplantation assessment and services using a national survey and creation of a national level research project afterwards;
- Promote better understanding and treatment of persons with mental and/or physical disabilities by the transplant medical profession community;
- Stimulate major information exchange gatherings among the diverse disability movement members and the transplant profession to overcome barriers and stereotypes;
- Nurture a commitment among the disability and family population cohort to become life sharing donors to build the national pool of organs and reduce the heart wrenching shortages that exist; &
- Explore the establishment of a National Resource Center for Disability & Transplantation

The precedent-setting struggle and success occurred in getting a heart-lung transplant for Sandra Jensen, a 32 year old California disability rights self advocate, the first person with Down Syndrome in the world to receive such an operation. This exposed the unacceptable national default in each of the above system arenas. Now, nearly a decade later, a wellspring of leadership interest has reignited the agenda of concern for system development. What is clear is that policy and practices in the transplantation field have added to effectively excluding persons with mental retardation and other disabilities through the "psycho social" official criteria and absence of awareness training that perpetuates de facto discrimination.

This exclusionary bias is heavily exercised at the primary care 'gateway' where access and the decision occurs to make referrals to specialists and beyond. This exclusion is equally applied in the OPO system by many decision-making health professionals who are not privy to the true realities of persons with mental retardation and other major disabilities. These people are most often seen through negative stereotypic and biased professional eyes. Lacking policy guidelines, little or no expertise is sought from centers of disability service and research excellence to objectively and specifically define the true capacities of applicant individuals with special needs in coping with and mastering the post-surgical personal management demands. Thus, a large percentage of such individuals are easily deterred from even seeking life extending and saving treatment offered by organ and tissue transplantation. This dynamic is compounded by the extremely fragmented US system of medical services and financing where no consistent policies are applied from level to level of the system. The need for the JCAHO to examine and modernize its accreditation standards in this specialized area is just the tip of the proverbial iceberg in addressing the huge variance of access, fairness, and quality service across our health care system.

Our call is for access, equity, unbiased fairness, and substantive training to provide a caring challenge to the transplant professional community as the norm of practice. This initial survey effort aims to catalyze more scientific research, professional training and public outreach efforts to follow.

Our NWGDT meetings to address this problem of people with disabilities being "disappeared" by the system serendipitously began as the Joint Commission on the Accreditation of Health Organizations (JCAHO) mounted their historic focus to look at how to address the need for more donors and the need for revisiting its organ transplantation policy and standards setting role in the nation's health system.

This representative national survey begins to explore the undocumented truths in the situation, coupled with an intuitive sense of the general benefit that will come from examining those truths. When complete in April, it will hopefully reach nearly 1 million families and advocates at no cost.

The survey was cooperatively designed and posted online at www.govoter.org/transplant/survey.htm by TheArcLink Incorporated. Each member of the NWGDT e-mailed their members and organizational allies to continue to send out the link in expanding circles throughout the US. Respondents had but to fill in the survey on line. A committee of the whole worked on interpreting the study for this report. An initial deadline date was set to gather an initial report for this meeting. A final tabulation will be done after the final deadline of April 15 in order to provide to the Board of American Society of Transplantation and the American Society of Transplantation Surgeons in time for their May Joint Congress.

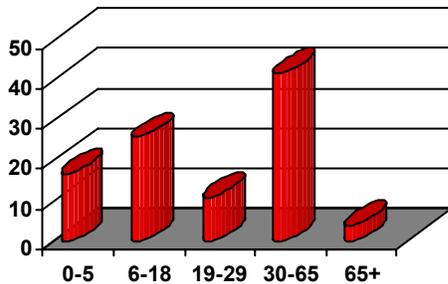
THE SURVEY QUESTIONS

1. I am a person with a disability filling out this survey on my own behalf. All the information pertains to me and my personal health condition
2. I am responding on behalf of someone with a disability. My relationship to that person is:
3. City, State, Zip Code:
4. Age of person with a disability:
5. Gender of person with a disability:
6. Ethnicity/Race of person with a disability:
7. Insurance coverage for the person with a disability (check all that apply):
8. Does the insurance coverage for the person with a disability in Question 7 include organ transplantation costs?
9. Disability Diagnosis: (e.g., intellectual disability, emotional disability, physical disability, sensory disability, autism spectrum disorder, Down syndrome, learning disability, mental retardation, etc.) Fill in as appropriate, single or multiple diagnoses.
10. Please identify the organ system involved in the chronic, severe health problem or disease experienced by the person with a disability (check all that apply):
11. Do you feel that the health problem is severe enough to consider and seek organ transplantation?
12. Did you ask your primary care physician for a referral to a specialist or specialty clinic?
13. If no, why not?
14. If yes, did your primary care physician or specialist then refer you to a transplantation center or clinic for the problem?
15. If not, are you in agreement with that decision? If not, specify why.
16. If you were referred to a specialist or transplantation center, was transplantation ever suggested as a possible option?
17. If not, are you in agreement with that decision? If not, please specify why
18. If transplantation was suggested as an option for you please check one of the following outcomes:
19. Please feel free to explain your answer to the above question. If you are on a waiting list, please say how long you have been on the list and what your rank is on the list.\
20. We are interested in the experiences of people with disabilities with transplantation-related health problems, both good and bad. We realize that you may also have experienced non-transplantation related barriers in your medical care. If you want to briefly share your experiences please utilize the space below.
21. Do you believe that there is a problem in accessing or obtaining an organ transplant that is associated with negative attitudes towards persons with physical, mental, or intellectual disabilities?
22. For family members and advocates responding on behalf of a person with disability, would you:
23. For family members and advocates responding, would ensuring equal access to transplantation medicine for people with disabilities effect your decision to become a donor?
24. Do you know of anyone who in your view might have died as a result of lack of access to transplantation medicine?
25. If your answer to Question 24 was "Yes", please provide more details.
26. Please identify the organization or association from which you received the link to this survey (no acronyms please!). Please note that many disability organizations are participating in this survey. We ask that you respond to the survey only once.
27. Would you (or family members or friends responding) be interested in further information about opportunities to become donors?

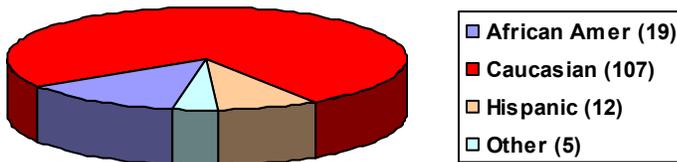
SELECTED SURVEY FINDINGS

DEMOGRAPHICS

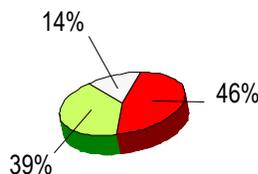
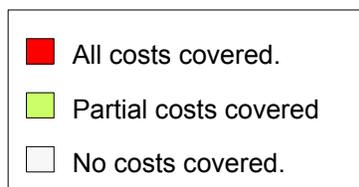
- An initial 143 responses were received between 2/6/04 and 2/26/04 as the basis for this report.
- 1/3 of the respondents were persons with disabilities themselves, 2/3rds were family members advocates, professionals and other respondents.
- Responses came from 40 states in the US.
- The gender split was roughly half and half.
- The age grouping of those with disabilities were for 0-5 years old - 17%, 6-18 - 26%, 19-29 - 11%, 30-65 - 42%, and for 65 plus - 4%. This bimodal data raises questions about the program and organ management issue differences between pediatric and adult cohorts.



- The racial profile seemed to indicate representation that suggests a class and cultural skew that favors people with on line computer access, and those with membership in the mainstream disability organizations. The implications require future research to take into account alternative culturally appropriate organizational and outreach channels and languages to reach the whole population.



- The health insurance coverage profile showed a large percentage of Medicaid respondents which typifies persons with mental retardation. It is likely that given the low reimbursement rates from Medicaid, transplant operation profitability is not reached, thus setting the stage for de facto limits in the numbers of persons with such coverage being accepted for surgery.
- Half the respondents reporting that health insurance provided “full coverage”, 40% with “partial coverage”, and 14% reported their insurance provided “no transplant costs covered”. It is not clear whether this reflects their actual experience with transplantation costs, or their expectations, or the fact that Medicaid provides “full coverage” for whatever it costs.

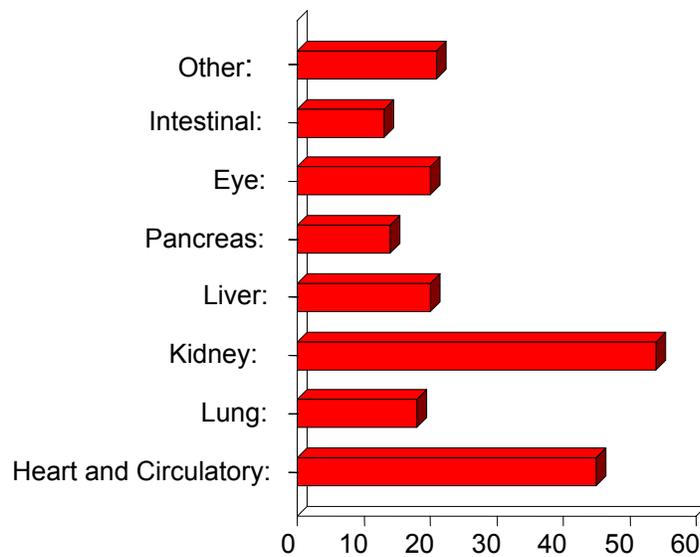


- Throughout the study, despite its catch-as-can character, a great diversity in self-identified primary and secondary disabilities was reported.

Medical	25%
Mental Retardation	23%
Physical	21%
Sensory	4%
Psychiatric	3%
Multiple Diagnoses	25%

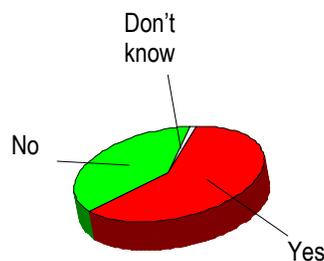
ORGAN TRANSPLANTATION

To understand the reported profile of involved organ systems a comparison to the incidence in the general transplant system population would be helpful to interpret any variances. For example, the significant incidence of Down Syndrome in our respondents due to the participation of two national Down Syndrome organizations undoubtedly results in a higher Cardiac problem presence.



The Survey looked at the key steps in the referral 'gauntlet' traversed by consumers in seeking transplant evaluations and services. Each step - seeking primary care and referral to a specialist, - the specialist referral to the transplant center, - the transplant center's decision to evaluate, list or not list the patients showed the following:

- Of the 143 respondents, more than 1/3 did not seek primary care referrals while 2/3rd did.



- The spread of reasons when we asked, “why not?” included both clear and explicit examples of discrimination, as well as examples of perceptive and concerned pass through to the specialist level by the primary MD.

“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.”

“At this time the impairment to the liver’ is stable’ although failure is a great possibility in the future. GI and special needs pediatrician as well as surgeons have advised me that the chances of securing a liver due to ..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 the medical problems related to damage causing his disabilities”.

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

“ It never comes up when I talk to my doctor.”

- Asked, did the primary care physician or specialist then refer the person to a transplant center or specialist? 44% of the remaining 105 indicated NO, 56% replied YES. Again people were asked their take on whether they were in agreement with the non referral decision.

Examples of clearly positive stories said:

“My nephrologists referred me to the Transplant Clinic at Virginia Mason Hospital in Seattle.”

“Ella’s heart defect is relatively common, AV canal, and she underwent corrective surgery.”

But the preponderance of responses again showed a pattern of clear-cut discrimination:

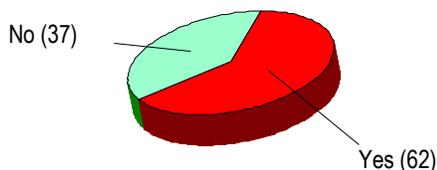
“(Our) pediatric cardiologist said it wasn’t time yet. He also said that because my son had Down Syndrome that you know that will never happen”

“I was told she has Down’s and would not even be considered for transplant. This was at (the university hospital) in Miami. This was before she lost her private insurance and before ... Addison’s Disease was diagnosed.”

“I am not sure ... they have said in the past that she is too severe for transplant.”

“The doctor continued to say this individual was “medically ineligible”. When this was investigated by me and an advocate from The Arc, we found that NOTHING made this individual medically ineligible. We argued this and argued this...finally calling a large meeting with his nephrologists, family, care team, and an ARC advocate. As soon as the doctor figured out The Arc’s role at the meeting he said he’d get the individual on the donor list ASAP. In the 2 years following this battle with my friend, I met 3 other individuals who see the same nephrologists ... all were given the same line.”

- Finally, of the remainder, 99 respondents, that were referred to a transplant center specialist, the question as to whether a transplant was suggest as a possible option resulted in 1/3 saying NO, and, 2/3rds saying YES.



- Reasons respondents gave for “not” getting the transplant as an option resulted in replies such as:

“I do not want it for multi reasons. One is personal, I don’t want to take a transplant from someone else who wants one.”

“My anatomy makes transplant exceptionally high risk, low likelihood of positive outcome.”

“A transplant was not necessary. Just open heart surgery to fix 3 holes and faulty valves.”

However again, strong examples of bias and financial need were dramatic:

“I was told that it was not an option because she had Down Syndrome.”

“I’ve not yet been referred and with advocacy may be able to get those doors open. But it calls for walking a fine line because with an emotional disability any questioning they’re uncomfortable with can be easily dismissed.”

“We were told at first that our son could not get a liver transplant even though he was medically qualified. We contacted the US Justice Dept Disability Section and received help from them. Because of the inquires to the doctors and hospital involved, we were then informed that they could not discriminate against anyone with a disability.”

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

“ Not enough money.”

“No, because his disability affects his normal daily activities to the extent that he requires help with daily hygiene.”

“I did not agree. People with Developmental Disabilities should still have a right to life.”

Our findings show that even with significant disabilities, real percentages of people get properly evaluated and treated. Nevertheless, for those professionals who see people with disabilities as hopeless, less valued, helpless, we find a stubborn implacability and access barrier erected. The mindless stereotyping easily leads to ignoring the benefit of a thorough and individualized evaluation, and more, does not consider seeking the expertise to assess the feasibility and relevance of accommodations both in adaptive technology and existing human service supports that would make any given individual achieve a successful and highly functional surgical outcome. It is notable that what is good for persons with disabilities may augment outcomes of typical patients.. ‘what is good for the goose..’

This commonly found deterrents to transplant access on the part of so many of the primary care gatekeepers in the referral gauntlet, without their seeking the benefit of qualified expert evaluation, foreclosed on enough of the respondents in this initial survey to warrant mounting the most serious and thorough national study to assess this unprofessional stance.

- A spectrum of options was offered regarding respondents’ experiences and consequences when finally reaching the transplant specialist’s evaluation point and whether an organ transplant was suggested in the process. 1/3rd of those referred received no specialist evaluation and a few felt what was provided was unsatisfactory giving their reasons. The balance indicated a “satisfactory evaluation was performed” with a variety of outcomes, commenting:

“Both the physician and I 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. 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) and makes it to all his

appointments...and never misses his dialysis 3 times a week."

"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".

"Due to budget cuts, there is no money."

"My daughter was diagnosed with severe pulmonary hypertension and Eisenmenger...at 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 lung."

"My friend was not put on a waiting list as he was told that he must have a "family friend or relative" for a care-giver for the 3 month recuperation period after transplant. Unfortunately he has not been able to find someone willing to not get paid and take off work in order to help him through this time. We are in the process of appealing this."

"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...and in 13 days...we got the call."

Invited to share their experiences, both good and bad, that included non transplant related barriers in their medical care", poignant and predictable concerns were expressed:

"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."

"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."

"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."

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

"For us the transplanted kidney and pancreas was a success and a blessing. Bill has a degree of independence not before possible, while for those of us who care for him the daily care is greatly reduced."

"I had 2 kidney transplants and I'm feeling great now."

"The transplant process was very successful. The younger brother was a perfect

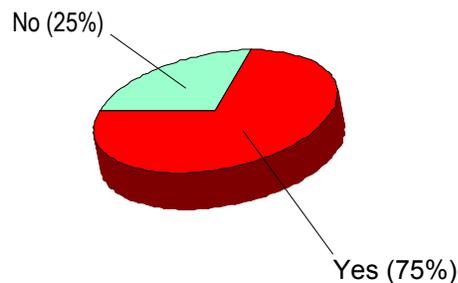
match and very willing to donate the kidney. Both boys are doing great and back at work.”

“All experiences have been very positive.”

(For complete and lengthier replies see Web link full data on Question #20 at www.theaclink.org/egroup/InitialTransplantationSurveyResults.pdf.)

EXPERIENCES AND OPINIONS

In response to, “Do you believe that there is a problem in accessing or obtaining an organ transplant that is associated with negative attitudes towards persons with physical, mental, or intellectual disabilities, the response was consistent and dramatic: 75% responded YES.



Thus, at the bottom of this quest to informally determine if a problem exists, either perceived or in reality, this Survey speaks plainly and unequivocally.

- Respondents were asked about their attitudes toward organ donation, including being a “living donor”. Based on the replies alone, approximately 1/3 of those responding indicated that they would be more inclined to be a donor IF they could be assured equal access to transplantation medicine existed for people with disabilities. In this response, 1/5 were already committed to donation and 2/5s indicated that accommodation to the disability community as such would not affect their decision to be a donor.
- 1/4 of those responding indicated that they know someone that might or did die not seeking an organ transplant. In explanations, loss came from people 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.
- Finally, 2/3 of those who responded expressed interest in getting more information and asked for a call to help them.

DISCUSSION AND RECOMMENDATIONS

Still today, government, UNOS, academic, and professional medical literature is virtually barren of information that would describe the experience of persons with intellectual, mental and physical disabilities seeking or getting organ transplants despite the minimum of 6-7 million individuals in the US with such conditions. The knowledge about and effort to access transplantation services among the community of persons with disabilities and their families and the service industry workers whose lives are intertwined with this population are equally a mystery. From prior experience with the US Department of Health’s administration of the transplant system and UNOS, there is no information of anyone with such a disability serving on any of the myriad of policy and advisory bodies, nor the intention to insure such diverse participation. There is also a demonstrable hiatus between the scientific, university based leadership that provides the national expertise and consultation on behalf of the disability world and the organized or

practicing professional organ transplant community. Individual cases, cries for help, isolated professional or clinic examples of excellence and compassion continually pop up with no centralized source to monitor, assist, or study how to make the system “indivisible with liberty and justice for all”.

It is not the examples of pathos or the inescapable stories filled with sadness and suffering that weaves through this struggle for prolonging life and forestalling death that demands our attention and action in this Survey. It is the fundamental reiteration of wholly illegal, explicit and defacto discrimination, ignorance, and the lack of systematic professional training, scientific and objective information exchange, that require bold action by all parties. We must have data and research. We must have continuous meaningful inter-professional and ongoing information rich dialogue with the concerned citizen and consumer organized community. We must have standards of practice, accreditation and excellence in service. We must have an expansion of public support for “Sharing life” through a elevated sense of identification with each other through organ donation, and we must have progressive and massive reform in the way in which health care is paid for towards it’s becoming a basic human right, independent of one’s wealth, class, race, religion, gender preference, age and or disability. The overall challenge is incontrovertible and clear. Professional and political solutions must be aggressively put forth. And our success here must become a source of national and personal pride.

Therefore, we propose the following as a first set of steps to correct this situation:

1. Immediately fund and mount a proper, scientific study, appropriately sampled using multiple methodologies, to address the absolute dearth of national and local data regarding the experience of persons with disabilities and the transplantation system.
2. Prioritize and address those transplantation system organizational, informational and program areas where corrective intervention would have the most immediate effect of upgrading and expanding services to persons with disabilities. This should include a training initiative inserted into JCAHO accreditation standards to initially target the gatekeepers and decision makers of this system.
3. Designate or establish an institutional focal point for scientific, philosophical, and organizational advocacy, consultation, oversight and coordination to systemically insure equal and quality access to, and services from, the organ transplant system to be organized and funded. This apparatus, “Center for Leadership, Research and Training Center on Disability Transplantation” should be established either as an empowered component of the existing national system under UNOS or as an independent collaborative entity derived from the national university disability training and research network and citizen/consumer organizational universe.
4. 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 as it seeks organ transplant services and, the full spectrum of basic and specialized health care in America.
5. A major focus must be made to intensify the campaign to reform the state and federal financing system that, in dominant part, defines the American health care experience for all of us in order to remove the myriad barriers to affordable, universal health coverage and service access as a right.

- See full data at: www.thearlink.org/egroup/InitialTransplantationSurveyResults.pdf

++ Please continue to disseminate the Survey link (www.govoter.org/transplant/survey.htm) to expand the response base by April 15 deadline.

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