

**National Work Group on
Disability and Transplantation**

Contact: William Bronston, M.D., NWGDT, 916-922-0100
Colleen Wieck, Ph.D., MGCDD, 651-296-9964
Steven Reiss, Ph.D., Nisonger Center, 614-292-2390
Roy Wallace, The Wallace Group, 651-452-9800

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**NATIONAL STUDY PANEL CITES BIAS AND CALLS FOR REFORM OF POLICIES
AND PRACTICES GOVERNING TRANSPLANTS FOR PEOPLE WITH DISABILITIES**

Survey by National Work Group on Disability and Transplantation reveals dimensions of the problem; panel makes urgent call for corrective action; National Disability Transplant Support Hot Line and information center established at Ohio State University

A preliminary survey by a national professional study panel revealed that a large majority of the people with disabilities interviewed regarding organ transplantation believed they were subject to "wholly illegal, explicit and de facto discrimination" regarding organ transplant availability. The people with disabilities and others who responded also said they encountered ignorance, as well as a general lack of professional training and objective information on working with the many disability communities.

The National Work Group on Disability and Transplantation (NWGDT) reported that "survey results indicate that policy and practices in the transplantation field have resulted in effectively excluding persons with intellectual and other disabilities." The study group attributed this to the improper use of "psychosocial" criteria employed in qualifying transplant candidates and the lack of awareness training, which serves to perpetuate express and de facto discrimination.

The survey was conducted early this year, with more than 200 responses received in the February through April period. Some 24 percent of the responses were from people with disabilities themselves, while the remaining 76 percent were comprised of family members, advocates, health care professionals and others involved in assisting them, as well as others in the disability community. Responses were received from 44 of the 50 states and were fairly evenly distributed by gender, with 45 percent male and 55 percent female.

William Bronston, M.D., coordinator of the National Work Group Survey, said, "There has been an absolute dearth of medical reporting of people with significant disabilities in the world literature seeking or receiving organ transplantation."

The survey data suggests that the exclusionary bias is most often found at the primary care level, the "gateway," where decisions are made about providing people with disabilities access to transplant specialists. Health care professionals in national organ procurement organizations may follow the same discriminatory or exclusionary practices, the report said.

"People with disabilities are often seen through negative stereotypic and biased professional eyes," the report said. Without policy guidelines and with little or no expertise in disability services, it was said, medical professionals may not be objectively assessing the true capacities of applicants with disabilities in coping with and mastering management demands after surgery.

Prompted in part by the results of the NWGDT on-line survey, the Nisonger Center for Mental Retardation of Ohio State University is launching a new initiative, Lives Worth Saving, A National Project on Mental Retardation and Solid Organ Transplantation. Features of Lives Worth Saving include a national disability transplantation support hot line which families and people with disabilities can access for advice on how to gain information regarding transplant services and policies. This innovative new program will also establish a center offering professional training for transplant nurses and decision makers. The Nisonger Center is headed by Steven Reiss, Ph.D., Professor of Psychology and Psychiatry at Ohio State University. Dr. Reiss, himself, is a post-transplant liver patient.

Dr. Bronston indicated a challenge by leaders of the American Society of Transplantation, members of the NWGDT, was a prime motivator for the recently completed survey. "The reason we did the study is that people in the field requested evidence that a genuine problem existed. The study is a tremendously meaningful wakeup call to us all, and now warrants a definitive national study."

Too many medical professionals do not understand the significant support systems that exist or can be provided to people with disabilities, the study found. As a result, the report said, "a large percentage of such individuals are deterred from even seeking life extending and saving treatment offered by organ and tissue transplantation."

The NWGDT suggests that the problem is compounded by the fragmented U.S. system of medical services and financing, noting that coverage policies are not consistent anywhere. The report calls on the Joint Commission on Accreditation of Health Organizations, which is seen as responsive, to continue to examine and modernize its nationwide standards and policies on this subject. "We have thus far only examined the tip of the proverbial iceberg in addressing the huge variance of access, fairness, and quality services across our health care system," said the NWGDT report.

The full survey report will be covered in an article by Fred Pelka, which appears in the December 2004 issue of *Exceptional Parent*, and invites the 43 million members of the U.S. population with disabilities to understand and to participate equally in using this remarkable life extending technology.

Noting that the preliminary survey was intended to determine the need for action, the NWGDT calls for more scientific research, professional training, and public outreach over the next several years. "The needs for full inclusion in universal health care for people with disabilities must be addressed," said Dr. Bronston, "rather than seeing these millions of people as less than human and an expendable burden."

While some individuals with disabilities have managed to move through the transplant system referral "gauntlet," many still face barriers at each step of the way. The study also showed that though some people with disabilities are categorically excluded from transplantation opportunities, this is not universal. The report says. "We need to know more about these exclusionary processes and how they operate."

A majority of the people with disabilities participating in the survey reported they felt that they had experienced discrimination, ranging from ignorance exhibited by health care staff and poor training of professionals, to the lack of sound objective information. The survey panel said this underlines the need for additional research about the questionable processes involved, how they work and how to end them.

Noting the 43 million people in the U.S. with disabling conditions, the report points to the public and private system wide policy leadership and academic and professional medical literature as lacking data on the experiences of people with intellectual, mental and physical disabilities seeking or receiving organ transplants. "From prior experience with the Department of Health and Human Services administration of the transplant system and the United Network for Organ Sharing (UNOS), there is no information of individuals with such a disability being sought to serve on any of the myriad of national policy and advisory bodies, nor the intention to insure such diverse participation," the report said.

In summary, NWGDT proposes that funding be provided immediately for a proper and definitive scientific study using multiple methodologies, and appropriately sampled, to remedy the lack of national and local data on the experiences of people with disabilities seeking transplantation. In addition, the group wants to prioritize and work on those organizational, informational and program areas within the system where corrective intervention would be most effective in upgrading and expanding services for people with disabilities.

Further recommendations included the creation of an institutional center for a national hotline, advocacy, and coordination, activities being undertaken by the new program at the Nisonger Center at Ohio State University.

The panel also calls on the Joint Commission on Accreditation of Health Organizations to continue its pioneering leadership role in shaping policies to bring competence, parity and equity to the broad disability community as it seeks organ transplant services, as well as the full spectrum of health care in the U.S.

Finally, the NWGDT urges reform of state and federal health care financing in order to ensure that barriers to affordable, universal health care coverage and services are removed.

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Formed in 2003, the NWGDT is an all-volunteer group of leaders and advocates representing people with disabilities, family members, and professional and trade associations, together with members of the medical community.

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NATIONAL WORK GROUP SURVEY, CONTRIBUTING MEMBERS
(partial list)

COORDINATING TEAM

William Bronston, M.D., Coordinator

David Goode, Ph.D., Professor of Sociology, City University of New York (Survey Content)

Robert Griss, Director, Center of Disability and Health

Elbert Johns, President, The ArcLink Incorporated (Online Survey Design and Management)

CONSULTANTS

Ronnie Cohn, Developmental Disability National Consultant and Federal Court Evaluator

Doreen Croser, Executive Director, AAMR

Steve Eidelman, Executive Director, The Arc of the United States

David Hammer, Ph.D., Adjunct Associate Professor, Psychology, & Director of Psychology Services, Nisonger Center, Ohio State University

Robert Metzger, M.D., Vice President, United Network for Organ Sharing (UNOS)

Steven Reiss, Ph.D., Professor, Psychology and Psychiatry, & Director, Nisonger Center, Ohio State University

Nancy Weiss, Executive Director, TASH

Colleen Wieck, Ph.D., Executive Director, Minnesota Governor's Council on Developmental Disabilities