

July 8, 2004

Attention: Robert Jaeger, Ph.D.  
Executive Secretary  
Interagency Committee on Disability Research  
United States Department of Education  
550 12<sup>th</sup> Street, SW, Room 6050  
Potomac Center Plaza  
Washington, DC 20202-2700

**VIA ELECTRONIC MAIL**

Re: Comments by the National Association of Councils on Developmental Disabilities on Future Federal Research for Individual with Disabilities (Federal Register, Vol. 69, Number 125, Pages 39444-39445, June 30, 2004)

Dear Dr. Jaeger:

The National Association of Councils on Developmental Disabilities (NACDD) is pleased to provide written comments on the Interagency Committee on Disability and Research (ICDR) disability research agenda. NACDD is a national, member-driven organization consisting of 55 State and Territorial Councils on Developmental Disabilities. NACDD and its member Councils advocate and work toward positive system change on behalf of individuals with developmental disabilities and their families. We believe strongly that meaningful research outcomes help to further this goal.

### **Background**

NACDD is a newly-formed national disability organization, established in 2002 to bring together the two organizations that previously supported Councils on Developmental Disabilities – the Consortium of Developmental Disabilities Councils and the National Association of Developmental Disabilities Councils. NACDD represents the diverse interests of its Council members and serves as its national voice. Its purpose is to support Councils in implementing the Developmental Disabilities Assistance and Bill of Rights Act and to promote the interests and rights of people with developmental disabilities and their families.

NACDD supports the notion that each person with developmental disabilities is unique and that appropriate treatment and rehabilitation will vary from individual to individual. The rehabilitation process is different for everyone. Rehabilitation programs should be individualized and should cater to each person's unique needs. The goal of rehabilitation should be to help people regain the most independent level of functioning possible in the most integrated setting possible – the community. Further, we believe that programs and treatments must change over a person's lifespan, just as a person's individual needs will change over time. It is critical to recognize that "more therapy" does not necessarily equate to "better therapy" and that "appropriate therapy" is the key.

## Medical vs. Non-Medical Interventions

We believe that an alarming trend is growing in the United States, relative to the use of more and more pharmacological treatment for persons with developmental disabilities versus the use of non-medical therapies such as positive behavior supports, positive developmental strategies or social relationship methods. We have observed the medical and research communities routinely resorting to treating children and adults with medications as a “quick fix” without trying the non-chemical/less harmful course first. Further, persons with developmental disabilities often are given drug upon drug without regard for how these drugs may interact, nor is careful consideration always given to how these medications may affect a person who experiences developmental challenges.

Often, these medications have significant negative side-effects such as intense sedation which can hinder the way in which a person with a developmental disability learns and functions and which can cause new disabilities to occur. It is also our concern that poly-pharmacy may cause serious long-term, developmental outcomes. Practitioners may not be schooled in how various medications affect a person with a developmental disability, as opposed to a person who does not have a disability. More systematic methods of monitoring for *tardive dyskinesia* should be available and accessible for those interested in this issue.

- **Research Suggestion**

We would like ICDR research to focus on positive outcomes resulting from non-pharmacological therapies and to steer research toward sound, non-chemical developmental strategies. It is common knowledge among families and providers in the disability community that positive behavior supports consistently have proven effective. We would like to see more formal studies conducted to support this widely-known fact. We would like research to be conducted that underscores and appreciates non-medical supports and for ICDR to recognize that pharmacology is not the panacea for persons with developmental disabilities.

Currently, if a school system or an entire state wanted to implement positive behavioral approaches, there is no compendium of research studies to support such a progressive approach.

## Recognize that Health Disparities Exist

It is a sad reality that people with developmental disabilities (and other disabilities) are discriminated against by our U.S. health care system because of great disparities that continue to exist regarding treatment, follow-up care, physician-patient communication, health care delivery mechanisms, availability of medicine and medical devices and poor diagnoses. According to the Centers for Disease Control and Prevention (CDC) although limited, current data indicate **that health disparities between people with and without disabilities are as pervasive as those recognized between ethnic minority groups.**

- **Research Suggestion**

We believe that an investigation into the crisis of health disparities that exists for persons with developmental disabilities is warranted, especially when compounded by other factors such as education, geographic setting, race and ethnicity and availability of family supports.

### **Focus on Children**

We believe that research studies relative to children with disabilities are lacking in the Federal disability research agenda. The good work being done by the Office of Special Education Policy cannot serve as a substitute for solid, innovative studies on children with developmental disabilities and their integration into all aspects of society, beyond the classroom.

- **Research Suggestion**

We would like to see an ICDR research agenda that focuses on the inclusion of children in all facets of society outside of the school environment. We would like for ICDR to recognize that children with developmental disabilities have long been subjected to an historical bias in the United States toward segregation, especially when it is more “convenient.”

### **Focus on Persons Who are Aging**

Persons with developmental disabilities experience a different set of issues and impairments as they age. Often, they experience secondary conditions and the onset of new disabilities which compound their medical and cognitive issues. Further, the lack of critical long-term services and supports for persons with developmental disabilities who are aging creates a whole new set of problems, including unnecessary institutionalization in nursing homes.

- **Research Suggestion**

We believe it would be helpful for ICDR to conduct research that would identify strategies for reducing the onset of secondary conditions for individuals with disabilities due to aging, particularly those strategies that maintain independence and quality of life. Even more important would be to conduct studies on outcomes, therapies, interventions, etc. that are unique to persons with disabilities who are aging.

### **Employment**

We would like ICDR studies to focus on competitive employment with supports for persons with developmental disabilities and to go beyond the concept of sheltered workshops.

- **Research Suggestion**

We believe that ICDR should research and disseminate state and Federal legislation that provides incentives for employers and service providers in facilitating competitive employment and policy that prohibits or discourages funding for segregated vocational services. We believe that ICDR should explore in greater depth the many aspects of employment that warrant investigation, including: how people with developmental disabilities can enter white collar work environments; how self employment can be a meaningful outcomes for individuals with the most significant disabilities; and how detrimental sub-minimum wage certificates are to individuals with developmental disabilities.

### **Public Policy Studies on Transportation**

For all persons, but especially for persons with developmental disabilities, reliable, safe, affordable and accessible transportation is the essential link to quality of life. Without it, employment, recreation, access to continued medical treatment and rehabilitation and full enjoyment and inclusion in society are not possible.

- **Research Suggestion**

We believe it is essential for ICDR to recognize that sound public policy studies on transportation are critical to achieving the goal of complete community inclusion and to end the discriminatory practice of segregation of persons with developmental disabilities in society. We would like to see studies conducted on how transportation or the lack of it impacts employment of persons with disabilities, as well as their inclusion into other areas of life.

### **Public Policy Studies on Housing**

Like transportation, safe, affordable and accessible housing is essential to quality of life and inclusion in society.

- **Research Suggestion**

We would like ICDR to include in its research agenda studies a public policy analysis on housing and its availability to persons with developmental disabilities. We would also like to see a public policy study on how private and Federal dollars are being used to assist persons with disabilities. It would also be useful to conduct a study on how affordable, accessible housing impacts the successful employment of persons with developmental disabilities. We note that neither the 1999 U.S. Supreme Court decision, *Olmstead*, nor state implementation plans have led to the creation of an action agenda that is creating systemic changes.

## **Assistive Technology**

The current Assistive Technology (AT) loan programs offered by the U.S. Department of Education lack some thought and direction as to how they are to be implemented at the state level. We do want to commend ICDR for its work on rehabilitation engineering – the Centers do an excellent job of funding new technologies.

- **Research Suggestion**

Currently, ICDR focuses mainly on “high-tech” AT supports such as computers and Personal Digital Assistants. Equal focus should be placed on simple, basic, rehabilitative “technology” that persons with disabilities or their families are able to fabricate on their own at minimal cost. We would like to see funding for a resource directory, printed and on the web that provides information on the production and use of “low” technology devices.

We also would like to see studies on AT and voting – since this is integral to a person’s constitutional right to participate in our democratic form of government. This project could be done in collaboration with the Federal Election Commission and following the guidance set forth in the Help America Vote Act (P.L 107-252).

## **Explore Use of Telemedicine**

For persons with developmental disabilities and their circles of support living in rural areas, access to quality, innovative medicine and rehabilitation often is lacking. This is especially a concern for children with developmental disabilities who need to be assessed as early as possible, since early intervention is linked directly to positive outcomes.

- **Research Suggestion**

We believe ICDR should focus on the emerging field of telemedicine with the goal of achieving early intervention for all children. This recommendation must be coordinated with the development of an infrastructure that allows all parts of our country to have access to telecommunications. It is essential, however, that a solid infrastructure be put in place before any focus on telemedicine occurs. As an anecdotal aside, it was discovered recently that the Native American reservations were encouraged to use telemedicine. It soon became apparent, however, that the reservations were not equipped for telemedicine since most had only one telephone line.

## **Recreation**

Disability advocates know well that quality of life and full enjoyment of life’s many pleasures is not only healthy but essential to a person’s well-being and developmental growth. Full inclusion into all recreational activities afforded by society is a right that all persons should demand, particularly persons with developmental disabilities.

- **Research Suggestion**

We believe that ICDR should conduct studies that identify the benefits of recreational activities upon an individual's quality of life, particularly related to community inclusion.

### **General Comments**

- **Leadership Role in Public Policy**

We believe that ICDR should take a leadership role in shaping public policy that affects persons with disabilities. For example, guidance and comments by ICDR on ways to improve and revamp legislation such as the Assistive Technology Act and the Rehabilitation Act would be quite useful and appreciated by disability advocates. We would like to see ICDR affirmatively impact public policy and take action when possible, rather than to be reactive or to participate at the end of the process.

- **Improve Dissemination Methods**

While we are grateful to ICDR for allowing us the opportunity to comment on its future research agenda, during the comment process it became quite apparent that long-time disability and policy experts within our member Councils on Developmental Disabilities knew little about the current projects being conducted by ICDR, nor about the results of past studies. As such, we would like to see more information coming from ICDR on a regular basis, compiled in user-friendly language about its current research projects and information about past studies. We believe it is important not to assume that disability advocacy organizations, parents, providers and others know about the good work ICDR is conducting, nor the results of its studies.

We observe that the notice in the Federal Register announcement pertaining to this request for comments includes mention of the ICDR website. It would be helpful to see a summary of ICDR research activities posted on this website and even an archives section where one could search past studies. Also, it would be helpful for ICDR to create some type of listserv that would facilitate direct and open communication between ICDR and the public. Finally, ICDR might want to consider cross-linking its website with the disability advocacy community. Many disability organizations have a "research" section on their websites that could be linked to the ICDR website. These points fit nicely within the ICDR's stated goals to 1) increase public input and involvement in ICDR deliberations to ensure research efforts lead to solutions for identified needs and 2) improve the visibility of ICDR and Federal disability research agenda in general.

- **Conduct More Longitudinal Studies**

We observe that some of the current Federally-sponsored research studies consist of small projects with short time frames. We place a higher value on longitudinal studies that track issues over time and that can monitor in a meaningful way the issues and challenges facing persons with disabilities as they change over the course of a lifetime.

An excellent model of successful longitudinal studies that ICDR might wish to replicate is housed at the Harvard Medical School and Harvard School of Public Health in Boston, Massachusetts. Harvard has been conducting a longitudinal study covering a variety of life and health care factors via a survey process. For example, researchers are tracking lifestyle practices, nutritional factors, occurrences of major diseases and conditions such as breast cancer, especially in young women. The study is not limited to individual health, but rather is geared exclusively toward nurses. One family we know of has been involved in this survey process for at least 5 years. Harvard's survey process may serve as a good model for a longitudinal survey of parents who have children with disabilities.

- **Health People 2010**

For the first time in history, people with disabilities are *fully* included in the U.S. Healthy People plan for 2010. Data from this plan provide a broad look at the health of people with disabilities compared with people without disabilities. Of the 467 objectives listed in *Healthy People 2010*, there are 207 sub-objectives that address people with disabilities. Some of the sub-objectives focus on areas outside the usual scope of health care or health services, such as education, employment, transportation, and housing, all of which deeply affect wellness and quality of life. We encourage ICDR to follow the lead of *Healthy People 2010* which recognizes that positive outcomes span into many facets of a person's life.

### **Conclusion**

On behalf of our 55 State and Territorial Councils, NACDD would like to thank ICDR for the important work it has done and continues to do to improve the lives of persons with disabilities and their families through quality research. We applaud the Office of Special Education and Rehabilitative Services and the U.S. Department of Education for allowing us this opportunity for public comment and for striving to maintain an open and inclusive process.

Should you have any questions about the comments we have submitted or should you require additional information, please do not hesitate to contact me.

Sincerely,

Karen Flippo  
Executive Director

Cc: Mr. Steven James Tingus, Director, NIDRR