

Interagency Committee on Disability Research (ICDR)
Public Comments on Behalf of the
Association of University Centers on Disabilities (AUCD)

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The Association of University Centers on Disabilities (AUCD) is a national network of university-based, interdisciplinary centers dedicated to advancing policy and practice for and with people with disabilities, their families, and communities through research, education, and service. AUCD represents and is composed of three overlapping networks of centers. These include: 67 University Centers for Excellence in Developmental Disabilities (UCEDDs) funded by the Administration on Developmental Disabilities; 35 Leadership Education in Neurodevelopmental and related Disabilities (LEND) programs funded by the Maternal and Child Health Bureau, and 19 Developmental Disabilities Research Centers (DDRCs) funded by the National Institute of Child Health and Human Development of NIH. There is at least one center in every state and US territory.

In FY2006, Centers within the AUCD network were involved in over 1,090 research projects, including clinical trials, education, behavior, health, and technology interventions, program evaluations, and policy analyses. These research and evaluation efforts were supported by over \$175 million in federal funding from the Departments of Education, Health and Human Services, National Institutes of Health, Health Resources Services Administration, Administration of Children and Families and other federal agencies and private foundations. Representing the network, AUCD also partners on projects with the National Center for Birth Defects and Developmental Disabilities of CDC and the Social Security Administration.

Given this broad level of involvement with multiple federal agencies across the network, AUCD is highly supportive of the efforts of the Interagency Committee on Disability Research (ICDR) to strengthen coordination of disability research. We are pleased to have the opportunity to provide input and identify some areas where we foresee future research needs.

Greater Collaboration on Long-Range Research Plans

The ICDR is poised to provide a platform to foster greater collaboration among federal agencies when developing long-range plans for research. Research efforts within one agency could be enhanced by building upon efforts of other agencies and organizations. In some areas of disability research, cross agency goals should be developed into which individual agencies could infuse their individual plans and priorities. For example, the *Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities* provides an excellent vision and blueprint for future goals in the area of health promotion. As another example, in 2003 a conference was held entitled *Keeping the Promises: National Goals, State of Knowledge, and Research Agenda for Persons with Intellectual and Developmental Disabilities*. Over 200 researchers and national experts convened and produced a detailed, broad-based research agenda for the field of intellectual and developmental disabilities. However, there still appears to be little proactive planning at the federal level in using national goals to coordinate research activities across agencies.

It is also important that across agencies a balanced portfolio of disability research is funded that includes not only randomized control trials but also survey research, qualitative research, evaluation research, descriptive and population studies and other ways of creating new knowledge that will drive policy and provision of effective supports and services. The

complexity of disability and societal issues facing individuals with disabilities and their families warrant multiple methods and sustained efforts.

Translation of Research into Practice

Another area where greater collaboration among federal agencies is needed is the translation of research into policy and practice. AUCD recently attended a stakeholder meeting convened by NICHD. While advocacy groups at the meeting were very supportive of the research being conducted by investigators, they called for greater partnerships among federal agencies so that new findings make their way into practice as soon as appropriate. For example, research on cognition and learning of children with developmental disabilities and specific conditions should translate to practices promoted by the Department of Education. While this is only one of many possible examples, it is common for individuals with disabilities and family members to express frustration at the gaps in applying knowledge to practice.

Participatory action research (PAR) and community based participatory research (CBPR) hold promise to increase the relevance of research to the lives of individuals. Within AUCD our Council on Community Advocacy (COCA), which consists of individuals with disabilities and family members, recently engaged in a project funded through the Administration on Developmental Disabilities aimed at enhancing participatory action research. Participatory action research occurs on a continuum and fundamentally aims to level power dynamics and broaden the input into the research process and ultimately increase the utilization of the results. The ICDR could encourage greater participatory research as a means to enhance the social validity of research, open up creative lines for dissemination, and lead towards more speedy translation into policy and practice.

Moreover, the ICDR could also assist with dissemination of research through federal partners and as well as advocacy groups. As a network, AUCD is able to capitalize on individual strengths of researchers and centers and share information and knowledge to others across the country.

Disability Statistics and Research Registries

The multiple conceptualizations and differing definitions of disability have hampered the advancement of disability research based on population datasets and through comparison of findings across studies. For example, different US federal programs use more than 60 different definitions of disability. We support the advancement of the International Classification of Functioning framework for considering disability, and the Healthy People 2010 objective of establishing standard definitions.

The ICDR could also assist with developing new initiatives to enhance the ability of researchers to produce knowledge. ICDR could play a role in promoting the inclusion of disability related questions in many large generic population-based studies and databases, so that information could be extracted that could be influential in guiding policy. Researchers in the area of intellectual and developmental disabilities need the capacity to identify people with these disabilities in ongoing federal survey research programs such as the American Community Survey and the National Health Interview Survey. Current questions do not allow identification of the broad group of people with intellectual and developmental disabilities, much less specific populations within that group such as persons with Autisms, intellectual disability (formally MR), Cerebral Palsy, Epilepsy, or Down syndrome.

There are also needs for developing concerted longitudinal research, such as the National Children's Study, to explore many unanswered questions that cross-sectional studies cannot

adequately address. In addition, the ICDR could assist with linking existing databases within federal agencies, such as data on government benefits and program participation, with other data sets in ways that create opportunities to explore questions while maintaining confidentiality and protections.

Research registries could uniquely address the dilemma of how to utilize traditional research designs with low-incidence disability populations, such as Down syndrome, Autism, Fragile X syndrome, and other genetic conditions. The ICDR could assist with the development of research registries and datasets with common fields that investigators could utilize across different projects funded by different federal agencies and organizations. As a network of university-based centers, AUCD could assist with providing a foundation for recruitment of participants and registry development. The ICDR can play a leading role in strategizing about innovative ways to increase the collection of disability statistics and data about the status of people with disabilities and their families.

Trends and Emerging Areas

Finally, AUCD would like to highlight a few key areas where we foresee trends and future research needs. First, there is growing demand among individuals with disabilities and families to address the transition-related needs of individuals with disabilities from school to adult life. Included within this are needs for increased community-based adult services and greater access to post-secondary education. These issues extend across multiple federal agencies and a concerted effort is needed to advance policy and practice to better meet the needs of individuals and families.

Second, coordinated efforts are needed to address the needs of a growing population of individuals with autism spectrum disorders. Earlier this year, the CDC released updated

prevalence rates indicating that 1 in 150 children has a potential diagnosis of autism. Last year the Combating Autism Act was signed into law, which could significantly expand research and interdisciplinary training of professionals if funds are appropriated. However, significant research gaps remain concerning evidence-based treatments, effective interventions and needed supports across the life-span. Moreover, significant gaps exist in knowledge-translation and access to appropriate services and supports.

Third, there are broad demographic trends occurring within the US and globally that will influence the future of disability in multiple ways. Population aging will significantly increase needs for healthcare and long-term services and supports in coming decades. Demographic and economic trends are impacting the security of families, who provide the backbone of long-term services and supports. The health and wellbeing of family caregivers, aging caregivers, and the ability of individuals with disabilities to provide care and parent are issues that deserve increased attention. The projected shortages in direct support professionals are clearly a challenge that needs further study and testing of effective solutions. Immigration will continue to rapidly shape and change the racial and ethnic diversity of the US. The impacts of these trends cross agencies and organizations and the ICDR could play a leading role in coordinating research to paint a better picture of their multiple impacts on disability and supports.

Thank you for the opportunity to provide comments and suggestions to the Interagency Committee on Disability Research. AUCD commends your efforts to improve coordination and enhance disability research. We would welcome any additional opportunities to engage with the activities of the ICDR and its subcommittees. We look forward to providing additional suggestions and working with you in the future.