

## **Center on Human Development and Disability works for the inclusion of all**

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Forty years ago, President John F. Kennedy created a network of research and training centers across the United States focused on providing an interdisciplinary approach to help people who were mentally retarded. The UW Center on Human Development and Disability (CHDD) was one of them.

The center was initially named the Child Development and Mental Retardation Center (CDMRC). But it has evolved over the years to reflect the breadth and complexity of the center's work involving individuals with all types of developmental disabilities and related problems, said Michael Guralnick, director of the center for the past 20 years.

"The center's name change was made also because the problems of disability are relevant throughout the lifespan," Guralnick explained. "We still have a strong emphasis on children, but we needed to acknowledge that children become adults and adults become elders, and we need to pay attention to all phases of life."

Guralnick, who is also UW professor of psychology and pediatrics, noted that "developmental disability" is a term applied to problems detected before adulthood that significantly impair an individual's ability to function effectively in many typical aspects of daily life, such as the capacity for independent living or maintaining economic self-sufficiency. An individual with a developmental disability will likely require continued support and intervention from an interdisciplinary perspective.

When the centers were created, there were no university programs providing systematic interdisciplinary research, training, or services related to individuals who were mentally retarded. Mental retardation was one of Kennedy's special interests; he had a sister who was mentally retarded. Kennedy set aside monies for universities interested in competing to develop interdisciplinary centers where academics from many disciplines could together establish clinics, research projects, training programs, and advocacy efforts on behalf of people with mental retardation. As the centers evolved, mental retardation became just one of a number of disabilities that engaged their research, training, and clinical programs.

Today 600 people, including 125 faculty members from 26 academic departments, work through the CHDD on a broad spectrum of problems relevant to individuals with developmental disabilities. For example, numerous projects include individuals with Down syndrome, autism, fetal alcohol syndrome, and fragile X syndrome, the latter being the most common inherited cause of mental retardation.

Although the 125 faculty members involved with the CHDD have academic homes elsewhere within the University, when it comes to projects focusing on developmental disabilities, the CHDD provides support in a variety of ways: from developing clinics for specialized training and as model services; providing an infrastructure -- space, administrative structure, and support; and for research -- providing technical support, access to state-of-the-art equipment, and funding for pilot projects.

The center is uniquely organized to foster efficient and seamless translation of basic research into clinical practice and vice versa. At the CHDD, clinical functions (diagnosis, evaluation, treatment, and intervention), interdisciplinary training, and research operate under one director.

"We're one of only three or four centers in the nation that have the interdisciplinary clinical services, training, and research pieces as one integrated program," Guralnick said. "Other centers operate these functions separately under separate directors. Our structure helps foster clinicians' interactions with basic scientists, and helps basic scientists connect with clinicians. I think it means we all can ask better questions and learn from each other." The effectiveness of the CHDD model can be exemplified through the history of fetal alcohol syndrome, Guralnick explained.

"Clinicians affiliated with our Center first detected certain commonalities in a whole variety of children based on what's called dysmorphic features, unusual facial and other features, of these individuals. These features seemed to correlate with certain developmental and behavioral patterns observed in the children and appeared to be related to alcohol consumption by the mother. As a result, a syndrome could be identified.

"Clinicians then worked with researchers to develop an animal model for what was being called fetal alcohol syndrome and to conduct long-term developmental studies to understand the workings of the syndrome," Guralnick said. "If it was a syndrome, what were the pathological features of it? And, how did the alcohol get to the brain? How did the damage occur? Where in the brain was the damage occurring? How did that correlate with the behavior pattern that we saw?"

Research findings related to fetal alcohol syndrome combined with clinical observations provide information that can be translated into intervention strategies, such as screening programs and clinical treatment programs that involve physicians, psychologists, speech pathologists, nutritionists, and policy makers. This information also serves as a basis for major policy decisions for prevention, such as warnings about drinking while pregnant.

The CHDD has been at the forefront of taking an interdisciplinary approach to problems, an approach that is increasingly being called for in many domains. The UW, like most universities, is moving much more towards an interdisciplinary framework, Guralnick noted.

"Having centers that focus on a problem, such as developmental disabilities, is really a very useful addition to the university environment. It's an opportunity to bring to bear the resources and minds from many disciplines to tackle a problem, to see what people at different levels of analysis can contribute to understanding that problem. I think it's a terrific experience not only for the people who are doing the work -- the faculty members -- but I think it adds something to the university that's unusual. We have trainees who come through and spend years with us. Those are the kinds of people who later become leaders in their fields because they have this broader perspective," said Guralnick.

Beyond major advances in biomedical and behavioral areas, including prevention and treatment of many different types of disabilities, measures of success for the center include support for the inclusion of those with developmental disabilities into everyday life. An important value of the center is inclusion and maximizing the independence and productivity of people with disabilities and their integration into all kinds of community settings.

"We do a lot of research, program development, and advocacy to make that work. The more we can support individuals with disabilities and their families, for example, and help improve their health and development, the more likely they are to succeed in those environments," Guralnick explained. "Plus, we train numerous professionals from different disciplines to provide services and supports in typical settings so children and families can maintain a high level of participation in everyday life. This complements our commitment to minimize or prevent disabilities through drug trials, public health models, early intervention, social skills and employment training--as all of these and other efforts minimize the primary and secondary complications of disabilities."

Guralnick has specialized in early intervention since he began his career in this field in the early 1970s. He came to the UW in 1986 from Ohio State University, where he directed a center similar to the CHDD.

Over his career, he has witnessed phenomenal changes in the field of developmental disabilities and the treatment of those with developmental disabilities. "It wasn't until 1974 that children with disabilities were guaranteed even the most basic of civil rights. "It wasn't until 1974 that children with disabilities were guaranteed even the most basic of civil rights. In 1974 a law was passed that mandated that children with disabilities be educated," Guralnick said. Prior to that time, children with disabilities were often excluded from public schools and placed in residential facilities because families couldn't or didn't want to deal with the complexities or social stigma associated with having a child with a developmental disability.

By acknowledging and legislating the civil rights of those with developmental disabilities, the country took a major turn. "The civil rights of people with disabilities have been a driving force in the way these individuals interact with their families and with their communities at large.

Since 1974, and spurred by related legislation and rulings, the laws made it clear that children with disabilities should go to school, to the maximum extent appropriate, with people without disabilities, rather than in segregated facilities which had been constructed for them over the years. So, things have changed in many ways. For example, instead of working in segregated employment, people with disabilities now work in the community where there are job counselors to support employees with disabilities at work sites. In only 30 or so years the change has been absolutely extraordinary with respect to the quality of life for people with disabilities."

There have been numerous breakthroughs in understanding the genetic causes of many disabilities, many involving the CHDD, as well as the development of many drug and environmental therapies to prevent or minimize the effects of disabilities. Despite all of the scientific progress, Guralnick thinks "the most salient advance is the fact that people with disabilities are now a part of everyday life." However, there's still much work to be done. "There are still attitudes that need to be changed and adequate resources allocated to make the full inclusion of people with developmental disabilities a reality. But, I'm optimistic. It will just take time."

**CHDD's Clinical Services include:**

Adult Phenylketonuria Program  
Autism Clinical Services  
Biochemical Genetics Clinic  
CARE Northwest Teratogen Information Service  
Child Development Clinic  
Congenital Hypothyroidism Clinic  
Experimental Education Unit Classes  
Fetal Alcohol Syndrome Diagnosis and Prevention Network  
High Risk Infant Follow-up Clinic  
Neurogenetics Clinic  
Pediatric Audiology Clinic  
Pediatric Neurogenetics Clinic  
Phenylketonuria Clinic  
Washington Assistive Technology Alliance

**CHDD's research areas include:**

Autism  
Craniofacial Malformations  
Developmental Toxicology  
Ecological Factors  
Fetal Alcohol syndrome  
Fragile X syndrome  
Infectious Disease and Immunology  
Joubert Syndrome and Related Cerebellar Disorders  
Neurodegenerative Disorders  
Neurodevelopmental Oncology

For more information, call 206-598-4317 or visit [www.chdd.washington.edu](http://www.chdd.washington.edu).