New name is a better fit for Center’s growing program

The name has changed, but making a positive contribution to the lives of people with developmental disabilities and their families remains foremost at the University of Washington’s Center on Human Development and Disability (CHDD), formerly called the Child Development and Mental Retardation Center (CDMRC).

“The new name more adequately describes our programs and activities,” explains Dr. Michael Guralnick, director of the CHDD and professor of psychology and pediatrics. “The Center has increasingly adopted a life span approach to developmental disabilities. We’ve retained the emphasis on development in young children, while extending our involvement with school-age children, adolescents and adults and, most recently, elders with developmental disabilities.”

“Our name change coincides with a period of rapid growth for the Center. We have new scientific core facilities, and new research affiliates who are working more closely than ever on interdisciplinary research issues and on fostering the connection between clinicians and researchers. We’ve added clinical and community outreach programs and expanded linkages to other departments around campus. This continuing expansion will enable us to reach more and more people with developmental disabilities and better address high priority research topics.”

Research at the CHDD, like the other Mental Retardation and Developmental Disabilities Research Centers (MRDDRCs) around the nation, was originally directed at studying the underlying causes of mental retardation. “Mental retardation was the prototype developmental disability when the centers were established, but interest has broadened to include a wide array of developmental disabilities,” Guralnick points out.

Nearly 130 CHDD research affiliates in the Center’s MRDDRC collaborate on studies of biomedical and behavioral processes that cause or are associated with developmental disabilities. Affiliates work within six major areas of research to understand normal and abnormal human development.

Research affiliates in the Teratology Program are investigating the mechanisms that lead to congenital defects when pregnant women are exposed to certain drugs and chemicals. Affiliates in the Developmental and Molecular Genetics Program are studying genetic factors that account for a large number of developmental disabilities and investigating prospects for gene therapy.

CHDD research affiliates in the Perinatal Biology Program are learning about the causes and outcomes of premature births. They are also studying ways to prevent preterm births and seeking to determine the best treatments for infants born prematurely.

Affiliates in the Developmental Neuroscience Program are investigating processes involved in normal and abnormal development of the central nervous system including the role of genes, the expression of neurotrophic factors and neurotransmitters, the plasticity of neural systems and the possibility that regeneration and transplantation procedures may restore function.

Knowledge about sensory, motor, cognitive and language processes is fundamental to designing therapies and interventions to enhance development. Affiliates in the Developmental Processes Program are investigating these areas, as well as how to foster good...
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family and peer relationships, factors that have long been recognized to play a key role in child development.

Affiliates in the Biomedical and Behavioral Outcome and Intervention Program are working to better understand biologic or environmental conditions that can cause adverse health and developmental outcomes. They are also examining the effectiveness of interventions that have been designed to improve those outcomes.

The CHDD is one of the few centers in the United States in which a MRDDRC and a University Affiliated Program (UAP) are together in one integrated comprehensive program. Major components of the UAP include the Adolescent Health Unit, Clinical Training Unit, Experimental Education Unit, Pediatric Genetics Program, Assistive Technology Program, Adults and Elders Program, Pediatric Neurology Program, and Community Policy Institute on Disabilities. Each of these components is involved in one or more UAP activities, which aim to increase and support the independence, productivity and integration into the community of people with developmental disabilities.

In the UAP, the CHDD trains professionals within an interdisciplinary framework to meet the needs of people with disabilities. About 150 graduate-level trainees participate in the CHDD interdisciplinary training programs each year, preparing them to take leadership roles in the field of developmental disabilities.

The Center’s UAP also provides services for individuals with a wide variety of developmental problems and develops model programs to be used in the community. Every year approximately 2,000 people with developmental disabilities and their families receive clinical and educational services through the Center’s UAP programs, either at CHDD or in the community.

A note to our readers

We hope you enjoy the updated design of Outlook. The rays of our logo, which emanate from and converge toward a circle representing the Center, stand for the Center’s many interdisciplinary activities and programs, as well as the various levels of scientific analysis required to fully understand human development. These levels of analysis are reflected in the six research programs of the MRDDRC. The rays are open to the larger universe signifying the two-way flow of knowledge and service that is central to the CHDD’s goals — to foster the independence, productivity, and inclusion of people with disabilities, and to prevent or ameliorate developmental problems. The four broad areas of activity through which the CHDD carries out its mission — research, clinical services, training and community outreach — are represented by the four sides of the diamond enclosing the logo.
Each year, hundreds of babies are born with fetal alcohol syndrome (FAS) — a birth defect that results in lifelong physical, intellectual, cognitive and behavioral disabilities. Caused by maternal consumption of alcohol during pregnancy, FAS is one of the major known causes of mental retardation in the western world. The estimated incidence of FAS is 1 to 3 per 1000 live births.

Efforts to prevent FAS hinge on effective surveillance that provides an accurate gauge of its prevalence, so that cost-effective programs can be implemented for treating women whose use of alcohol places them at risk for giving birth to children with the syndrome. Preventing or reducing secondary disabilities such as low self esteem, depression and school failure in individuals who already have FAS depends on early diagnosis leading to appropriate interventions.

Studies conducted by CHDD research affiliates Drs. Susan Astley and Sterling Clarren aim to bolster FAS prevention efforts by laying the groundwork for improved surveillance and diagnostic tools.

"FAS is characterized by central nervous system dysfunction, a cluster of minor facial anomalies that is unique to FAS, and growth deficiency," explains Astley, assistant professor of epidemiology. "Because central nervous system dysfunction and growth deficiencies are also characteristic of other developmentally related conditions, the ideal case definition for screening and surveillance of FAS would focus on the unique cluster of facial features."

To derive a more specific and objective definition of the facial phenotype of FAS, Astley and Clarren, professor of pediatrics, studied facial measurements recorded directly from children evaluated in the FAS Clinic at CHDD. They also studied facial measurements recorded from photographs of individuals diagnosed with FAS.

The cluster of facial anomalies that characterizes the FAS facial phenotype includes small palpebral fissures (eye openings), a smooth philtrum (an indistinct or missing groove between the upper lip and nose), and a thin upper lip. However, criteria have never been established as to how small, how smooth, or how thin these features must be, explains Astley. Nor, she notes, have criteria been established as to how many of these features must be present. Are two of the three sufficient, must all three be present or does it depend on the magnitude of expression of each? “In our studies we were looking for the minimum number of facial features in the cluster that could be measured accurately, precisely and efficiently to define the facial phenotype,” says Astley.

“There are several advantages to using photographs,” Astley notes. “Since a computer is used to capture the measurements from the photographs, the data can be collected with greater accuracy and precision. We also frequently have to rely on a childhood photograph when performing a diagnostic evaluation on an adult, for the facial features of FAS often diminish with adulthood. "In both the direct and photographic studies, we collected key facial measurements from individuals with and without a continued page 7
New training project promotes the health of older adults with developmental disabilities

Health promotion — the practice of reducing the risk of disease by fostering healthy lifestyles — has become a major part of health care for all age groups in the United States. For older adults, health promotion programs resulting in positive changes in health habits have been shown to preserve function, delay disability and improve the quality of life.

Research on health promotion programs specifically designed for older adults with developmental disabilities suggests that such programs can play a major role in reducing mortality, enhancing functional health and reducing the cost of long-term care. However, most community-based providers who serve older adults with developmental disabilities are not adequately prepared to implement health promotion programs for their clients.

CHDD and the University of Washington's Northwest Geriatric Education Center (NWGEC) are collaborating on a new training project funded by the Administration on Aging that aims to give service providers the resources and skills they need to promote a healthier lifestyle among older adults with developmental disabilities.

The need for such training is growing as increased average life expectancy for people with developmental disabilities, mirroring the aging of the population of the United States in general, means that more adults with developmental disabilities are living to old age. “People alive today who have survived into their 60s with developmental disabilities tend to be physically very healthy. They were born before the modern innovations in surgery and nutrition that have increased the life expectancy of people with developmental disabilities so dramatically,” notes Dr. Doug Cook, head of social work at CHDD and chair of the Center's Task Force on Aging and Developmental Disabilities. “Now there is a bow wave of people with developmental disabilities in their early 50s coming through the system who really need health promotion measures to maximize their quality of life.”

Health promotion is relatively new in the field of developmental disabilities, according to Cook. In working with older adults with developmental disabilities, he's found that health screening procedures such as prostate exams and mammograms, which are relatively common in the general population, are uncommon among this group.

“We have developed really good pediatric care for children with developmental disabilities in the last 20 years, including extensive training programs for health professionals,” explains Cook. “But because there have been fewer adults and elders, the emphasis on health issues for older people with developmental disabilities has been much less. Even the work that has been done on health promotion for older adults with developmental disabilities has not been disseminated widely to families and service providers.”

The goal of the new training project is to enable health and social service providers who work with older adults with developmental disabilities in community-based settings to implement health promotion interventions. To accomplish this, the project includes several activities. The major activity is developing and field testing curriculum modules for use in training. Another activity involves training agency staff who train other service providers. To augment the training and curriculum, the project is also establishing a resource network that will provide ongoing technical assistance to community-based agencies implementing health promotion programs.

Each of the curriculum modules developed by the project will cover a specific health promotion topic, presenting interventions that specifically address the various health risks and quality of life...
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Issues associated with aging. Adults with developmental disabilities may experience an earlier onset of age-related conditions such as muscle weakness and cardiovascular problems. There is a greater incidence of obesity among older adults with developmental disabilities than among the general population because activity level is usually low and caloric intake high. Curriculum modules on nutrition and physical activity interventions will be directed at reducing obesity and improving muscular strength, endurance and cardiovascular fitness.

Individuals with developmental disabilities also tend to have more sensory problems as they age than the general population — their hearing and sight decline faster. Health screening interventions covered by the curriculum will be especially geared toward early identification of age-related sensory loss. Depression and other mental health problems are also common among this population and may result in behaviors that differ from the usual clinical manifestations. A module on mental health will emphasize interventions that promote positive mental health outcomes.

Reflecting the different settings in which community-based providers work with their clients, techniques for implementing both group and individual interventions will be covered in the modules. Agencies that work with older adults with developmental disabilities in a variety of community-based settings are participating in the project and helping in the development of the curriculum modules. Some of the participating agencies work with people in residential settings, such as group homes, some work with people who live in their own homes through tenant support, and others provide day programs.

Personnel from the participating agencies will field test and evaluate the curriculum modules to assure their effectiveness. Every three months, the project will provide a half-day training session, using one of the curriculum modules, for core-staff representatives from each of the participating agencies.

The initial draft of each curriculum module to be used in the training sessions will be written by an expert in a particular health promotion area, such as nutrition. This draft will then be reviewed and revised by an expert in the developmental disabilities field, who knows nutrition. Training sessions for core-staff representatives will be conducted by the expert consultant in each particular health promotion intervention area, using the revised version of the curriculum module.

After the training session, the agency representatives will return to their agencies and train their service-provider staff. After receiving their training, the service providers will initiate health promotion interventions for their clients. Coming full circle, the evaluation and feedback from core-staff representatives and the service providers from each agency will enable the project to make improvements to the curriculum modules.

“We hope by the end of two years to have fully developed curriculum modules that we can disseminate throughout the Northwest and nationally,” says Cook.

By providing technical assistance, the project will support community agencies as they implement health promotion programs. The library housed at the NWGEC has books and other resources on health promotion available to agencies on loan. Health promotion information from the project will be accessible via the Internet. The project will also make available to the agencies the expert consultants who develop the curriculum modules for questions that arise after training.

As community liaison for the project, Cook meets with the agencies once a month for problem solving regarding training, resources and implementation of interventions. “It’s a fun job for me,” he reports “because people at the agencies are enthusiastic about the project and very interested in the material. I’m sure that the feedback they provide will be very helpful and lead to an excellent product.”

Agencies participating in the project include: The Arc-King County; Evergreen Community Tenant Support Program; Creative Living Services, Inc.; Services Alternatives for Washington, Inc.; Seattle/King County Division on Aging; Sunrise Community Living; Camelot Society, and Fircrest School.
CHDD researcher looks beyond prenatal period in search for causes of poor pregnancy outcomes

Although the advent of modern neonatology now enables the medical community to save the smallest babies, preventing low birth weight from occurring in the first place is still an unsolved problem.

Babies who weigh less than 2,500 grams (about 5.5 pounds) at birth require more care and are at increased risk for developmental problems. Additional health services required by low birth weight infants are estimated to cost nearly $4 billion per year.

Efforts to prevent low birth weight have emphasized prenatal care. These efforts have been largely unsuccessful because they neglect the host of complex factors that play a role in birth outcomes and are present long before conception, according to CHDD research affiliate Dr. Irvin Emanuel.

Although prenatal care is important, it is not a cure-all, argues Emanuel, professor of epidemiology and pediatrics, and former director of CHDD. "Improvement in pregnancy outcomes is a long-term process," he says. "There is no panacea, no way of solving it immediately."

Increasingly, evidence uncovered by Emanuel and other researchers who study birth outcomes in populations points to the significance of nongenetic factors that are passed from one generation to the next. These intergenerational factors encompass the conditions under which a child is born and grows up. They are closely tied to socio-economic status and their effect is measured by quality of growth.

"Good growth means good health and good health means good growth," stresses Emanuel. "Poor kids don't grow as well as kids from families who are well off."

Intergenerational factors can interfere with the genetically controlled aspect of growth, preventing full genetic expression. In an individual — a mother-to-be — the intergenerational effect shows up in her own pre- and post-natal growth. In a population, the intergenerational effect is evident in the trend of increasing adult stature in affluent populations. The opposite trend appears in economically declining populations, which have been shown to undergo a decrease in adult stature. Although the reasons are not understood, it has long been known that tall mothers have better birth outcomes, Emanuel points out.

Emanuel has been studying intergenerational factors and pregnancy outcomes for more than 20 years. Over that time the epidemiological investigations he has undertaken have shown a relationship between maternal growth and such pregnancy outcomes as low birth weight, prematurity, intrauterine growth retardation, and infant death.

Emanuel and his colleagues conducted one of the first studies to investigate the relationship between maternal birth weight and pregnancy outcome. The cohort they studied consisted of 748 white women who delivered babies during a two-year period from 1977 to 1979, and were born in Washington state after 1948, when the recording of birth weight on birth certificates began. The researchers found that a mother's weight at her own birth was related to the risk for low birth weight in her offspring as well as the risk for preterm birth, the baby's need of neonatal intensive care, and respiratory distress syndrome in the infant.

In subsequent work using data on singleton births from the 1958 national cohort of British births collected for the British National Child Development Study, Emanuel found evidence of the intergenerational effect passing through the mother's line and extending through at least three generations. He and his colleagues examined a variety of associations between characteristics of parents and grandparents and baby's birth weight. Even after adjusting for such important factors in birth weight as maternal birth weight, smoking during pregnancy, and baby's sex and birth order, he found a significant relationship between the baby's birth weight and the maternal grandmother's height. The grandmother's height was used as a measure of growth because the data didn't extend far enough back in time to include the grandmother's birth weight. In general, the taller the grandmother, the more the baby weighed at birth.

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When Emanuel looked at twin birth data from the same cohort, he discovered a paradox that provided a clue as to how the intergenerational effect might work. Although the female twins in the cohort were of lower birth weight than the singletons, they went on to have bigger babies. This seeming contradiction suggested that certain times during intrauterine growth, specifically the early portions of pregnancy, are significant in long-term reproductive effects. In twin gestation, growth in the first two trimesters follows a pattern similar to singleton gestations, but diverges in the last trimester, when there is a high rate of increase in fetal body mass. The growth of twins is retarded only in the last trimester, so they gain less body mass.

Birth defects and congenital malformations are known to be related to disruptions during critical periods in development. A small number of autopsy studies of low birth weight infants who died perinatally have shown that these infants' organs, except for the brain, were small. Small organs could be attributed to a reduced number of cells in the organs, a reduced amount of cytoplasm in the cells, or perhaps a combination of both, explains Emanuel.

“In effect, we're looking at a sort of microscopic birth defect,” Emanuel says. “Although the organs of living children haven't been thoroughly studied, it appears that tiny infants have small organs. We know that small infants remain small as they grow. There are permanent physiological consequences of being abnormally small at birth.”

A number of questions about intergenerational factors and birth outcomes remain. A big question is the cause of the excess number of low birth weight and preterm births in African Americans as compared with whites and other racial/ethnic groups. In a new study, funded by the federal Maternal and Child Health Bureau, Emanuel and his colleagues are using data from several existing statewide databases in Washington state to examine the maternal factors have been conducted

environmental circumstances that impair their growth, so the issues just repeat themselves from one generation to the next.”

Both analyses identified the same cluster of three facial features—a thin upper lip, a smooth philtrum and small eye openings. When the measures were collected directly by the clinician, the clinician ranked the thinness of the upper lip on a three-point scale (very thin, somewhat thin, not thin at all) using a photographic example of each as a guide. The clinician used the same technique to rank the smoothness of the philtrum. The size of the eye opening was measured with a ruler and compared to a norm based on age.

In contrast, the photographic method relied almost entirely on a computer to measure the level of expression of each feature. The thinness of the lip was measured by outlining the upper lip with a computer drawing tool and having the computer compute a thinness score. The higher the score, the thinner the upper lip. Philtrum smoothness was ranked as by the clinician, but on a finer five-point scale. The size of the eye opening was measured indirectly by having the computer measure the ratio of the eye size to the distance between the eyes. Although a reduced ratio is not always indicative of small eyes, this reduced ratio in combination with the other two features was highly specific to FAS,” explains Astley.

Both analyses generated formulas which could be used to compute an overall score for each individual face. “We can take the facial measurements, run them through the formula, and if the score is greater than or equal to 1.5 from the direct measures, or greater than or equal to 0.7 from the photographic measures, the facial phenotype is consistent with that of FAS,” explains Astley.

These formulas performed with very high accuracy. The formula derived from the direct facial measures performed with 100 percent sensitivity
New Research Affiliates Join CHDD

Dr. Margaret Byers is a research professor of anesthesiology and biological structure. She received her doctoral degree in anatomy from Harvard University. Her research focuses on the neurobiology of peripheral nerve fibers that cause pain, including their development, normal functions, and reactions to anesthetics, inflammation and wound healing.

Dr. Damir Janigro is an associate professor of neurological surgery and environmental health. He received his doctoral degree in physiology from the University of Milan in Italy. His research focuses on non-neuronal mechanisms involved in the regulation of neuronal function, including investigations of cerebral blood flow, the brain blood barrier and glial/neuronal interactions.

Dr. Richard Morrison is an associate professor of neurological surgery. He received his doctoral degree in anatomy from the University of California, Los Angeles. His research interests include studying the role of tumor suppressor genes in regulating neuronal development and neuronal responses to injury.

Dr. Wendy Raskind is an associate professor of medicine and an adjunct associate professor of orthopaedics and psychiatry and behavioral sciences. She received her medical degree and her doctoral degree in genetics from the University of Washington. Her research interests involve the roles genes play in both inherited and acquired disorders. She is investigating genetic contributions to the development of cancer and how genetic predisposition is related to learning disorders.

Dr. Jong Rho is an assistant professor of neurology and pediatrics. He received his medical degree from the University of Cincinnati College of Medicine, and completed training in pediatric neurology at the University of California, Los Angeles and in neuropharmacology at the National Institutes of Health. His research focuses on investigating epileptogenesis in the developing brain and the mechanisms of antiepileptic drugs.

FAS diagnostic aid

(identified all 39 patients with FAS correctly) and 89 percent specificity (misclassified 17 of the 155 patients without FAS). The formula derived from the photographic facial measures performed with 100 percent sensitivity and specificity. It differentiated the 42 patients with FAS from the 84 patients without FAS, without error. The accuracy of both methods was unaffected by race, gender and age.

Although the two methods were highly effective in differentiating individuals with and without FAS, further studies are necessary to validate the results in larger, more diverse populations.

Like positive results from a routine Pap smear or tuberculin test, which indicate that it is worthwhile to proceed with further testing and evaluation, a positive result from either of these facial measurement methods is only a first step in the diagnosis of FAS. “Whether these tools are being used as diagnostic aids or for screening, final diagnosis must remain in the hands of a skilled clinician who can consider the case as a whole,” says Astley.