Social work: One of many disciplines serving families

One of the hallmarks of the Center on Human Development and Disability at the University of Washington (CHDD) is the interdisciplinary framework in which services are offered. Clinical services, outreach programs to community providers, training programs, dissemination efforts and research projects are characterized by the breadth and depth of knowledge of the many different professionals involved.

Social workers are important members of the interdisciplinary teams providing direct services to patients and their families. “Families come here because of concerns about their children’s often very difficult and complex behaviors,” said Sally Stuart, MSW, lead social worker in CHDD’s Child Development Clinic, which sees children with a wide range of developmental disabilities, including autism, Asperger’s syndrome, Tourette syndrome and mental retardation.

“The interview process can be very emotional for parents. Their children are failing in school, they’re not following directions and they’re having problems with relationships. They are referred here to see whether there may be a neurodevelopmental issue. The parents have not been able to find answers elsewhere and many times they have been blamed for their child’s behavior.

“We let them know they did not cause their child’s behavior; it is a disability manifesting itself behaviorally. Once a diagnosis is reached, we direct them to resources to help them cope, emotionally and financially.”

“With our team approach, we’re able to sort out subtleties. It’s by knowing what questions to ask and how to probe for more information that we’re able to arrive at a diagnosis. Then, we might let the rest of the team know a parent finds it difficult to contemplate a diagnosis of mental retardation. The team can tailor its feedback in a way that the parent can understand and accept.”

“A family may go through five or six evaluations,” said Linda Backenstose, MSW, also a social worker in the Child Development Clinic. “They’re sitting at a table with all these professionals and it can be pretty overwhelming. The social worker helps translate the findings for the family. It can be traumatic for a parent to accept that their child has a disability. When families are more open from the beginning, the outcome for the child is better.”

Catherine Kendall, MSW, is the social worker for CHDD’s Neurogenetics Clinic, which sees people with or at risk for devastating inherited neurodegenerative diseases, such as Huntington’s disease and spinocerebellar ataxia. With other clinic team members, Kendall assists patients in making difficult decisions about gene testing. “While most people choose not to be tested, those who are tested ac-

See ‘Social work’ on page 2
Social work . . . from page 1

People benefit from having an advocate to help negotiate the difficult maze of government programs,” Kendall said. “I try to make sure families have everything they need to promote good dietary management.”

Kendall runs a support group for people with or at risk for a neurogenetic disease, enabling them to discuss the decision to be tested and the impact on their lives. “There are major psychological issues with these diseases,” she said. “For example, several group members who tested positive for Huntington’s disease experienced disruptions in their marriages. The social fallout can be devastating.”

On a toll-free help line, Kendall takes calls from throughout the Northwest from people asking about issues like how to assist a parent in getting tested, how to advocate for disability accommodation in employment, how to apply for social security, or deal with the onset of symptoms in a family member.

She provides psychosocial assessments in the clinic, referring individuals to community mental health providers. Inevitably, crisis management is part of her job. “The onset of grave disability, hospitalization and suicide threats are the biggest crises,” she said.

To increase understanding of these diseases, Kendall also provides professional consultation and community in-service training at residential facilities and community mental health centers.

Janet Garretson, MSW, is the social worker for CHDD’s Pediatric and Adult Phenylketonuria (PKU) programs. People born with PKU lack an enzyme to process an amino acid, phenylalanine, a component of protein. Unless they adhere to a stringent, lifelong restrictive diet, the buildup of phenylalanine in the brain causes severe mental retardation. With the advent of a newborn screening test and a dietary treatment, people with PKU can now live normal lives.

“Because it’s such a restrictive diet, people may struggle with self-esteem and family dynamics. They often need support,” she said. “I try to make sure families have everything they need to promote good dietary management.”

Garretson follows about 200 children with PKU from across Washington state. Clinics for infants, children and adolescents are held monthly at CHDD. She coordinates parent support groups that convene while their children attend nutrition classes and provides services to ensure families have the financial and emotional resources to maintain their child’s treatment.

She also works with 50 to 75 adults with PKU, arranging for annual clinic visits and frequent checks of their phenylalanine blood levels, assisting with insurance issues and providing emotional support. She assists women of childbearing age in adhering to the diet, since a pregnancy with elevated phenylalanine levels carries severe risks for the fetus. “Children born to women who don’t manage their blood levels meticulously often have underdeveloped brains leading to mental retardation, and some babies develop severe heart defects,” she said.

CHDD social workers put families in touch with needed services in the community and act as their advocates. “A great deal of my time is spent educating insurance companies that they are mandated to pay for the special protein formula that people with PKU require,” said Garretson. “Few families could afford it without insurance coverage.”

“People benefit from having an advocate to help negotiate the difficult maze of government programs,” Kendall said. “I do everything from filling out the paperwork to writing advocacy letters to working with attorneys representing people in appeal hearings.”

“Teaching people to advocate

See ‘Social work’ on page 7
Illuminating the role of dopamine in neurological processes involved in movement and addiction

Research led by CHDD research affiliate Nigel Bamford, M.D., is providing a greater understanding of how dopamine, a neurotransmitter that regulates the firing of neurons, affects the function of the synapse, the junction between neurons. Varying levels of dopamine are implicated in numerous developmental, neurological and psychiatric disorders, including various movement disorders and addiction.

Bamford, an assistant professor of neurology and pediatrics at the University of Washington and a pediatric neurologist at Children's Hospital and Regional Medical Center in Seattle, and colleagues published results of their study in the May 27 issue of the journal Neuron. The study investigated how dopamine affects the release of glutamate, the major excitatory neurotransmitter in the brain.

"Our lab is interested in how the cortex communicates with the basal ganglia and in the role of various neurotransmitters in both the developing and the mature brain," said Bamford. "The basal ganglia provides feedback to the cortex and allows modification of instructions. This system is related to memory, emotion and learning. Movement disorders such as Huntington's disease, Parkinson's disease, and Tourette syndrome are also associated with problems in the basal ganglia. In addition, our research could help explain the brain mechanisms that underlie addiction to such drugs as cocaine and methamphetamine, and could point the way to determining what treatments may be useful to control drug dependence."

While Bamford's research provides a basic understanding of how the striatal microcircuit filters and amplifies information from the cortex, he is also interested in examining maturational changes that occur in the striatal system throughout development, using additional studies to understand the effects of synaptic dopamine and psychostimulants such as methylphenidate (Ritalin), amphetamine and cocaine on the developing system.

The detrimental effects of embryonic exposure to psychostimulants during the development of the basal ganglia remain unclear, said Bamford. "We plan to simulate human embryonic exposure to amphetamine and cocaine in mice, and follow the pattern and timing of striatal neuronal migration and maturation. Additional studies will focus on striatal neuronal cell apoptosis (cell death) and functional performance following exposure to stimulants."

For the study reported in Neuron, Bamford and colleagues developed an innovative technique that enabled them to directly image presynaptic activity in slices of mouse brain tissue stained with a special dye called FM 1-43. In order to directly measure the effects of dopamine at the level of individual presynaptic terminals, they administered electrical stimulation or amphetamine to induce the release of dopamine. Using a state-of-the-art multiphoton confocal microscope that produces three-dimensional images below the surface of the tissue being studied, they were able to image the dye as it was released from the terminals of cortical glutamatergic neurons in the striatum. Precise measurements of the dye release, combined with electrophysiological recordings, enabled them to pinpoint the effect of dopamine on glutamate release.

"The study was a technical tour de force, combining optical measures of glutamate release, real-time electrochemical measures of DA (dopamine) release, and electrophysiological measures of glutamatergic synaptic activity," wrote neuroscientists John A. Dani and Ming Zhou of Baylor College of Medicine in a commentary in Neuron.

The striatum is part of the basal ganglia, located beneath the cortex and is involved in motor coordination and cognitive functions. The striatum acts as a gateway, filtering out unwanted impulses from the cortex and maintaining a smooth flow of information. If the striatum is dysfunctional, it may disrupt signals and pass along unwanted impulses, leading to disordered physical movements and inappropriate behaviors and emotions.

Dopamine input to the striatum is required for voluntary motor movement, behavioral reinforcement and responses to drugs of abuse, said Bamford. Dopamine modifies cortical signals so that the brain can adapt appropriately to new stimuli. "When one is exposed to a novel situation—for example, when a child sees a bus for the first time—a large amount of dopamine is released in the basal ganglia. As time goes on, the more buses the child sees, the less dopamine is released. We adapt to new environmental cues and when we're stimulated enough times, we don't pay as much attention as we did..."
it has long been known that secure attachment between a mother and her baby is a crucial component of the child’s well being. Countless studies in both humans and animals have demonstrated that a close bond between the infant and the primary caregiver is vital for many spheres of development.

“Research on attachment has been going on for more than 40 years,” said Susan Spieker, Ph.D., research professor of family and child nursing at the University of Washington and a research affiliate at the Center on Human Development and Disability. “It is a major topic in developmental psychology, and it was transforming for the field of child development to begin assessing the quality of the relationship that infants develop with their primary caregivers.

“Research suggests that secure infants have a cognitive and language advantage, at least early on,” she said. “Infants learn within the context of social relationships.”

Much of Spieker’s research has focused on how mothers in various high-risk circumstances are nonetheless able to foster a secure relationship with their child. High-risk circumstances include teenage motherhood, poverty, depression, lack of a partner, and lack of family or other support. “These risk factors tend to cluster,” she said. “They don’t often exist separate from each other.”

Teen mothers, said Spieker, haven’t finished their own development. “They may think that by having a baby they will have someone who loves them unconditionally. But the baby makes its own demands, and the teen mother finds it hard to be needed so much.”

In conditions of poverty, there is great stress, said Spieker. “The caregiver is focused on survival—on the physical needs of herself and her family. The baby’s emotional needs may become an irritant, leading to neglect, abuse and rejection.”

The indifference or rejection can turn into a vicious cycle, she noted, because a baby who is less secure exhibits more difficult behaviors like crying and clinging. Ironically, children will do everything they can to maintain attachment, even when the attachment is negative. “They will compromise in order to retain attachment. But after a certain point,” said Spieker, “there is an emotional dampening; the child’s behaviors become less demanding, and thus the child is able to stay physically closer to the mother.”

Spieker notes that experts estimate that in American children, the rate of secure attachment is about 65 percent. Worldwide, the rate is believed to be about the same. “Insecurity is on a continuum,” she said. “There are variations in intimate relationships; but we believe the rate of severe lack of attachment is the same, about 10 to 15 percent.”

Spieker’s studies show that if the child has developed a secure relationship with the mother despite such challenging circumstances, that sense of attachment is somewhat protective when the child faces challenges later. “It doesn’t make children invulnerable, by any means,” she said, “but they may be a little more resilient and cope a little better. Conversely, if the early relationship is insecure, there is a buildup of vulnerabilities, so that subsequent bumps in the road have a more negative impact.

“We measure outcomes in terms of behavioral problems. Years down the road, we’re still finding associations,” said Spieker. “The quality of the relationship in infancy tends to be carried forward.”

Spieker is an investigator in a long-term study, Tandem Risk: Outcomes for Children of Teen Mothers, for which Lewayne Gilchrist, Ph.D., UW professor of...
and studying the long-term contributions of various aspects of the attachment relationship to the child's development.

She is principal investigator on another longitudinal study, Attachment in Early Head Start Process and Outcome, evaluating children who participate in Early Head Start, the federally funded program that aims to enhance the development of very young children and promote healthy functioning in low-income families. The researchers looked at how the mothers' own childhood experiences influence their ability to benefit from Early Head Start, as the children reach preschool age, the study has examined parent-child relationships, the child's cognitive and language development, ability to regulate emotions, and the quality of attachment.

Spieker is also involved in phase three of the NICHD Study of Early Child Care and Youth Development, with principal investigator Cathryn Booth-LaForce, Ph.D., UW professor of nursing and a CHDD research affiliate. The study began looking at the children at one month of age; the current phase follows them through sixth grade, focusing on their achievement and cognitive abilities, social and emotional development, and health, as well as on the well-being of their parents. If the fourth phase of the study is funded, the children will be followed through the tenth grade.

"There have been other longitudinal studies in this area," said Spieker, "but our data are so rich and well documented that the field is going to benefit for years to come. We study the quality of the mother-child relationship, the quality of the father-child relationship, relationships within child care, and peer interactions."

During observations in the home, Mrs. D. engaged in severe tickling of her baby, to the point he cried helplessly. She would occasionally move her face close to him and show a frightening grin with bared teeth. Her facial expression changed within seconds from angry and unhappy to smiling, suggesting shifts in her emotional state. A few months later during the Strange Situation, the baby displayed disorganized attachment when he lay flat on the floor when reunited with his mother. He then moved toward his mother, but again lay flat on the floor.

During observations in the home, Mrs. R. responded in a timely and appropriate manner to her infant son's cues for attention, help, and comfort. A few months later during the Strange Situation, the child stayed close to his mother when the observer entered the lab, and cried bitterly when she left the room. When mother returned, the youngster toddled over and clasped his mother around the knees, then reached to be picked up. After a brief cuddle, he soon returned to exploring and playing, occasionally showing his discoveries to his mother.

During observations in the home, Mrs. J. frequently played with her infant daughter with a variety of stimulating toys. She was very focused on the baby doing these activities the "correct" way. When her daughter got fussy and tired from these activities, Mrs. J. lost patience and spoke to her in an annoyed voice with a frown, and put her in her crib to settle herself. A few months later during the Strange Situation, the baby played throughout the session, displaying superior exploratory skills, apparently not even noticing when her mother left the playroom or when she returned.

In addition to her long involvement in observational studies of mothers and infants at risk, Spieker is increasingly gravitating toward prevention projects. She is director of the new Birth to Three Research Laboratory at the University of Washington's Center on Infant Mental Health and Development, one of eight major components of CHDD's University Center of Excellence in Developmental Disabilities and operated jointly with the UW School of Nursing.

The lab's focus is on research to determine best ways to intervene to prevent attachment problems. Spieker and col-

See ‘Attachment’ on page 8
Good oral health and nutrition are vital ingredients in the ability of children to grow and thrive. While children with special health care needs are at increased risk for oral health problems and their consequences, there is a high incidence of oral health problems among all children. Dental caries—cavities—constitute the most common chronic disease of childhood. Despite advances in prevention and treatment, almost one-fifth of children aged 2 to 5 in the United States have untreated cavities.

In a new initiative to address childhood oral health problems, nutritionists at the Center on Human Development and Disability (CHDD) at the University of Washington and at the University of Southern California’s University Center of Excellence in Developmental Disabilities have collaborated to produce a distance-learning program for community health care providers.

Leading the effort are Cristine Trahms, M.S., R.D., who heads CHDD’s nutrition program, and Beth Ogata, M.S., R.D., a nutritionist on the CHDD staff. Consultant on the project is Penny Leggott, D.D.S., M.S., professor of pediatric dentistry and co-leader of the UW School of Dentistry’s Center for Leadership Education in Pediatric Dentistry.

The project will be the second nationally distributed curriculum for the Pacific West M aternal and Child Health Distance Learning Network, a collaboration between leadership training programs at CHDD and USC, supported by the M aternal and Child Health Bureau. The first curriculum, focusing on nutrition for children with special health care needs, is available on CD-ROM or as a free web-based program on the network’s web site. The new oral health curriculum will be posted on the web site, depts.washington.edu/pwdlearn.

New distance learning program for community health care providers promotes children’s oral health

The curriculum covers factors in-
as one of the most accomplished young scientists in pediatric neurology. "Dr. Bamford has developed some exciting and elegant techniques for the study of motor systems within the developing brain," said Sidney Gospe, M.D., Ph.D., division head of Neurology at Children’s Hospital and also a CHDD research affiliate.

Bamford and colleagues are continuing their investigations with a breed of mice developed by U.W. professor of biochemistry Richard Palmiter, Ph.D., to be dopamine-deficient, allowing the scientists to study the electrophysiology of brains with chronically depleted dopamine. Their new research may have further implications for treatment of Parkinson’s disease and of Segawa’s disease (dopamine-responsive dystonia), a disease of childhood in which there is a biochemical block in the ability to make dopamine. Their work will be published shortly in the Journal of Neuroscience.

In another study, Bamford and colleagues are studying a mouse model of drug addiction, treating mice with methamphetamine, then putting them through a period of withdrawal. "The release of glutamate from cortical terminals is dramatically reduced, and when we reinstate the drug there is a paradoxical increase in glutamate. In a normal mouse, there would be a decrease," he said. "So the increase in glutamate is probably a measure of how the animal is responding to drug reinstatement; it is a physiological abnormality caused by the addiction itself. The abnormality increases with the amount of original drug given and the effect is long lasting." He goal is to develop an effective way to stabilize glutamate release following drug use; this treatment might then reduce drug craving in addicted individuals.

Bamford noted that his research has implications for infants born to drug-addicted mothers. After pregnant mice are sensitized to methamphetamine, their offspring are born with the same abnormalities as the mothers, but to a lesser degree. The abnormalities tend to resolve spontaneously over time. "It's unclear what the response to sensitization will be as these mice get older," he said, "and we don’t yet know if they would have similar responses to cocaine and nicotine as they do to methamphetamine. It's important to know what's happening physiologically in newborns, because changes in the release of glutamate may be harmful to striatal neurons." Perhaps, he suggested, strategies employed during the newborn period could help infants recover from drug sensitization and help to prevent neural injury.

For more information on Bamford's research, visit his laboratory's website at http://depts.washington.edu/nigellab/.

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Social work . . . from page 2

for themselves is another important role," said Stuart. "We educate parents in how to request services and get the help they need." She recalls advocating for a woman with five children, four of whom had been removed by Child Protective Services. "When she came to CHDD with her remaining child, I sensed she might have mental retardation herself. I quickly determined she was in the moderate range of mental retardation. In fact she herself was entitled to services to help her care for her children. An important part of our job as social workers is to advise case-workers, school personnel and others working with our clients, to help change the way they view the situation.”

As interdisciplinary training director for CHDD’s Clinical Training Unit, Stuart has designed a web-based social work curriculum for trainees involved in CHDD’s interdisciplinary training program and for community health care professionals. "The role of social work has expanded to provide leadership in developing programs that serve children and adults with developmental disabilities and their families," she said. "We focus on their long-term needs, and we emphasize strengths and empowerment to facilitate self-advocacy and self-determination. Our goal is to support, not supplant, family resources."
New research affiliates join CHDD

Robert Rostomily, M.D., is an assistant professor of neurological surgery. His laboratory is investigating the molecular biology of cancerous tumors in the skull base, with the goal of devising better treatment strategies, such as gene therapy, for patients whose tumors cannot be surgically removed or treated with additional radiation. His major research interest is to understand how the molecular and cellular regulation that characterizes normal developmental processes is similar to the pathologic behavior of cells in tumors of the human central nervous system.

Nephi Stella, Ph.D., is an assistant professor of pharmacology and psychiatry and behavioral sciences. He is working to identify signaling molecules produced by microglial cells, which may influence the growth of astrocytomas and glioblastomas, the most common brain tumors in children. The hope is to identify enzymes that produce such signaling molecules as likely targets for therapy. His laboratory is researching whether cannabinoid compounds can prevent or reverse growth of these tumors in mice. Such cancers are generally resistant to therapies currently available.

Attachment . . . from page 5

Leagues will study the development of infant-parent relationships, disruptions or disturbances in those relationships, and the social, emotional and biobehavioral consequences of such disruptions. They will evaluate intervention programs for infants and parents at risk.

The laboratory’s first project is a pilot study of babies’ reactions to maternal depression, conducted with Sandra Jolley, Ph.D., a postdoctoral trainee with the School of Nursing’s Center for Women’s Health Research. They will examine mothers with and without postpartum depression, and observe their interactions with their babies during play and feeding. The lab will be equipped to take infant psychophysiological measurements of such factors as heart rate variability and cortisol levels, an indicator of hormonal reaction to stress. A further goal will be to test and refine an assessment protocol, crucial for future research projects and an important teaching tool for professional trainees in infant mental health.

“I am focusing increasingly on intervention and prevention, using lessons learned in the observational studies,” said Spieker. “My interest is in strategies to prevent adverse developmental, social and emotional outcomes in children. It’s time to move beyond observing and start intervening.”

Oral health . . . from page 6

Child’s risk for oral health problems, actions to prevent early childhood caries and other oral health problems, treatment techniques for children’s oral health problems, and resources available on the local, state and national levels for oral health promotion. In all areas, the emphasis is on a family-centered approach, taking into account cultural differences. Case studies and problem-solving strategies and examples will be offered. The curriculum will offer links to a wide variety of resources in the community, including community organizations and educational materials.