CHDD OUTLOOK

News from the Center on Human Development and Disability at the University of Washington Health Sciences Center

INSIDE

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Learning disabilities research encompasses education and biology

An estimated 10 to 15 percent of school-age children in the United States have some form of learning disability. Most of these children are bright and motivated and have average or above-average intelligence, but they experience extreme difficulty when trying to acquire skills such as reading or writing from standard methods of instruction. If a child's learning disabilities are not identified and treated with appropriate educational interventions, there could be lasting consequences. Untreated learning disabilities are often accompanied by failure in school and jobs, as well as low self esteem and other emotional problems.

Although the causes are not fully understood, studies have shown a relationship between some learning disabilities and subtle abnormalities in parts of the brain that process language. Delving deeper into the biological underpinnings of learning disabilities, other studies point to genetics as accounting for 30 to 40 percent of the factors contributing to learning disabilities. The bulk of the contributing factors are thought to be environmental.

A multi-faceted effort, led by two CHDD research affiliates, seeks to gain a better understanding of both the biological and educational aspects of learning disabilities, and the links between them. Drs. Virginia Berninger, professor of educational psychology, and Wendy Raskind, associate professor of medicine, are co-principal investigators of the UW Learning Disabilities Center. The Center is funded by a five-year grant from the National Institute of Child Health and Human Development (NICHD). One of five such centers in the nation, the UW Center is the first to involve a major collaboration between medicine and education, explains Berninger.

"We're tapping into each other's expertise," says Raskind, an internist and geneticist. "As a physician, I can make a diagnosis of a hematological disorder, but I can't diagnose a learning disability."

Focusing on the physical sensations of making specific sounds is an effective way to teach children with learning disabilities the sounds associated with letters and letter combinations.

"Our approach is important because learning disabilities are both educational and biological problems," says Berninger, an expert in assessing and teaching children with learning disabilities who has conducted learning disabilities research for the past 10 years. "Investigating the biological aspects helps us understand why some children have an inordinate struggle in learning to read and write despite adequate intelligence and instruction. Research on the educational aspects sheds light on specific instructional strategies that are effective in teaching children with learning disabilities to read and write. One of our main goals is to disseminate our results to help children, teachers and families better deal with learning disabilities."

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>
> Dr. Virginia Berninger

The Center includes three major research projects and several smaller-scale projects involving children, teachers and families in the Seattle area. Three cores and a scientific advisory board chaired by CHDD research affiliate Dr. Alan Unis, associate professor of psychiatry and behavioral sciences, provide administrative and technical support for the research projects. One core is responsible for testing study participants for specific learning disabilities—dyslexia, which is defined as a discrepancy between verbal IQ and achievement in word recognition, and dysgraphia, a discrepancy between verbal IQ and achievement in handwriting, spelling or composition.

Two of the Center's major projects are exploring different educational aspects of learning disabilities. In one project, Berninger,

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Learning disabilities research

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Dr. Robert Abbott, professor of education, and their colleagues are evaluating the effectiveness of alternative educational interventions for treating reading disabilities. This project parallels a separate NICHD-funded effort headed by Berninger that is investigating treatments for writing disabilities. Together, Berninger's studies cover learning disabilities that affect either the processing or production of written language. Both projects include prevention, and short-term and long-term intervention studies with children in primary grades. The long-term treatment studies aim at demonstrating that individualized theory-based intervention can bring children with severe reading or writing disabilities up to grade level. The prevention and short-term studies are designed to test the idea that teaching combinations of connections between units of print and sound is more effective than teaching single connections.

"When you spell, you go from a sound representation to a written representation. You can make this translation at different units of sound and print, for example, a phoneme will translate to one or two letters, a syllable to a small group of letters, and a name code to a word-specific representation or sequence of letters. Our hypothesis is that it isn't just one of these units of translation that is used in learning to spell, but rather a combination of them or multiple units," explains Berninger. The same concept applies to word recognition in reading, except the translation process is reversed, going from a written unit to a sound unit. Individuals with learning disabilities have trouble with some part of the translation process.

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> Dr. Virginia Berninger

"Our research will be comparing the conventional approach of teaching component reading and writing skills with alternative approaches informed by neurodevelopmental theory," Berninger points out. "We will be using state-of-the-art statistics to analyze the effectiveness of the various interventions, including growth-curve analysis that measures change over time, rather than just pre-intervention and post-intervention."

Another major project seeks to apply the results of research that demonstrate effective methods for teaching children with learning disabilities. Led by Dr. Deborah McCutchen, professor of education, and Dr. Susan Nolen, associate professor of education, the project conducts summer training institutes for primary grade teachers. Training focuses on giving teachers a variety of instructional strategies for teaching component reading and writing skills. The project will follow participating teachers as they implement the strategies they have learned.

Biology is the focus of the Center's third major project—an investigation of genetic contributions to learning disabilities. "There is no argument that there is a genetic component to learning disabilities," says Raskind, who heads the project. Studies have shown that learning

disabilities cluster in families and have suggested that genes on three different chromosomes may play a role in learning disabilities. But, Raskind explains, many questions remain about how genes are involved, what function such genes might have and how much weight the genetic component carries in relation to environmental factors involved in learning disabilities.

To find answers, Raskind and her colleagues, Dr. Ellen Wijsman, research associate professor of medicine, and Dr. Li Hsu, staff scientist at the Fred Hutchinson Cancer Research Center, are investigating genetic factors in specific subtypes of learning disabilities and identifying genes that contribute to those learning disabilities.

"Learning disability isn't one defined condition, but a heterogeneous group of problems," explains Raskind. "Learning disabilities that affect reading and writing may be distinct disorders. Furthermore, each of these disorders has distinct and shared components and subcomponents that could represent the functions of different genes. Alternatively, there might be a 'master' gene involved."

By constructing pedigrees of families whose members have specific learning disabilities, Raskind and her colleagues will be able to determine the pattern of inheritance, then work to pinpoint genetic mutations shared by individuals who have learning disabilities. Eventually they hope to identify the responsible gene or genes.

"Uncovering the gene or genes related to learning disabilities could help us identify children who are at increased risk for learning disabilities, which could enable them to begin intervention programs before they have trouble in school," notes Raskind. "It will also make it possible for us to learn what these genes actually do, what proteins they code for. Knowing the function of the genes may allow us to understand the problem at a more basic level and help in developing specific educational interventions that correspond to specific types of learning disabilities.

"Learning disabilities are not disorders that are likely to be amenable to genetic engineering," Raskind emphasizes. "If we can't modify the genes, we have to find out what we can do to modify the environment."

In another project related to the biology of learning disabilities, Dr. Stephen Dager, associate professor of psychiatry and behavioral sciences, and Dr. Todd Richards, associate professor of radiology and CHDD research affiliate, are using an innovative functional imaging technique to study brain activity in children with learning disabilities. One goal of this

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Adolescent Health Unit focuses on youth at risk

Adolescence, the years of growth and change stretching from childhood to adulthood, is a time of distinctive developmental concerns. As young people reach sexual maturity and continue to develop their self-esteem and ability to relate to others, they face new challenges and problems. Many of these problems, such as substance abuse, risky sexual behavior and delinquency, can pose serious threats to an adolescent's health and long-term development, as well as to the development of children born to teenage mothers.

Since the mid-'70s, the adolescent program housed at CHDD has been striving to improve health and development through the teenage years. The program has now become a major component of the CHDD's University Affiliated Program (UAP) and is known as the Adolescent Health Unit (AHU).

"This change represents another in a series of major expansions of the UAP aimed to insure a life-span perspective," says Dr. Michael Guralnick, director of the UAP and professor of psychology and pediatrics. The new unit contributes to the UAP's mission of reducing the incidence and impact of developmental disabilities with its emphasis on critical areas of adolescent health. "In line with the UAP's university/community partnership approach, the adolescent program has enjoyed notable success forging links between university resources and community resources to address the increasingly serious problems faced by today's adolescents," notes Guralnick.

The AHU trains health professionals to recognize and treat the special problems of adolescence, provides clinical services for adolescents in a variety of traditional and nontraditional community-based settings, and conducts research toward identifying effective interventions for high-priority adolescent health problems.

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>
> Dr. Jim Farrow

Most adolescents served in the AHU's various clinical settings have complex medical and psychosocial needs. Some are older children with special health care needs. Many are teens who face high-risk health issues because of drug and alcohol abuse, homelessness and sexual behavior that increases risk for sexually transmitted diseases, including AIDS. These health issues pose particular hazards for pregnant and parenting teens whose age alone increases the chances for poor birth outcomes.

"About 85 percent of the kids we see are at increased risk for health and developmental problems due to low income, lack of family support or other environmental factors," explains Dr. Jim Farrow, associate professor of pediatrics and medicine, and AHU director. AHU trainees gain a solid foundation for tackling high risk health issues as they pursue their careers across the nation by working directly with young people with such complex needs, he points out.

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Head Start/ECEAP and laboratory school partner to enhance inclusive preschool programs

Vicki Nalls from The Creative Child Enrichment and Development Center, A City of Seattle Head Start/ECEAP site, shares a book with children in the model classroom.

A demonstration project at CHDD's Experimental Education Unit (EEU) is helping preschool children from families with low incomes take a running start at the future. The Training Partnerships Project has grown out of an ongoing collaboration between the EEU and City of Seattle Head Start/Early Childhood Education and Assistance Programs (ECEAP).

The collaborative effort strives to enhance the quality of Head Start/ECEAP programs in Seattle and to better meet the needs of children with diverse abilities and their families. Major goals of the project include developing an effective and sustainable model of inclusion for Head Start/ECEAP classrooms and a model of transportable training for Head Start/ECEAP staff.

During the 1995-96 school year, the EEU created a new inclusive classroom for children enrolled in Head Start/ECEAP. Like all classrooms at the EEU, the Head Start/ECEAP classroom includes children with developmental disabilities and typically developing children in a setting that builds on the strengths and supports the needs of each child. The new classroom also serves as a training site for teachers, coordinators and other staff who operate Head Start/ECEAP programs in the community.

Head Start/ECEAP is a federal and state-funded program for children ages 3 to 5 from low-income homes. The program provides educational activities to pave the way for success in school. It also gives children and their families access to a variety of support services designed to meet their health and social service needs, including the special needs of children with disabilities. The EEU project is supported by State of Washington ECEAP funds.

"It has been a nice two-way street—we're able to share our expertise and, in turn, learn from Head Start/ECEAP about different components of family support," says Cecile Lindquist, Admissions and Community Liaison Coordinator at EEU and director of the project. "Learning about the family supports that are part of the Head Start program has broadened our knowledge of other services available in the community and of what services might be supportive of families. We have other families in the EEU school program with the same sorts of needs."

> "It has been a nice two-way street—we're able to share our expertise and, in turn, learn from Head Start/ECEAP about different components of family support."
>
> Cecile Lindquist

Supports that are hallmarks of Head Start/ECEAP include health screening for children enrolled in the program, education about nutrition, support for parents and their education, parenting training, access to services that meet further family needs, and activities that encourage parents to network and become more involved in school.

"It has worked well for us because we already have a social worker and nurse as part of our staff," explains Lindquist. "We have access to nutrition resources through the Clinical Training Unit at CHDD and the UW School of Dentistry is able to provide dental

screening. Having all of these resources readily available made it fairly easy for us to plug into the Head Start program."

This year's class was made up of 19 preschoolers, including eight children with disabilities. A head teacher, an assistant teacher, an aid and a trainer round out the classroom.

After starting each day with a healthy breakfast, children in the class participate in a half-day program of planned activities and free play, which also includes a nutritious lunch. The preschool curriculum emphasizes activities of daily living such as washing hands, brushing teeth and thinking about safety. In both large and small group settings, children learn skills by participating in developmentally appropriate activities. During play time, children can choose from a number of activities designed to reinforce the skills they are learning. They also get a chance to exercise sharing and other peer-interaction skills they are acquiring in the group situations. Activities designed to foster social competence are an important aspect of the program's goals to build self-confidence and prepare youngsters for school.

"The feedback we've gotten so far tells us that parents like the classroom and the Head Start/ECEAP trainees like the training."

Cecile Lindquist

"The feedback we've gotten so far tells us that parents like the classroom and the Head Start/ECEAP trainees like the training," notes Lindquist.

Nineteen staff members from seven City of Seattle Head Start/ECEAP sites participated in the inservice training this year. "Next year we're hoping to train 30 people," says Barbara Matlock, trainer for the project, whose experience teaching preschool at the EEU as a graduate student and later training teachers who work with children with disabilities was ideal background for the job.

To begin the two-week training program, Matlock visits the site where staff have requested training. She meets with the staff and together they work to assess training needs. Based on their needs, Matlock designs an individualized training program that emphasizes preschool activities and incorporates best practices for working with children with special needs. This includes targeting specific areas to work on such as communication, behavior management and class organization. It also involves negotiating a way to fit training time at the EEU into staff schedules. Arranging substitutes so staff can be away from their sites is a challenge that usually requires some flexibility.

Head Start/ECEAP staff come to the EEU to observe and participate in the model classroom by helping to plan, implement and assess activities. "An important part of my training philosophy is to present the theoretical background on something, then get trainees working on it with kids right away," says Matlock.

For example, Merrie Barnes and Vicki Nalls from The Creative Child Enrichment and Development Center, a City of Seattle Head Start/ECEAP site in south Seattle, wanted to know how to encourage language development in children. After discussing concepts with Matlock and observing techniques used in EEU classrooms, Barnes and Nalls gave it a try themselves in the model classroom. "We learned about introducing a picture in a picture book to a child and describing one feature of the picture, then encouraging the child to expand on the other things he or she sees in the picture," explains Barnes. "Instead of an adult dominating the scene, the child is interacting with the adult and developing language skills."

The final aspect of training is the transfer process, explains Matlock. According to a regularly scheduled follow-up plan arranged at the beginning of training, Matlock goes to each community site and assists staff in putting what they have learned to work at their own facility. On site, she can take a look at the environment and determine how to make the transfer from the model classroom to a preschool in the community, taking into account how space, staffing and other factors differ from the EEU.

"I've been impressed with the community sites and they've been impressed with their experience at the UW," says Matlock. "It's been a good reciprocal relationship."

The Head Start/ECEAP classroom at EEU is starting up again in September. For more information, call 206/543-4011.

Merrie Barnes, director of The Creative Child Enrichment and Development Center, works with a preschooler in the EEU's Head Start/ECEAP classroom.

CHDD researcher investigates neurological underpinnings and consequences of childhood epilepsy

Although epilepsy is a neurological disorder that affects people of all ages, the incidence of seizures is higher in young children than in adults. It is unknown why the developing brain is more prone to seizures than the adult brain. The knowledge gained in the process of answering that question could have profound significance for treating epilepsy in young children and for increasing understanding of normal brain development.

In recent years, the topic of pediatric epilepsy has received more attention as clinicians and researchers recognize that epilepsy in children is often much different from epilepsy in adults, says CHDD research affiliate Dr. Philip Schwartzkroin. "For many years clinicians tried to apply the same principles used in treating adult epilepsy to infants, but the drugs and treatments that had been successful in adults didn't always work in children," he notes. "Now pediatric epilepsy has emerged as an independent field, and new drugs and treatments especially for children are being developed."

However, there is still a long way to go toward understanding the basic mechanisms of seizure activity in the immature nervous system and how those mechanisms are linked to development. Investigating the relationship between pediatric epilepsy and other developmental problems is a research question that has important implications for clinical management, explains Schwartzkroin, professor of neurological surgery and of physiology and biophysics.

"We know that some pediatric epilepsies are associated with developmental abnormalities of the brain. These epilepsies are often accompanied by motor and cognitive deficits, so we are asking, do developmental problems give rise to abnormal brain structures which in turn cause epilepsy, or is it the other way around?"

Dr. Philip Schwartzkroin

"We know that some pediatric epilepsies are associated with developmental abnormalities of the brain. These epilepsies are often accompanied by motor and cognitive deficits," explains Schwartzkroin. "So we are asking, do developmental problems give rise to abnormal brain structures which in turn cause epilepsy, or is it the other way around?"

The answer is significant for clinical problems, such as whether it is necessary to stop all seizures that occur in children. Currently available drugs can have significant side effects. Some forms of pediatric epilepsy appear to be "benign" and are outgrown. So there is often a real question about how important it is to stop the seizures, explains Schwartzkroin. If seizures lead to cognitive dysfunction, the risk/benefit balance rests on the side of stopping seizures. On the other hand, if the seizures are harmless and soon stop on their own, there may be no need to treat them, especially if the treatment involves drugs that have adverse side effects.

Schwartzkroin's research aims at understanding the basic cellular mechanisms underlying epilepsy. Using electrophysiological recording, Schwartzkroin and his lab group measure and characterize the patterns of electrical activity of cells in brain tissue from animal models, as well as human epileptic brain tissue removed during neurosurgical operations. They also do anatomical studies to relate their findings about electrical activity with structural changes in brain cells.

The goal of this research is to gain an understanding of seizures by uncovering the cellular circuitry and properties of nerve cells in the hippocampus, a part of the brain that plays a major role in many forms of epilepsy. Schwartzkroin's studies of hippocampal neurons have shed much light on the ability of cells in that region to reorganize and to interact with each other differently after being damaged by trauma—a characteristic known as "plasticity." The work on plasticity has led to studies to determine why some cells in the hippocampus are particularly vulnerable to injury and how cellular organization changes with damage. Determining how brain cells can forge new pathways of interaction has significant implications for understanding complex behaviors such as learning and memory, and unraveling the details of epilepsy in the immature brain.

A major emphasis of Schwartzkroin's research is investigating the properties of the cells of the immature brain that might be responsible for the special forms of seizures seen in young children. These properties might also explain why the immature brain is so seizure-prone. Schwartzkroin and his colleagues are developing animal models to study differences between the young nervous system and the adult nervous system. They are currently investigating the relationship between traumatic incidents around birth—such as periods of low oxygen levels—and seizure activities in babies. They are asking if trauma-induced seizures in a baby can predispose the adult to epilepsy. To learn further about the developmental consequences of some types of childhood epilepsy, they are looking at possible relationships between abnormal brain development, the resulting anatomical anomalies and the occurrence of seizures.

Schwartzkroin and his colleagues have also begun working with molecular biologists in collaborations aimed at understanding the genetic contribution to seizure susceptibility. "It may not be one gene that causes an epilepsy, but many predisposing genes which, when interacting with a trauma, increase the likelihood of an individual having seizures," Schwartzkroin points out. "It's an exciting time with so many techniques available to study genes and development. As we begin to study some forms of pediatric epilepsy arising from developmental abnormalities, we are likely to uncover information relevant to other developmental disabilities."

Book on pediatric epilepsy integrates perspectives of clinicians and researchers

Clinicians who treat epilepsy and investigators who study its biological underpinnings agree that epilepsy in children is different from epilepsy in adults. Yet, in the epilepsy field as in other fields, there has been a communication gap between basic scientists and clinicians as they search for answers about pediatric epilepsy, according to Dr. Philip Schwartzkroin, CHDD research affiliate and professor of neurological surgery and of physiology and biophysics.

Focusing on seizures and epilepsy in the immature brain, a national conference held in 1992 attempted to bridge the gap. The conference was unique in bringing together clinicians, neuroscientists who specialize in pediatric epilepsy and neurobiologists who study normal development, explains Schwartzkroin. Basic neurobiology has had a great deal of success in the past 15 years or so gaining insights into mechanisms of normal brain development, he says. And, knowing what is normal is important if you are going to answer questions about what has gone wrong. Such background is especially important for learning how to approach the epilepsies of the developing brain.

Schwartzkroin, one of the conference organizers, is also co-editor of a book that grew from interactions among conference participants. The volume, entitled *Brain Development and Epilepsy* published by Oxford University Press, is geared toward both clinicians and researchers. By providing overviews of experimental research integrated with clinical issues, the editors aim to foster communication about childhood seizure disorders in the context of development. Chapters in the book address key questions in pediatric epilepsy research and suggest directions for future investigation.

Finding the causes of pediatric epilepsies and developing appropriate treatment approaches will take a combined effort encompassing a variety of disciplines, emphasizes Schwartzkroin. "Pediatric epilepsy is so complex, and there are so many ways of thinking about it, that no one scientist can do it all," he says. "Collaboration and interaction among a variety of disciplines are crucial."

Learning disabilities research

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project is to examine the link between biology and the environment by imaging brain activity before and after educational intervention.

The non-invasive imaging technology called Proton Echo Planar Spectroscopic Imaging (PEPSI) was developed by a group of investigators from the UW and the National Institutes of Health. It uses the same equipment as Magnetic Resonance Imaging (MRI), a diagnostic technique that gives a view inside the body and is commonly used to diagnose brain tumors and joint injuries. PEPSI is software that enables the MRI scanner to map the spatial distribution of certain chemicals within the brain.

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>
> Dr. Wendy Raskind

With this technique, Dager and Richards can measure these chemicals as a person is thinking and generate images of chemical activity that correspond to mental activity. Creatine and phosphocreatine are chemicals known to be important in brain activation and learning. By mapping those chemicals in a region of the brain involved in language, they will compare brain activation in children with dyslexia or dysgraphia with brain activation in controls who do not have learning disabilities.

Mapping is done as study subjects are given language tasks specifically designed to test underlying problems in reading and writing. "In people with learning disabilities, we expect to find different patterns and intensity of brain activation," says Richards.

Those patterns may change as educational treatment improves reading and writing skills, explains Dager. "Along with learning more about why some children have learning disabilities, for the first time we may be able to show that learning has altered brain chemical activity," he says.

The UW Learning Disabilities Center takes parent, teacher and psychologist referrals for children with suspected learning disabilities in grades 1 through 6. For more information, call Dr. Mardean Francis at 543-1846.

Anne Marolich and research assistant Laura Rogan feel the sounds they are making.

Adolescent Health Unit

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"Interdisciplinary training is a major focus of the AHU," says Farrow. "All of our clinics provide services and support training, but the training mission actually outweighs the service mission."

The AHU's Adolescent Health Training Program is funded by the Maternal and Child Health Bureau (MCHB). Each year nearly 100 long-term and short-term trainees in medicine, psychology, nursing, nutrition and social work participate in the program. The Program's primary training site is the Adolescent Clinic at CHDD, which consists of an interdisciplinary primary care clinic and specialty clinics geared to meet the needs of special populations of adolescents.

One of the specialty clinics helps adolescents and young adults with developmental disabilities and chronic conditions make the transition from the pediatric health care system to the adult system. AHU physicians, nurses and social workers assist adolescents and their families in health, social and vocational planning for the future.

Another multidisciplinary specialty clinic provides comprehensive prenatal and postnatal care for pregnant teenagers 16 and younger, an age group whose children have a higher likelihood of developmental problems. By emphasizing pregnancy and childbirth education and nutritional guidance, health providers in nursing, medicine, social work and nutrition work to reduce risk for poor birth outcomes. Social workers in the clinic also provide family intervention, helping the teenage mom's family and/or partner support her effectively.

Collaborating with several community agencies, AHU faculty and trainees provide services in a variety of nontraditional locations for teens who need services, but are unlikely to go out of their way to seek them. A school-based clinic provides a wide range of services and counseling aimed at early detection and treatment of illness, promotion of healthy living habits and teaching teens how to use the health care system effectively. (See *Outlook*, Summer 1995)

The AHU places special emphasis on working with homeless and incarcerated youth, many of whom have developmental problems. A study of street youth in Seattle conducted jointly by faculty from the AHU and Youth Care, a community agency, found that nearly 70 percent of the adolescents in the study had some form of developmental problem such as learning disabilities, mild mental retardation, mild cerebral palsy or epilepsy.

The AHU works to improve the health of youth who live on the streets through two night clinics located in downtown Seattle that provide free services. Screening and educating about AIDS transmission is one of the major concerns at these drop-in clinics. The AHU also operates the health clinic at the King County juvenile detention facility.

In a collaborative project with the Seattle-King County Department of Health, the AHU reaches out to homeless pregnant and parenting adolescents. The goal of the project, which is known as the Out-of-Home Teen Pregnancy Project, is to improve birth outcomes and prevent child abuse. A case management team, consisting of a public health nurse and a social worker, helps pregnant teens younger than 18 who have a history of high-risk behavior and are estranged from home, family and adult supervision to stabilize their living situation and gain access to a supportive network of community services. The project also educates moms-to-be about good health practices during pregnancy and provides them training in parenting skills. (See *Outlook*, Winter 1995)

AHU faculty and trainees also conduct research that covers a broad range of problems in adolescent health. One study is investigating effective ways to treat drug and alcohol addiction in young mothers and improve infant outcomes. Research funding for the AHU comes from sources such as the Health Resources and Services Administration and the National Institutes of Health. ◆

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