

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

CHDD serves families and community providers who care for children with feeding and nutrition problems

All parents have concerns about feeding their new babies and making sure they receive adequate nutrition to give them a healthy start in life. Are they eating enough? Why are they fussing? Why won't they breastfeed? Are they gaining weight as they should? When should solid foods be introduced? When should they be weaned? Nursing and meal times can be occasions of joy and connection between parent and child, but if things are not going well, it can be an unhappy time for both and a source of worry for parents.

Parents of children who have or are at risk for developmental disabilities and other special health care needs have special concerns, since such children experience a higher incidence of problems related to feeding and nutrition. They may have a wide range of diagnoses, including autism, Down syndrome, cystic fibrosis, cerebral palsy, pediatric AIDS, spina bifida, muscular dystrophy or Prader-Willi syndrome.

Feeding and nutrition problems may arise from such issues as prematurity, extended hospital stays and

tube feedings at the beginning of life, poor muscle tone, compromised oral-motor abilities, effects of medications, biochemical imbalances, gastric reflux, behavioral problems, and even anxious parenting.

"Good nutrition is essential to promote optimal growth and development," said Betty Lucas, RD, MPH, nutritionist at the Center on Human Development and Disability. "It's important to intervene early on and help families who have children with special needs. An estimated 40 percent of all children with special health care needs may be at risk for nutrition and feeding problems. Children present for a variety of reasons: underweight, failure-to-thrive, overweight, obesity. Picky eaters may have inadequate dietary intake. For example, the rigid patterns in children with autism may be reflected in their food intake as well as in other aspects of life. A child who is not a self-feeder is always at risk because he has to be fed by someone. If a child is not able to

chew, she may be limited to soft, mushy foods. With children who have developmental delay, the parents sometimes don't understand stages in feeding, such as readiness to start finger foods. So there is a need for education and guidance on moving the child to a more mature diet."

Some of the more challenging cases, said Lucas, involve babies born prematurely or at low birth weight. "They often have major issues," she said. "They're sometimes in the hospital for a long time, they have breathing problems and other

medical issues, they can't feed orally, and they receive tube feedings and oxygen. Once these babies come home, there may be difficulty transitioning to bottle or breastfeeding. Some may have gastroesophageal reflux and so it hurts to feed. The baby's distress makes the parents worried and anxious, which can compound the problem."

CHDD approaches childhood feeding and nutrition problems of children with special health care needs on a number of fronts, including clinical services, professional training, outreach to the community and dissemination of information on relevant research.

In collaboration with the Children with Special Health Care Needs Program of the Washington State Department of Health, CHDD administers a program called Nutrition for Children with Special Health Care Needs (CSHCN) to support nutrition services



Betty Lucas

David was born with brain calcification and breathing difficulties. When he was referred to a feeding team at age five months, he no longer needed a feeding tube but had oral hypersensitivity, poor sucking ability and growth problems. He was being fed an inappropriate formula of whole cow's milk and corn syrup. After evaluation, oral motor feeding therapy and follow-up visits for four months, he increased intake of a concentrated infant formula and gained weight appropriately. Reinsertion of the feeding tube was avoided.

Jenny, aged 34 months with spastic quadriplegia, was unable to consume an adequate diet. After 11 sessions with a dietitian, she began eating an appropriate diet, gained weight, and avoided hospitalization for failure to thrive.

statewide for children and adolescents and their families. Some 90 registered dietitians—from local health departments, community clinics, hospitals, early

intervention centers and home health agencies—belong to the CSHCN Nutrition Network. CHDD holds three-day training sessions for new members every two to three years, and network members meet twice a year for continuing education and information exchange.

CHDD launched and continues to coordinate some fifteen

Community-Based Feeding Teams, also part of the contract with the Department of Health. These interdisciplinary teams typically include a registered dietitian; a feeding specialist such as an occupational therapist, speech therapist or physical therapist; a public health nurse or school nurse; a feeding behavior therapist such as a social worker or psychologist; sometimes a physician; and other professionals as appropriate. The teams are based in community facilities across the state and work directly with families and other caregivers to resolve feeding and nutrition problems. Team members meet annually at the UW for continuing education and sharing of information.

CHDD staff member Sharon Feucht, RD, MA, is a member of a community-based feeding team at Holly Ridge, an early intervention center located in Bremerton, Wash. "Our four-member team's activities are typical of most feeding teams," she explained. "Someone—often the child's direct therapist—videotapes the child eating in the home. As a team we watch and analyze the video. The child's growth and food intake are evaluated and a feeding assessment is completed. The team report goes to the child's doctor and direct therapist, making recommendations for nutrition therapy interventions."

Clinical feeding and nutrition services are an important component of CHDD's Child Development Clinic, which offers comprehensive interdisciplinary evaluation, diagnostic, intervention and referral services for children with a wide range of developmental disabilities. Lucas coordinates the nutrition evaluations. While CHDD has a feeding team, since the state's community feeding team network is now well established, most children can be referred for follow-up services in their own communities.



Sharon Feucht

Lucas and other specialists in the Child Development Clinic also see infants, children and adolescents with Prader-Willi syndrome, a genetic disorder. In the early months, a child with PWS is at risk for failure-to-thrive, because the sucking ability is impaired by low muscle tone. By school age, children with PWS usually develop an obsessive interest in food, which can lead to overeating and life-threatening obesity. Intensive intervention is required. "Success is making sure they don't gain excess weight, and that the family is managing as well as they can," said Lucas. "Since PWS can now be diagnosed in the first few weeks of life, we have the opportunity to intervene early."

Children and young people with phenylketonuria receive ongoing dietary management in the PKU Clinic at CHDD, coordinated by Cristine Trahms, MS, RD. People with PKU lack a liver enzyme to metabolize an amino acid called phenylalanine, and must



Learning to eat finger food is an important milestone for a baby.

remain on a lifelong highly restrictive low-protein diet to prevent severe brain damage. (An article on the PKU clinic is in the Spring, 2003 issue of *CHDD Outlook*.)

CHDD also produces *Nutrition Focus*, a bimonthly newsletter for health professionals and others who serve children with feeding or nutrition problems in a community or ambulatory setting. The newsletter, edited by Feucht, is available by subscription. Each issue highlights a specific disorder or nutrition concern and offers practical suggestions, including nutrition assessment and intervention strategies, case studies, and references and resources for clients, families and health care professionals. Sample topics include updates on pediatric formulas, growth assessment, prematurity, prevention and management of childhood obesity, issues related to specific syndromes and health conditions, and costs of nutrition services.

Subscribers to *Nutrition Focus* may also receive a membership in the Pediatric Nutrition Consultation Online Listserv, a closed, consultative online forum for registered dietitians who serve children with special health care needs or chronic conditions. It is unique in providing evidence-based answers to posted questions, using

nutritionists and dietitians from CHDD and Seattle's Children's Hospital and Regional Medical Center as consultants. Information on the newsletter and listserv is available online at http://depts.washington.edu/chdd.ucedd/co/co_NutriFocus.html or from Feucht at 206-685-1297 or sfeucht@u.washington.edu.

The listserv was developed as part of a federal grant to CHDD and Children's Hospital that also funded development of a three-day pediatric nutrition course, "Assuring Pediatric Nutrition in the Hospital and Community," now offered every summer to participants from across the country and abroad, as well as development of a new Pediatric Nutrition web site at <http://depts.washington.edu/nutrpeds/>.

"Without intervention, many children with feeding problems require costly medical treatments," said Lucas. "Early assessment and intervention by qualified nutrition and other health care professionals can lead to improved diet, appropriate growth, improved health status and fewer hospitalizations, as well as cost savings in overall health care expenditures."

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