Quality Care through Interprofessional Teamwork in the NICU Follow-up Clinic

BY LINDA L. LINDEKE PHD, RN, CNP, FAAN

Stunning views of the shimmering Mississippi River and expansive Twin Cities skyline form a dramatic backdrop for the University of Minnesota Amplatz Children’s Hospital Neonatal Intensive Care Unit (NICU) Follow-up Clinic. Each week a dozen or so families of discharged prematurely-born children consult there with an experienced team of pediatric professionals. The team consists of neonatal physicians and fellows, pediatric nurse practitioners (PNPs), occupational therapists (OTs) and neuropsychology staff. During periodic visits, the team members’ varying professional backgrounds assist children and their families during the critical early years following NICU discharge. For more than 30 years this NICU Follow-up Team has been Associate Professor Dr. Linda Lindeke’s clinical practice site where she is continually energized by the shared commitment to excellence within a team-based model of care delivery. The team is coordinated by Marla Mills, DNP, RN, CNP, who holds multiple degrees from the School of Nursing. Her doctoral project developed comprehensive care coordination for infants discharged with chronic lung disease, a key component of this team’s activities.

The NICU Follow-up team works hard to create an atmosphere of collegiality and respectful communication as it partners with parents to assess the children and create shared plans of care for these very special little ones who have benefited from state-of-the-art NICU care and are now at home. Children often go home on special diets and therapies for chronic lung disease and many other health issues. Assessing for neurological and nutritional issues is critical to enhance growth and development. Care is coordination based on children’s risk factors, past history, and ongoing needs. Coordinating care is a shared responsibility of families, the NICU Follow-up team, specialists and community providers, using the medical/health care home model.

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FROM THE DIRECTOR

Family-centered care and care coordination for children and youth with special health care needs (CYSHCN) (ages 0-21) and their families have been cornerstones of the Center for Children with Special Health Care Needs since its inception in 1993.

In this issue, you will find exemplars of how Center faculty and trainees are working collaboratively to improve the quality of care for CYSHCN and their families through innovative education, research, practice, and policy initiatives.

The cover article Quality Care through Interprofessional Teamwork in the NICU Follow-up Clinic by Dr. Linda Lindeke clearly illustrates how an interprofessional team provides family-centered, comprehensive care over time to families of prematurely born infants. These NICU Follow-up Clinic experiences have grounded Dr. Lindeke in team models and care quality throughout the years which has in turn, informed her mentorship of trainees and the development of curriculum, quality care measures, and health care policy. For example, Lindeke is a coauthor of Pediatric Care Coordination Curriculum (R. Antonelli) soon to be released by Maternal and Child Health Bureau (MCHB). She has been very involved in creating a Position Statement for the American Nurses Association (ANA) as well as a White Paper on care coordination. She serves on the national Steering Committee on Care Coordination for the National Quality Forum (NQF) and the Pediatric Medical Home Project of the American Academy of Pediatrics.

Dr. Wendy Looman’s article Collaborative Research: How do Family Caregivers Define Quality of Life illustrates the added value of engaging leadership trainees and family caregivers in research initiatives. Questions about the interpretation of quality of life measures in an existing study led to the development of a substudy that will inform refinement of the quality of life scale for children with mobility impairments. Her expertise in family-centered care and care coordination is evident in her teaching, clinical practice, and research. For example Looman has began collaborating and providing measurement expertise to the Minnesota Department of Human Services on the Health Home Care Coordination Complexity Tiering Tool and the expert panel for the Center of Excellence on Quality Care Measures for Children with Complex Needs (COE4CCN) at Seattle Children’s Research Institute. Her research is focusing on the role of advanced practice nurses in coordinating care for children with complex special health care needs and testing telehealth nursing interventions in a health care home.

For more information about the Center and available resources, go to www.nursing.umn.edu/ccshcn.

Ann E. Garwick, PhD, RN, LP, LMFT, FAAN
Professor and Cora Meidl Siehl Chair in Nursing Research
Jocelyn Bessette Gorlin, a PhD pre-doctoral fellow in the Center for Children with Special Health Care Needs, is collaborating with her advisor, Associate Professor Dr. Wendy Looman, on a qualitative follow-up study of families of children with complex special health care needs. The aim is to identify how families of children with significant functional limitations describe quality of life for their children. This follow-up study is supported in part by the Telefamilies NIH National Institute of Nursing Research grant (#R01 NR01883; PI: S. Finkelstein).

Many health-related quality of life measures focus on functional status, with questions about the child’s ability to run or walk without difficulty, communicate clearly, socialize with same-aged peers, and meet academic goals. Using these measures, children with permanent disabling conditions such as quadriplegic cerebral palsy or congenital brain anomalies, tend to be rated with very low quality of life because of the focus on functional status. Yet families consistently report that for these children, a “good life” is defined as one in which the child is happy, pain free, integrated into the family, and meeting expectations for health given their existing condition(s).

Bessette Gorlin, who has extensive clinical experience as a pediatric nurse practitioner caring for children with hemophilia, developed a “Lifeline” activity to help parents describe their child’s wellbeing over time, from birth to the present moment. During audiotaped interviews with a subset of families from the TeleFamilies study, Bessette Gorlin and Looman encouraged parents to draw or depict on the Lifeline key periods when the child experienced high or low quality of life, and to talk about these experiences from their family’s perspective. Initial findings from the study suggest that many families experience a transformative shift from defining wellbeing in terms of what the child cannot do at the time of diagnosis to defining wellbeing in terms of thriving in the current circumstances.

As one mother explained, “It’s not about what you thought you had, but what you’re given and do with it. … Having a child with special needs is not gloom and doom...it’s finding a different way to live. I think you can have a beautiful life with a child with special needs. It makes you stop and smell the flowers.”

It’s not about what you thought you had, but what you’re given and do with it.
Putting children and families first is key to successful interprofessional team care. Equally important are the skills of listening, teaching, and negotiating towards shared goals. Team members support parents to be proactive and to anticipate what to expect from their children and from the community service providers. The goal is community-based, continuous, comprehensive, coordinated, culturally-appropriate high quality care.

The team must constantly adapt to changes and must integrate new members onto the team. Individual roles and responsibilities must be negotiated in ways that convey respect for varying perspectives and expertise. Problem-solving with input from the entire team is essential. Team members must approach children and families without overwhelming them, being efficient with time and space limitations. NICU graduates are a perfect example of the need for a “lifecourse” approach, and team care is very helpful with tailoring anticipatory guidance comprehensively, holistically and long-term to assist families and caregivers’ clinical decision-making.

For more information, watch the “What is Team-based Care?” interview with Linda Lindeke on Youtube at www.youtube.com/watch?v=hZx8MCdfY8Q
Kudos to our graduates

Doctor of Philosophy, Major in Nursing (PhD)

Diane Rose, PhD, RN, completed her dissertation on Rural Family Caregiving for Children with Complex Chronic Conditions: A Grounded Theory Study.

As a result of her interviews with family caregivers of children with complex conditions who live in northwestern Minnesota, she developed a model of how rural family caregivers manage caregiving challenges with limited resources while maintaining family integrity.

Post-Masters Doctor of Nursing Practice (DNP)

Three trainees completed their DNP programs in fall 2011. The systems change projects conducted by these graduates are making a difference in improving care for children in primary and specialty care settings as well as in school and community-based settings.

Sommer E. Anderson, DNP, RN
Fetal Alcohol Spectrum Disorders in Primary Care: A Health Program to Address screening and Clinical Pathways for Children Within a Pediatric Health Care Home

Angelynn Grabau, DNP, RN
Enhancing Continuity of Care through Care Coordination for Children with Special Health Care Needs

Mary Jane Krebs Turnbull, DNP, RN
The Development and Implementation of a Breastfeeding Web Site

BSN to DNP

These CSHCN trainees are the first cohort to graduate from the School of Nursing BSN to DNP program in spring 2012. All completed the pediatric nurse practitioner program with a specialty in children with special health care needs.

Sonja Dahl, DNP, RN
Implementing Standardized Infant/Child Developmental Inventory

Molly Hagen, DNP, RN
Improving Clinic Experiences for Children with Autism Spectrum Disorders and their Families

Kristina Koch, DNP, RN
Routine Standardized Depression Screening for Adolescents in Pediatric Primary Care

Jessica Kuhn, DNP, RN
Increasing Nursing Knowledge, Nurse Satisfaction and Nurse Retention through Neonatal Education to Improve NICU Outcomes

Jennifer Modell, DNP, RN
Improving Pediatric Developmental Screening at a Primary Care Clinic

Lisa Nordland, DNP, RN
Breastfeeding Education for Family Child Care Providers Promoting Infant Health

Master of Science, Major in Nursing (MS)

Karen Auel, MS, RN, completed her master’s degree with a specialty in children with special health care needs.

center news
Faculty

Mary Chesney, PhD, RN, CNP, received the Presidential Award from the National Association of Pediatric Nurse Practitioners (NAPNAP). She was also promoted to Clinical Associate Professor in the School of Nursing by the Regents of the University of Minnesota. Chesney is a former CSHCN PhD trainee.

Mary C. Hooke, PhD, RN, CPON, was awarded the Outstanding Dissertation Award from the Pediatric Research Section of the Midwest Nursing Research Society for her innovative research on Fatigue, Physical Performance, and Carnitine Plasma Levels in Children and Adolescents Receiving Chemotherapy. Hooke is a former CSHCN PhD trainee.

Susan O’Conner-Von, PhD, RN, received the Distinguished Alumni Award from Mount Mercy University and was selected to attend the 2011 NIH/ NINR Pain Research Methodologies Boot Camp. O’Conner-Von also received the 2012-2014 A. Marilyn Sime Faculty Research Fellowship from the Center for Spirituality & Healing at the University of Minnesota. The fellowship will focus on research and scholarship related to the spiritual needs of persons receiving palliative care. This fellowship was established in 1998 by a gift by School of Nursing Professor Emeritus, A. Marilyn Sime, PhD, RN.

Jennifer Platt received the Abbott Nutrition DNP Capstone Grant from the National Association of Pediatric Nurse Practitioners (NAPNAP).

Sara Romanski received the Abbott Nutrition DNP Capstone Grant from the National Association of Pediatric Nurse Practitioners (NAPNAP).

Former Trainee Leadership & Awards

Nicole Brown, MS, PHN, CNP, is the Newborn Hearing Screening/Intervention Coordinator at the Minnesota Department of Health. She has coordinated the Maternal Child Health Bureau’s Universal Newborn Hearing Screening and Intervention grant at the Minnesota Department of Health since 2005. Find Newborn Hearing Screening resources developed by Brown at: http://parentsknow.state.mn.us/parentsknow/Newborn/topicsAZ/PKDEV_000308.

Brown also represents NAPNAP on the Academy of Pediatrics (AAP) Early Hearing Detection and Intervention (EHDI) Task Force where she is collaborating with other pediatric health care associations to advance the EHDI agenda nationwide and at the state level. Learn more: www.medicalhomeinfo.org/how/clinical_care/hearing_screening.

Sarah Gutkneckt, DNP, CNP, RN, was named the 2011 Distinguished Nurse of the Year from the March of Dimes. Gutkneckt is a pediatric nurse practitioner who cares for children with special needs at Gillette Children’s Specialty Healthcare and Shriners Hospital for Children-Twin Cities. She does international work with Project Smile, serves on the Center’s Advisory Board, and on the national executive board of NAPNAP as the Certification Chair and the Advisory Board of the Center for Children with Special Health Care Needs.

Marla Mills, DNP, CNP, RN, received the 2011 Neonatal Nurse of the Year Award from the March of Dimes. Mills is a nurse practitioner in the NICU and NICU Follow-up Clinic at the University of Minnesota Amplatz Children’s Hospital. On the national scene, she represents NAPNAP on the Coordinating Committee of the National Maternal and Child Health Education Program (NMCHEP) that focuses on raising the awareness of late preterm birth and non-medically indicated inductions.

Mary M. Erickson, DNP, CNP, RN, received the 2012 Pediatric Nurse Practitioner of the Year Award from the Minnesota Chapter of the National Association of Pediatric Nurse Practitioners (NAPNAP). Erickson is the secretary-treasurer of the national Special Interest Group in NAPNAP for Pediatric Health Care Home. Currently, she is the nurse practitioner care coordinator for the Telefamilies project that is located in the Special Needs Clinic at Children’s Hospitals and Clinics of Minnesota where she is providing innovative telehealth care coordination interventions for children with complex health care needs. Learn more: www.telefamilies.com.

Vickie Parsons, MS, CNP, RN, received the President’s Award [Minnesota Chapter of the National Association of Pediatric Nurse Practitioners (NAPNAP). She received the award for her remarkable achievements in working with children with diabetes and their families. Parsons developed the first summer camp for children with type 1 diabetes in southern Minnesota and for the past three years, has served as camp director of “Camp Sweet Life,” a diabetes day camp. Learn more: www.campsweetlife.org.

Trainees

Tambra Dahlheimer (PhD trainee) was inducted into the Sigma Theta Tau International Honor Society.

Sandra Hagstrom (PhD student) received the Marilee A. Miller Fellowship for Educational Learning. She also received the Amy Wenger Fellowship in Pediatric Nursing for the 2011-2012 academic year.

Lindsay Ohmart, RN, (BSN to DNP trainee) completed a LEND fellowship in the Neurodevelopmental and Related Disabilities Program at the University of Minnesota.
Selected Center Faculty and Trainee Publications

Faculty Names are in bold and trainee names are italicized.


Web-based Continuing Education Modules

Since 2008, the Center for Children with Special Health Care Needs has developed 13 self-paced education modules and ANCC contact hours are available at no cost. Learn more at: www.nursing.umn.edu/ccshcn.

NEW modules are now available

Pervasive Developmental Disorders in Childhood. The purpose of this presentation is to provide an overview of pervasive developmental disorders (PDD) and strategies for caring for children with PDD in various clinical settings. Pharmacological management of children with PDD is also presented. Presenter: Jane Marie Sulzle, DNP, RN, CNS who is a Clinical Nurse Specialist in Child and Adolescent Psychiatry who works with children with mental health disorders.

Child and Adolescent Mental Health Disorders. This presentation focuses on how health care providers can facilitate an initial conversation with children and families about suspected mental health issues (i.e. in a primary or acute care setting) and how to ensure that care of children with mental health issues and their families is family centered. Presenter: Jane Marie Sulzle, DNP, RN, CNS.

Personalized Medicine & Pharmacogenomics. The National Organization of Nurse Practitioner Faculty recommends education on how to respond to advances in genetic technologies and how to utilize new knowledge and skills. This module is an overview on developments in the field of genetics and managing patient care by integrating knowledge of genetics into family history taking and identifying red flags in family histories. Presenter: Brian Van Ness, PhD is a Professor in the Department of Genetics, Cell Biology & Development, Director, Division of Medical Genomics, Institute of Human Genetics, at the University of Minnesota.

Our programs

Advance your leadership skills and prepare for faculty, research, clinical practice, administrative, advocacy, and health policy roles. Broaden your scope of practice and become a pediatric nurse practitioner or pediatric clinical nurse specialist.

- Doctorate with a research focus on children and families with special health care needs (PhD)
- Doctorate of Nursing Practice (DNP)

Learn More!

Check out the center’s website to learn more about our educational programs, continuing education opportunities, and free online resources on pediatric nursing and leadership. You will find resources on topics ranging from school nursing to youth with chronic health conditions transitioning to adulthood.