

Starting Life with Coordinated Care

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The Center for Maternal and Infant Health's Care Coordination Program is an interdisciplinary model designed by the UNC Departments of Pediatrics and OB/GYN in partnership with the School of Medicine and the UNC Health Care System. The program was launched in 1999 with funding support from The Duke Endowment and the Kate B. Reynolds Foundation. Since that time, the Center has provided patient-centered care for over 4,500 high-risk pregnant mothers and infants from 80 counties across North Carolina. The Center takes a family-centric approach that brings together a wide range of medical expertise in one location, coordinates care with a focus on the mother-baby-family unit, and maintains a continuous channel of communication among health care providers (both those at UNC and pediatricians/obstetricians in the community). The team supports families through the highly emotional and complex world of prenatal/infant diagnosis, prognosis, treatments, and specialty services. A primary goal of the program is to help parents learn how to navigate the health care system and become advocates for themselves and their babies.

Each patient has a care coordinator who is present with families from diagnosis through major surgeries and often through the baby's first year of life. The coordination team consists of nurses, a nurse midwife, and bilingual (Spanish/English) clinical social workers. Coordinators attend key health care visits and consultations with the patients, helping them generate questions to ask their provider before the encounter and checking afterwards to be sure they have a good understanding of what transpired. They share information about the family, their social situation, needs, and wishes with the interdisciplinary team as part of a collaborative effort to develop care plans. Coordinators also provide patients with education about their baby's condition, links to local community groups, appointments

with multiple specialty providers on the same day to create one stop services, referrals to clergy and mental health services, transportation, food, early intervention, home health agencies, and support groups. Having bilingual coordinators is essential to the program as Latino families face additional language and cultural barriers.

Additionally, the Center supports a perinatal palliative care program for families who have received a terminal fetal diagnosis. This service focuses on helping families play a leadership role in developing their birth plan, making decisions in advance on behalf of their baby, and preparing for the loss. The Center team also offers care coordination for pregnant mothers who are transported to UNC due to emergency medical conditions. The Center's newest program provides care to mothers who have infants in the intensive care nursery. These mothers have many unmet health, social, and emotional needs that impact their own well-being as well as their ability to care for their baby.

While each family faces its own unique set of challenges and circumstances, they share a deep love for their children. The Center team is united in their effort to work in partnership with families to encourage and support their transition into being parents of very special babies. To learn more about the work of the Center for Maternal and Infant Health please go to <http://www.mombaby.org> or call 919.843.7865.

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The co-directors for the Center for Maternal and Infant Health are John Cotton, MD, UNC Department of Pediatrics, Division of Cardiology, and Kate Menard, MD, MPH, UNC Department of Obstetrics and Gynecology, Director for the Division of Maternal Fetal Medicine.

- The care-planning process is driven by a compassionate, robust partnership between physicians, patients, and the patient's family.
- Patients participate actively in decision-making.
- Care is coordinated and/or integrated across all elements of the health care system (e.g., subspecialty care clinics, hospitals, home health agencies, nursing homes) and the patient's community (e.g., family, public and private community-based services) in a culturally and linguistically appropriate way.
- Information technology is utilized to support optimal patient care, performance measurement, patient education, and enhanced communication.
- Patients and families participate in quality improvement at the practice level.

An excellent summary of this national groundswell can be found in the 2008 publication of the Institute for Family-Centered Care, *Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System: Recommendations and Promising Practices*.²¹ The publication synthesizes results of an invitational expert panel convened by the Institute for Family-Centered Care in collaboration with the Institute for Healthcare Improvement. The report's recommendations are illustrated by examples drawn from health facilities and other organizations that have made exemplary progress in partnering with patients and families. The expert meeting and report were funded by the Robert Wood Johnson Foundation and the California HealthCare Foundation.