

Appendix C

Non-LEND Family Mentor Programs

The following is a sampling of programs involving families who provide mentoring to trainees and/or medical residents in non-LEND settings:

- **Family Centered Experience Program:** University of Michigan. This program pairs first- and second-year medical students with volunteers from the community who are willing to share the everyday difficulties of coping with a chronic illness, in order to gain understanding, compassion, and other essential elements of the art and science of healing.
- **Family Mentor Program:** Edgewood College, Madison, WI. Students in the field of Education are matched with a family who has a child with special needs for 12 hours of interaction to learn more about the joys and challenges of raising a child with developmental disabilities.
- **Family Mentor Program:** University of Wisconsin, Milwaukee; Vicky Johnson, Family Mentor Coordinator, and Kris Barnekow, Director. Students in the fields of Occupational Therapy, Early Childhood, Special Education, and Speech and Language partner together in Teams, called Diverse Urban Interdisciplinary Teams or DUIT, and are matched to a family with a child with special health care needs to learn more about the family's perspective. The goal is for future professionals to work as a team in providing services to families.
- **FIRST - Families in Resident Student Teaching:** (Parent to Parent Program of Vermont.) Pediatric Residents learn in depth about family center care over a period of three years. The first year residents visit family faculty in their home and make a school or early intervention visit. In the second year, residents identify families they have worked with to get to know outside of the hospital setting. In the third year they focus on adolescent issues and broad topics of culture and diversity.
- **Fourth Year Medical Student Selective in Chronic Care Pediatrics:** New York Medical College, Valhalla, NY. NYMC offers a four-week fourth year chronic care selective in pediatrics with a focus on children and their families in the community. This rotation takes place in an environment, outside of the tertiary setting so as to more broadly represent the lives of children and their families. Students receive an orientation on family-centered care practices, visit with families of children with chronic illness at home, and also provide respite for families of other children with developmental disabilities. As participatory observers and active learners, students visit schools and other community facilities serving children with special needs.
- **ID Train Family Mentor Program:** University of Wisconsin, Madison: Waisman Center. The ID Train (Interdisciplinary Training in Early Intervention) program is a pre-service interdisciplinary training program designed to address the on-going need for qualified personnel to provide

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services for young children (age birth to eight) with disabilities and their families. To focus on family awareness, each trainee is placed with a family for 60 hours a year (an average of two hours a week) to explore the day to day challenges and joys of living with and loving a child with disabilities.

- **Parent Partners in Health Education (PPHE):** Funded by the New York State Developmental Disabilities Planning Council, this program matches medical school residents with a child with developmental disabilities and his/her family to follow for the duration of their residency. The program's goal is to help medical residents cultivate sensitivity to and awareness of the issues faced by New Yorkers with disabilities and their families. Programs are located at St. Barnabas Hospital, St. Elizabeth Medical Center, Stony Brook University Hospital, Winthrop University Hospital, Maimonides Medical Center, New York Medical College, New York Presbyterian Hospital, and SUNY-Upstate Medical University, Syracuse. The NYS Council on Graduate Medical Education provides technical assistance for this program.
- **Partners in Health Education:** Regional Access & Mobilization Project, Inc. (RAMP), Center for Independent Living, Rockford, IL and Family Practice Residency Program, Department of Family Community Medicine, University of Illinois College of Medicine-Rockford. "*Developing Curriculum Models in Developmental Disabilities*" is a guide for medical educators developed by the University Of Illinois College Of Medicine. This guide describes components from successful pilot programs in three Illinois residencies funded by the Illinois Council on Developmental Disabilities. All three programs were built upon a foundation of joining whole-person, family-focused, and community-based approaches to care. The same components can be adapted to medical student education as part rotation in Pediatrics or Family Practice or as part of a pre-doctoral Community Medicine experience.
- **Simulation Project:** (A cooperative program between Matheny Hospital and School in Peapack, NJ, and the University of Medicine and Dentistry of NJ (UMDNJ). Provides comprehensive services for children and adults with developmental disabilities including physician training and residential and outpatient programs for people with physical disabilities. Designed to help third-year medical students develop interpersonal skills needed to elicit vital information directly from patients who are non-verbal in order to make more accurate diagnoses. Dr. Gary E. Eddey, Assistant medical director at Matheny Hospital and School in Peapack, NJ, and Clinical Associate Professor of Pediatrics at UMDNJ.

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The following is a sampling of Non-LEND programs that involve parents and families mentoring other families to provide support and offer resources in the early stages of their journey with a new child with special health care needs.

- **Caring for Adults with Disabilities:** University of South Florida College of Medicine, Tampa, FL. This educational module is integrated into the 16-week primary-care clerkship for third-year students. It addresses older adolescents and adults with physical, sensory, and cognitive disabilities through two afternoon seminars with guests from the local community of persons with disabilities, home and community visits, service learning projects, and writing a reflection on the experience. [From *New England Journal of Medicine*, 355:10. September 7, 2006, p. 976].
- **Oklahoma Family Network:** The Oklahoma Family Network (OFN) **Parent-to-Parent Mentorship Network** program links trained mentors to parents who are just starting out in raising a child who has either developmental delays, medical needs or a disability. Parents can gain support from an Oklahoma Family Network mentor whether their child is currently in an Oklahoma hospital or is living at home. Pre-natal to age two: jeni-bruce@oklahomafamilynetwork.org; Age two and above: heather-pike@oklahomafamilynetwork.org.
- **One-To-One Match Program:** Parent to Parent of Vermont: Julianne Nickerson, MSW, Family Faculty Director. Julianne.Nickerson@partoparvt.org.) A network of families that support other families whose children have a chronic illness or disability and/or may have been born prematurely. The One-to-One Match is a unique form of support that only a peer can offer. This model of support is based on perceived sameness and the principal that the Supporting Parent "has been there", which is reflected in the empathy shown for the referred parent's experience. www.partoparvt.org.
- **Parent Mentor Program:** The Parent Mentor Program (PMP) was created to provide families with individualized peer support and information to foster learning and independence. There are two components to the Parent Mentor Program: Parent Matching, when parents or guardians of children with special needs can be matched with a trained volunteer parent mentor who can provide one-to-one peer support and information; and Parent Mentor Training, twice a year the Parent Mentor Coordinator facilitates a 2-1/2 day intensive training for adult family members of children with special needs who are interested in mentoring others. www.supportforfamilies.org/parent_mentor_program.html.
- **Parent to Parent-USA (P2P-USA):** An alliance of statewide Parent to Parent programs following established best practice standards. Parent to Parent programs provide emotional and informational support to families

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of children who have special needs most notably by matching parents seeking support with an experienced, trained 'Supporting Parent'. Parent to Parent programs provide emotional and informational support to parents who have a child or young adult with a disability, chronic illness, or other special health care need. Parent to Parent programs match parents around similar disability and family issues, and because the two parents share many common experiences, the support is often uniquely meaningful. There are more than 600 local and statewide Parent to Parents programs in the U.S.

- ***Pilot Parents:*** Omaha, NE. The Pilot Parents Program links “veteran” parents with newly identified parents to provide support activities.
- ***Supporting Parents:*** Omaha, NE. Program that links “veteran” parents to newly identified parents to provide support.