

## **Family Support Specialists**

Dawn Graber

### **Research Mentor and other collaborators:**

Deb Downey, PhD, CCC-SLP; Diane Brenneman, DMin, FPSS

### **Objectives:**

1) To research the existence of a parent of a child with special healthcare needs as a patient/family support person in the pediatric clinic setting, and 2) research the outcomes of that role.

### **Methods:**

Researching the existence of a Family Support Specialist was difficult because there is no universal term for the role. I made 20 contacts from the LEND Family Discipline Network and AUCD as well as searching for terms like "parent advocate," "family liaison," "mentor" along with "medically complex clinic." To expand my understanding of the role and existence of an FSS, I attended the AUCD Annual Conference, observed in CDD interdisciplinary clinics, and interviewed FSS staff at the Munroe-Meyer Institute and University Developmental Assessment Clinics/Primary Children's Hospital.

**Results:** This position is held by a parent with lived experience in at least six different locations across the U.S., more commonly in clinics for medically complex patients. They provide families emotional support, systems navigation, connection to community resources, and feedback to clinicians about patient concerns. The Munroe-Meyer Institute had the greatest number of parents in this role and has developed parent trainings and outcomes reports.

**Conclusion:** Embedding an FSS in clinical settings may enhance positive health outcomes and lead to better treatment outcomes for patients/families. The UIHC system values family-centered care and has patient/family advisory board or supports at different levels, but may be missing an opportunity for parent peer support at a unique moment of need which occurs in the clinic setting.

### **References:**

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