

Background

Pediatrics, the official journal of the American Academy of Pediatrics (AAP), is actively accepting manuscripts addressing Family Partnerships, specifically articles that reflect the joint perspective of patients, families, and the health care professionals caring for the child and family. Three current and one former LEND trainee formed a group to co-author a manuscript to present a unique perspective from the following clinical and personal domains:

- Nursing
- Developmental Pediatric Medicine
- Occupational Therapy
- Parent/Family caregivers of loved ones with disabilities

Aims

- Share personal experiences of being a parent of children with disabilities and special healthcare needs.
- Identify concepts that are essential to establishing and maintaining effective family healthcare professional partnerships.

Methods

1. Literature Review to examine data and best practice surrounding
 - Grief among parents of infants diagnosed with disabilities or other complex health issues
 - Family Centered Care
 - Care Coordination
 - Coping among parents of children with special healthcare needs
 - Communication
 - Family Healthcare Professional Partnerships
2. Group meetings were held to discuss and analyze literature.
3. Manuscript was developed reflect the important concepts identified.

Results

Several themes emerged during the collaborative analysis and writing process. The manuscript was developed around these themes and the personal experience of a mother of children with special healthcare needs.



Lessons Learned

- While several themes relevant to establishing and maintaining family healthcare professional partnerships were identified, it was determined (based on expert feedback and self-reflection) that focusing on one of these themes would result in a stronger and more meaningful manuscript.
- Interdisciplinary collaboration in co-authoring called for open-mindedness and resulted in learning about the perspectives and role of each discipline as related to family partnerships.
- The manuscript is in the process of being revised and redeveloped to focus on the main theme of parental grief and empowerment within the family healthcare professional relationship.

Conclusion

The manuscript developed by this team for the Family Partnership section of *Pediatrics* revolves around the following vital concepts in establishing and maintaining effective family-healthcare professional partnerships:

- Recognizing the parents' emotional state sets the stage for meaningful collaborative communication and can empower the family to pursue their dreams of living a full life despite the challenges and complexities of their child's diagnosis.
- Practicing from a family-centered care (FCC) perspective promotes collaborative communication between healthcare providers and families resulting in:
 - Increased family advocacy
 - Increased patient satisfaction
 - Improved coping³
- Increasing family's accessibility to their child's medical records, as well as educating and empowering them to use their medical record strengthens family-healthcare professional partnerships.⁴

References

1. Marti-Morales M, Rohrer JE. Care coordination, family-centered care, and functional ability in children with special health care needs in the united states. *Population Health Management*. 2014;17(4):233-238. doi: 10.1089/pop.2013.0092.
2. Merrigan K, Steinmiller EA, Figueroa-Altmann A, Davis KF. KIDS CARE: A behavioral model to strengthen patient and family partnerships. *Pediatr Nurs*. 2016;42(2):89.
3. Drummond A, Looman WS, Phillips A. Coping among parents of children with special health care needs with and without a health care home. *Journal of pediatric health care : official publication of National Association of Pediatric Nurse Associates & Practitioners*. 2012;26(4):266-275. doi: 10.1016/j.pedhc.2010.12.005.
4. Laliberte, R. Going on record: patients have a right to their medical records but often don't know how to access them. Electronic systems and a concept known as open notes are changing that. *Neurology Now*. 2016; 12(6) : 36-45.

Acknowledgements

- Many thanks to Gina Jones, former LEND trainee, pictured in center with her family (sons Garrett & Gavin and husband Gordon) for her vision, leadership, contributions and support throughout this project.
- This work was supported by the Illinois LEND Program [Grant Number: T73MC11047; U.S. Department of Health and Human Services—Health Resources and Services Administration (HRSA)]