



Children and Youth with Special Health
Care Needs National Research Network

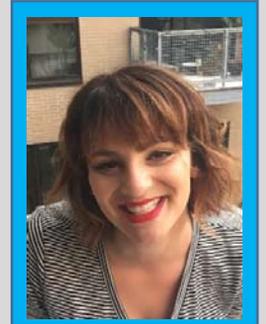
Research Project Brief

PROJECT | Creation of an Adaptive Taxonomy of Barriers and Facilitators to In-Home Care of Children with Cerebral Palsy

- *Term: September 2018 to August 2019*
- *Grantee: CYSHCN Net*
- *Sub-recipient: University of Wisconsin*
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Background | The objective of this study is to apply a HFE approach to understand the intersection between in-home caregiving for children with cerebral palsy (CP), the home environment, and outcomes that matter most to families. Aligning future interventions with outcomes that matter to parents affords the greatest potential for success. The intersection between caring for children with CP in the home, the home environment, and child / family health outcomes is currently unexplored. Although we suspect the home environment itself plays a critical (positive and negative) role, we do not yet understand its role in detail. Without that understanding, attempts to improve caregiving at home will be inadequately focused and likely ineffective. HFE provides the link to study the unique contribution of the home environment on caregiving and bridges the gap to develop interventions that support caregiving at home. Our proposed research clarifies these relationships, providing the critical first step to a continuum of research that will include at least two subsequent research directions: 1) creating tools to evaluate the home environment, and 2) designing interventions to improve the home environment to support family caregiving child and family health outcomes. Finally, by clarifying the outcomes of in-home care most important to families, our work will allow substantially more precise family-centered outcome measurement in intervention research. CYSHCN Net will be critical to successful exploration of future research directions as it will allow for exploration and testing at multiple diverse sites as well as a network of experts in the field with whom collaborations can be formed.

Potential Impact | Caring for children with CP at home can positively influence health. Healthy physical, emotional, psychological and social impacts are possible when care of children with complex health conditions is managed at home. Quality of life may be protected when the home environment includes continuity, nurturing and social stimulation. To maximize child and caregiver health benefits while minimizing the potential negative consequences to in-home care, we need to understand the most effective approaches to support caregivers in their home environments.



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Publication
Insert citation & URL here

Organizations Involved
University of Wisconsin



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