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## A CBPR-constructed intervention for children and youth with special healthcare needs: Preliminary results from the Family-Nurse Care Coordination Partnership

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The Family-Nurse Care Coordination Partnership partnered parents of children and youth with special healthcare needs (CYSHCN), nurse care coordinators (NCC) and administrators, community advocates, and university researchers to develop and evaluate an intervention to improve care coordination for CYSHCN. Limited research exists that identifies how parents coordinate care and learn to negotiate systems of care. The community-based participatory research team used a mixed-method approach to randomly sample (n=422) parents of CYSHCN enrolled in Florida's Title-V agency, Children's Medical Services (CMS), interview a sub-sample of parents (n=30), and engaged in a 9 month process to develop a parent-nurse partnered intervention consisting of a "Care Notebook" and "Navigating Guide." Trained Peer-parents delivered the intervention to a sub-sample of 108 parents of CYSHCN followed up by contact from their NCC to negotiate coordination roles. A post-intervention survey and in-depth parent interviews (in process) were conducted to evaluate the intervention. Preliminary analyses reveal the majority of participants increased their knowledge about CMS (69%); 73% indicated they had read/used any part of the Care Notebook and 87% indicated it was very useful/useful. Participants reported the Care Notebook: saved time caring for their child, made them more confident in arranging care, and helped them be more organized and less stressed. In qualitative interviews, participants reported that the Care Notebook would be most useful if provided at initial diagnosis. Follow-up focus groups with peer-parents and nurse care coordinators discuss intervention feasibility with overall results framed in the context of parent needs, agency policy, and care coordination practice.

### Learning Objectives:

1. Describe the purpose and components of the intervention to improve care coordination.
2. Identify the outcomes and feasibility of intervention replication.
3. Discuss the implications for future research and care coordination practice.