

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



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## Community-Based Participatory Research (CBPR)

CBPR grew from a long tradition of Participatory Action Research (PAR). According to Larry Green and colleagues, PAR is a "systematic investigation with the collaboration of those affected by the issue being studied, for the purposes of education and taking action or effecting social change."



CBPR developed because of research efforts that did not reflect the voices of those who were affected by the problem.

## Family Nurse Care Coordination Partnership (FNCCP)

The Community Research Partners for Kids with Special Needs (Partners) is a diverse group of parents, nurse care coordinators (NCC), and researchers who formed in response to an NIH CBPR grant announcement, but had previously been involved in other community groups that addressed Children and Youth with Special Health Care Needs (CYSHCN)

The FNCCP Study was an intervention study designed by the Partners, who articulated the research question, designed the intervention, and participated in the research.

### FNCCP Goal:

Improve care coordination for CYSHCN and teach parents how to navigate systems of care.

### FNCCP Objectives:

1) improve satisfaction w/ care coordination services; and 2) improve "team" relationship with NCC.

### Articulated by parent-partner:

*Parents can navigate any system they are taught to use.*

## Intervention

During Year 1, the Intervention Development Team (I-Team) worked together and organized a **Care Notebook and Navigating Guide**.

During Year 2, peer parents delivered the Care Notebook to parents of CYSHCN in a 4-county area. Peer parents discussed the notebook with the parents as well as helped them learn about the "system".



Following the Peer Parent Visit, NCC's followed up with their clients. The goal of the follow-up call was to build relationships and negotiate NCC and parent roles.

## Methods

- **Phase 1 (Baseline)**
  - A random sample (n=422) of parents of CYSHCN enrolled in Florida's Title-V agency, Children's Medical Services (CMS) and qualitative interviews w/ a sub-sample of parents (n=32).
  - Trained Peer-parents delivered the intervention to a sub-sample of 108 parents of CYSHCN.
- **Phase 2 (Follow-up):**
  - Post-intervention survey (n=83) and in-depth parent interviews (n=16) were conducted to evaluate the intervention.
  - Peer parent and NCC focus groups were conducted to evaluate the process.

## Follow-Up Survey Results (n=86)

### Child Demographics

- **Gender:**
  - 40 female
  - 46 male
- **Race:**
  - 44 white
  - 34 black
  - 8 other
- **Mean age:**
  - 10.7 years of age
- **Average length of time in the CMS system:**
  - 7 years

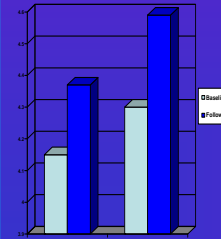
### Care Notebook

- 74% of participants used the Care Notebook
- 48% reported it increased their knowledge re: CMS
- 59% said it saved time
- 66% said it helped them feel more organized
- 63% said it increased their confidence re: their ability to care for child

## Survey Results (cont.)

This study assessed satisfaction with care coordination services and parent perceptions of how well the NCC and parent worked together through two questions, asked in both the Baseline and Follow-up surveys.

- **Question 1: How satisfied are you with the help you receive from your nurse care coordinator?**
  - Respondents answered using a five-point scale: 5 (very satisfied) to 1 (very dissatisfied)
- **Questions 2: How strongly would you agree or disagree with the following statement: "I feel like my CMS nurse and I work together well as a team. Each of us does what we are good at to get my child the things he or she needs."**
  - Respondents answered using a five-point scale: 5 (strongly agree) to 1 (strongly disagree)



**Analysis:** A paired samples t-test was used to calculate the difference between the Baseline (Time 1) and Follow-up (Time 2) surveys.

### Results:

- There was a significant difference between Time 1 and Time 2 related to Question 1 (satisfaction). The t-test showed a p-value of <0.03.
- There was no significant difference between Time 1 and Time 2 related to Question 2 (perceptions of working together). The t-test showed a p-value of <0.09 (non-significant).

## Qualitative Results

Themes identified through qualitative data analyses:

- Parents appreciated peer-parent visits to their homes and gained valuable information regarding CMS and NCC services through the visits.
- The Care Notebook is most useful at two time points: **diagnosis and transition.**

*"I like the notebook and I would give anything to have had it twenty years ago."*



- **NCCs did not follow-through with role negotiation**

*"Well, the question, 'Do you want me to call you and how often' I felt was useless. I never asked that because the one time I did, the lady said, 'Yes, I want you to call me.' Well out of 315 [clients], I'm not going to have time to call this lady every week or every two weeks..."*

## Conclusions

- Parents who participated in the intervention felt the Care Notebook was a useful tool and had benefits such as increase ability to care for their child, but was given to them too late.
- Knowledge of the CMS system increased because of the intervention, but the ability for parents and nurses to build relationships was limited because of system barriers and client case loads of more than 300 clients.

