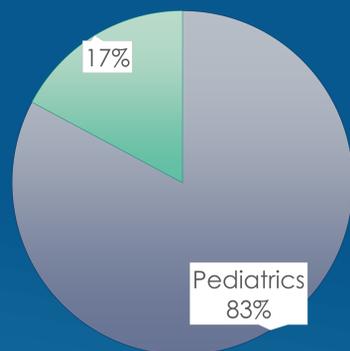


# Long-term Pediatrician Outcomes Of A Parent Led Curriculum In Developmental Disabilities

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## Participants

Pediatric and medicine/pediatric residents who participated in Project DOCC<sup>sm</sup> during their one-month required rotation in Developmental-Behavioral Pediatrics at the Boling Center for Developmental Disabilities between the years of 2002 and 2010 N=203. Fifty-eight responded to the survey. Of those, 48 were practicing pediatricians while the others (17%) were practicing in fields of pulmonology, internal medicine, cardiology, hematology/oncology, neurology, endocrinology, immunology and critical care.



## Research Design

Anonymous 10-item Project DOCC<sup>sm</sup> Resident Follow-Up Survey was created using a mixed methods approach administered electronically through email.

## Measures

Survey obtained data about:

- current clinical specialization,
- years in practice,
- means by which DOCC components are incorporated into practice
- Current setting of practice and
- training/advocacy efforts engaged in since DOCC

For quantitative items in the survey, pediatricians were primarily asked to endorse all categories that applied to them, comments describing how the Parent Interview and Home Visit experiences have influenced their subsequent training, advocacy, and clinical practice with CSHCN and their families.

Descriptive statistics were used to analyze the quantitative items and thematic content analysis was used to synthesize the qualitative comments made by the physicians.

## Results

Fifty-eight former residents completed the ten-item Project DOCC<sup>sm</sup> Resident Follow-Up Survey, a 29% response rate. Pediatricians affirmed the important role that Project DOCC<sup>sm</sup> had in their residency training and the heightened family-centered awareness it brought to their current clinical practice.

**Table 1 Awareness gained from Project DOCC<sup>sm</sup> experience**

Item	% Endorsement
Be aware that a child with developmental delay or dysfunction can influence the parent-child relationship	84.8%
Be aware of common immediate and continuing parental reaction to diagnosis of a disability in their children	69.6%
Recognize how common parental responses can influence their ability to cope with the child at a particular point in time	63.0%
Verbally communicate the initial impression or final diagnosis and recommendations for further assessment and evaluation to the family	56.5%
Be aware of parental "diagnosis shopping" and know ways in which to minimize its effect on the child	54.4%
Recognize special adjustments that siblings of children with disabilities may need to make	52.2%
Be aware of techniques to facilitate optimal family functioning	28.3%

Moreover, responding doctors reported that they shared materials with families in their waiting areas and clinical areas (62.1%); were engaged in the broader disability community through advocacy boards or groups (24%); and received materials from disability organizations through mailing lists and listservs (21%).

## Thematic Analysis

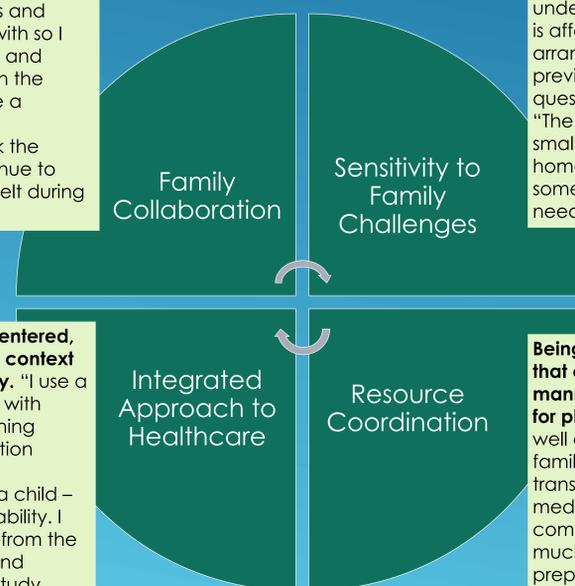
Forty-seven comments were collected on the qualitative measures of the survey. Using thematic analysis and coding, four major themes emerged.

**Physicians described having a reciprocal approach to clinical care that was collaborative in nature and informed by the family.** "When encountering a child with special needs or a unique diagnosis, I often ask the parents what signs and symptoms the child presented with so I can learn from their experience and hope to recognize similar signs in the future. Especially in cases where a diagnosis was not correctly or immediately differentiated, I ask the parents what made them continue to look for answers and how they felt during that time."

**Physicians espoused a family-centered, integrated system of care in the context of a medical home for the family.** "I use a holistic approach to interacting with parents/guardians and in obtaining medical histories. I elicit information about the challenges the parents/guardians face raising a child – healthy, acutely ill, or with a disability. I use the knowledge I've gained from the parents regarding the stresses and challenges they face to guide study design and public health interventions," and "[I'm] able to appreciate the well-rounded approach needed by multiple physicians, medical personnel, and family with the role of the primary care physician in integrating it."

**Physicians expressed an increased self-awareness, sensitivity, empathy, and understanding to the issues that families face when they have a child with a chronic health care need or disability.** "Helped me understand that every aspect of family life is affected, including sleeping arrangements which I had not thought of previously. Now I try to incorporate questions regarding stressors at home," and "The home visit made me aware of the small things that are needed to adjust to home life that may not be obvious to someone who does not live with a special needs child."

**Being a repository of community resources that can be delivered to families in a timely manner was viewed as an important function for physicians' offices.** "I've learned my area well and the resources that are available to families in need of assistance with transportation, child care, therapies, medications, etc. It helps in improving compliance for families and continuity is much smoother," and "It was good preparation to help parents with the non-medical needs of having a disabled child. I don't think medical training prepares us enough to know all that is available as far as school resources/rehab/medical support and [physical therapy] devices and all the challenges that parents face."



## Discussion

This study was designed to determine whether the high satisfaction and relevance of Project DOCC<sup>sm</sup> reported at the conclusion of residency training continued to have a positive impact on pediatric and medicine/pediatric residents well into their careers as practicing physicians.

The results indicate that:

- Many pediatricians continue to describe the parent led curriculum in developmental disabilities as having an important influence on their current clinical practice
- Physicians described themselves as more sensitive to family issues, more engaged among the network of available community resources, and active collaborators with families who are comfortable in coordinating team care.
- Physicians report greater ability to help facilitate a sustained awareness and mobilization to help families connect to community resources to better overcome barriers to services
- A parent led curriculum can help inoculate pediatricians from some of their reported professional isolation and stress associated with caring for a CSHCN

The four qualitative themes that emerged as enduring outcomes of the Project DOCC<sup>sm</sup> experience suggest that a parent led curriculum can serve as one option to address these concerns by helping to enhance physicians' connections to families, the other professionals caring for the child, and the broader community of resources that are available.

## Limitations

1. Low physician response rate; the most prevalent means for increasing response rates included reminder emails to non-respondents, reminder emails to the survey owners, and incentives in the form of prizes for respondents awarded through a lottery. None of these strategies were employed in the present study. However, since the survey was anonymous, the authors were not able to identify and contact those physicians who did not complete the survey.
2. Brevity of survey limited the reliability and validity of the measure. Developing a more in-depth survey with additional quantitative and/or qualitative items, or using a normed and validated dependent measure for pediatric service providers such as the Measure of Processes of Care for Service Providers might yield more robust findings.
3. Inability to firmly conclude that the practice outcomes reported by the pediatricians derived exclusively from their participation in a parent led curriculum or were the result of a general accumulation of clinical experience in the field. Future studies should compare the practice outcomes of pediatric cohorts who received Project DOCC<sup>sm</sup> training during residency with those who did not participate in this parent led experience.



DOCC<sup>sm</sup>

