

# Project DOCC

A synopsis of the Presentation of Project DOCC at the  
AAHBEL Convention in Chicago

by Kerri Ambrose  
AAHBEL Governing Board Member

"I credit my daughter's doctors for saving her life and I credit her early interventionist for saving her spirit." Donna Appell, PROJECT DOCC

It was with great pleasure that I got to listen to PROJECT DOCC close the AAHBEL Conference in Chicago. Donna Appell and her parent panel presented personal anecdotes about their lives as parents of children with special needs that made us laugh and cry. The issues they discussed, guilt and worry, love and pride and being overwhelmed at times, are universal to parents caring for a chronically ill child. The intent of their program is to provide a parent's perspective of what it means to provide Family Centered Care. And what is most unique about PROJECT DOCC, is they are including physicians to be an integral part of the family's team.

A few years ago three Long Island, New York, mothers, Maggie Hoffman, Donna Appell and Nancy Speller, each with a child with chronic illness, banded together to create a parent driven curriculum, PROJECT DOCC (Delivery of Chronic Care). Being used in many medical centers, this curriculum aims to teach pediatric resident doctors about chronic illness and its impact on families. The goal is that through seeing the child in a home setting, future physicians might gain insight into what having a child with special needs does to daily family living. There are three components of this program that a resident must participate in: a home visit, a parent interview, and a parent led panel specifically discussing the impact of their child's chronic illness. Because this program is parent led, residents learn what a family needs from them to be empathetic and effective care givers.

PROJECT DOCC also educates others involved with the care of children with chronic illness including nurses, teachers, social workers, therapists, pastoral care givers, and family members. With their parent panels, they teach individuals the impact of chronic illness on family dynamics, promote empathy and understanding regarding the chronic process, advocate for families, and encourage parent/professional relationships.

As a parent of a child with special needs, I love what this program is doing. The professionals that these parents educate will be uniquely qualified to encourage and support families. And by supporting families, these professionals will make a significant difference in the lives of our children.

