



## **PATH Parent to Parent/Family Voices of Connecticut Building Partnerships to Support Families**

Health care providers recognize that patients are often impacted not only by physical symptoms but also emotional ones. And, their families are affected, too. But, sometimes, providing the needed range of support stretches the capacity of practices or clinics. **Peer support** can be a resource that will help patients – and enhance the care provided as well as strengthen family engagement. By building strong partnerships with primary care practices and hospitals, a program in Connecticut has been able to increase the number of families who benefit from the unique support offered by peer mentors.

**Parents Available to Help (PATH)** began in 1986 when three families of children with special health care needs met at Yale New Haven Hospital and discovered the power of peer support. Over the years, PATH has integrated all parent-to-parent resources across the State of Connecticut and also leveraged national resources. PATH is an Alliance Member of Parent to Parent USA and a State Affiliate Organization of National Family Voices. In 2011, PATH /Family Voices of Connecticut (FVCT) was able to expand its services by becoming a Family-to-Family Health Information Center funded by HRSA.

## **Peer Support**

The heart of PATH/FVCT is its Listener/Support Parent Program that provides one-on-one support with trained, veteran parents or mentors. While health professionals provide important medical information about caring for children with special needs, only other families can fully understand how difficult it can be to find the best care. This peer support program empowers families to advocate for their children and reaffirms their value as parents and caregivers. Families also develop skills and confidence in managing their children's health.

*“Connecting with a seasoned parent who has similar life experiences regarding their child with a disability is priceless to a family. Professionals are amazing at what they do in providing medical care but connecting to a parent who has ‘walked the walk’ and is a veteran on the day to day reality of taking care of a child with a disability is truly invaluable.”*

*Carmina Cirioli, Co-Executive Director, PATH Parent to Parent/Family Voice CT*

On a yearly basis, PATH/FVCT connects between 300-400 families with mentors. The program serves families of children pre-birth to 26 years old with any disability diagnosis.

Each newly-referred family provides pertinent information (e.g. geographic location, diagnosis, preferred language) to ensure they are matched with mentors best suited to their needs. Parents may interact by telephone or meet in person with assigned mentors; often there are multiple calls, e-mails, texts or other forms of communication. Listeners “are there” for their mentees every step of the way!

Systematic evaluation ensures that needs are met and that matches are working well. This feedback is also used to evaluate the program’s overall effectiveness. In a recent survey of program participants, 94% of respondents indicated that PATH’s services had been “extremely” or “very” useful in helping them make decisions. Ongoing contact is maintained with families served; over 50% of them later become support parents or mentors.

### **Transition Support**

Another key program, called Charting the Life Course, is provided to children and families and is especially helpful during transitions. Life Course is a process that identifies and acts on what is important to a person to help him achieve a “good life,” now and in the future. Parents are encouraged to begin this planning early with their child and to continue throughout their life; the goal is to develop an action plan with clearly identified steps.

### **Training for Parent Mentors or Listeners**

Parent mentors, also called Listeners, are trained to help parents engage more effectively with clinicians and community resources to ensure the best care possible for their children. During training, mentors build their coaching skills in

assisting parents to navigate the health care system. Trainees learn from one another's lived experiences. Role-playing scenarios help them better understand the point-of-view of new parents and others involved. Trainees also develop respect for all members of the health care team and learn to support parents in engagement and conflict resolution.

### **Partnerships with Health Care Providers**

When clinicians engage parents in meaningful conversations about the value of peer support, they set the stage for successful referrals to PATH. Approximately 50% of program referrals come from health care providers. A simple release form sets the process in motion. New families can contact the program directly through its website; after requesting a mentor, they are connected with a match within 24-48 hours.

PATH/FVCT has a presence in hospitals (e.g., Connecticut Children's Medical Center/CCMC) and primary care practices to provide information and to create lasting partnerships with health care providers. Presentations at "lunch-and-learn" sessions or staff meetings increase awareness of PATH resources and clarify the unique role of parent mentors to support families..

Monthly support groups conducted by PATH at CCMC build lasting connections with the hospital and with families. Families receive needed support during hospitalization as well as information about PATH program services. As a result, involvement after discharge is facilitated.

In Western Connecticut, a PATH staff member is co-located in a pediatric advanced medical home clinic. Referrals are made real-time and parents are connected with the program immediately. Because PATH staff has access to the EMR, seamless information flows between the clinic and PATH.

### **Lessons Learned**

For years, PATH/FVCT has been providing peer support and other services to families of children with special health care needs in Connecticut. Its success lies with the power of peer support itself and with the program's ability to build partnerships within the health care system.

*"As a busy pediatrician for over 30 years, I find the resources and parent-to-parent support from Marni McNiff of PATH to be invaluable. I often do not have the expertise to guide families through the maze of school services and evaluations. All I need to do is send her a brief email describing the family's issue, and she expertly helps them. Families feel at ease knowing that she understands what they are going through."*

Dr. David Gropper, Pediatric Associates of Western Connecticut

