

POLLY ARANGO MENTORING INITIATIVE

The Polly Arango Mentoring Initiative honors an aspect of caring for children/youth with special health care needs (CYSHCN) that was near and dear to Polly, the inspirational first Executive Director of Family Voices - the development of diverse family leadership. Polly's insight into the care of her own son as well as other Native American children in New Mexico led her to be an early and steadfast advocate of the need for culturally competent health care. And Polly knew that systems of care could not achieve this without the voices of diverse families sharing their experiences and perspectives. Family Voices established the Polly Arango Mentoring Initiative to continue her leadership to help families with CYSHCN of diverse backgrounds. This program funds the growth of the Family Voices organization through the development and support of emerging family leaders from culturally and linguistically diverse backgrounds.

Family Voices is pleased to report on the success of four organizations that have, to date, received funding from this initiative to develop mentorship programs to build the leadership skills of such families.

ASK Resource Center, Iowa

ASK Resource Center has used funding from the Mentoring Initiative to convene a leadership council of 11 diverse families, *the Hispanic Advisory Leadership Team*, providing a venue for them to share their knowledge, advice, and expertise to improve ASK's ability to serve the needs of diverse families of Iowa. This leadership team created and disseminated a survey to obtain feedback from diverse families. This activity was followed by focus groups held with Spanish-speaking families to review and improve an existing ASK parent leadership curriculum.

While valuable insight was given regarding the training curriculum, most importantly, ASK staff learned two critical perspectives from Hispanic families: 1) families in rural areas feel very isolated and perceive that their children are not accepted within the community, and 2) although some Hispanic families had already taken on some leadership roles, many Hispanic families do not see themselves as leaders nor do they want to be viewed as leaders. 'Leadership efforts' have negative connotations within their family and community. This was key information for ASK staff that helped them realize that ongoing conversations with and individual support to Hispanic families through peers is an essential step in leadership development for this and other minority populations. To date, ASK has provided individual support to 17 Hispanic individuals and training to 15 parents in two newly developed programs, *Parents as Partners in Mentoring* and *Parents as Presenters*.



"Where would Family Voices be today if there were not always a new crop of family leaders from many different racial and cultural communities ready to learn, advocate, and change the world? . . . Family Voices will continue to respond to [this need] until the day when all members of all families have health care services that are family-centered, community-based, comprehensive, coordinated and culturally competent, all families are included as decision makers at all levels of health care, and partnerships between families and professionals are the norm."

- Polly Arango, 2006



Successfully Developing Hispanic Family Leadership in IOWA

After participating in the training:

- ✓ 27% of participants rated their skills and knowledge after training as 5 on a 5-point scale.
- ✓ 46% rated their skills and knowledge as 4
- ✓ 27% rated their skills and knowledge as 3

"The Parents as Presenters workshop helped me prepare my family story. Since completing this training I have been invited to share my story at a statewide training for migrant families, a college class of future teachers, and in a Spanish newspaper."

I participated in the focus group to review the training curriculum. I discovered my feelings and experiences were similar to other parents. I am glad this training is available so families can share experiences and learn that having a child with a disability is not something to be afraid of.

Exceptional Children's Assistance Center (ECAC), North Carolina

Like the ASK Resource Center, the Exceptional Children's Assistance Center (ECAC) has experienced a significant increase in requests for help from Spanish-speaking families over the last several years. Through a careful and thoughtful evaluation of consumer feedback, the staff at ECAC recognized the need for greater cultural competency in order to offer all families the highest quality service and encourage diversity within their family/professional partnerships.

Putting their grant from the Polly Arango Mentoring Fund towards developing more culturally inclusive trainings, ECAC has successfully mentored nine Spanish-speaking parent leaders, created linguistically diverse promotional materials, and established outreach and support services for non-English speaking consumers. This has allowed them to expand their reach into Hispanic communities and establish community-based, consumer-led programs that are reaching many more families than they could have done in the past.

Stone Soup Group, Anchorage, AK

In Anchorage, the Stone Soup Group has used their funds to establish a formal partnership with the *Partners in Policymaking* program (PIP). Through this partnership, the two groups have effectively leveraged their resources to develop the MAP (Mentor, Advocate, Partner) Family Project, which is aimed at training, mentoring, and providing general support to parents and families caring for children with special healthcare needs.

Having accepted 16 applicants, five of whom live in rural or "frontier" regions, Stone Soup has provided high-quality training in self-advocacy and how best to navigate the complex and challenging system many families face every day.

Given the difficult terrain of Alaska, keeping family partners involved hasn't been easy, but after two years 15 of the original 16 applicants remain active in the program and are applying their advocacy skills in their own community.

Family Voices of Minnesota

Family Voices of Minnesota contracted with one of their four Somali parent volunteers who was trained in project administration, using a computer, and leadership development around family-centered care, medical home, and communicating effectively with health providers. She connects with other FV of Minnesota Parent Support Navigators and an international group of Somali women on an ongoing basis and provides outreach and support to other Somali parents. She provides family outreach activities at Gillette Children's Specialty Healthcare Clinic and has participated in the Title V Needs Assessment Leadership Committee. She has provided many parents of Somali CYSHCN with resources and support not only on health care, but also housing, transportation, dealing with schools, nutrition, and recreation.

Increasing Outreach to Spanish-Speaking Families in North Carolina

- ✓ Pre-post evaluation responses show moderate to significant gains in confidence and knowledge from all participants.
- ✓ Interviews with community agency staff and anecdotal comments and observations acknowledged great skills across areas of communication, collaboration, conflict resolution, and advocacy.
- ✓ A greater working knowledge of local, state and national political processes was one area in evaluations where families spoke about their lack of understanding about complex political processes.

"I can say that thanks to these workshops I have been able to acquire an understanding and developed abilities to be able to communicate in a more effective form and without tremors with the medics, therapists and our children's educators. In the same way (we) offer some type of guide and help (to) other families like ours."



Improving Connections for Families across Alaska

- ✓ Parents who participated in this project have started their own Facebook page to compile ideas and strategies to submit to the state on waiver changes, including potential 1915 'I' and 'K' implementation.

"As the guardian of a special needs child and new to the disabled community I found this project immensely helpful and even life changing. A huge benefit was the opportunity to join other parents like myself to become part of a group of caring members of our community. This group not only wanted to become better advocates for our families but also reach out to help others become advocates as well. "



Helping Somali Families Thrive in Minnesota

"One mother contacted me regarding her son's major brain surgery. She was very concerned about the surgery. I helped her arrange transportation to the hospital, and I met her there to provide emotional support to her. Since that time, this parent has made additional connections with Islamic families who have provided much support for her family."