

AMCHP Case Study

Engaging Diverse Populations: State Examples

What is AMCHP?

The Association of Maternal & Child Health Programs (AMCHP) is a national nonprofit organization that supports state and territorial maternal and child health (MCH) programs and provides national leadership and technical assistance on issues affecting the health of women, infants, children, adolescents and children with special health care needs.

Overview

Family engagement is a critical part of Title V and MCH programs. The Title V MCH Block Grant is a federal program that provides core funding to states to improve the health of the nation's mothers, women, children and youth, including children and youth with special health care needs (CYSHCN) and their families. However, despite the program's history of engaging families, states and communities still struggle with employing, compensating and engaging families in practical and meaningful ways. Adding to the challenge are large environmental changes such as demographic shifts, technology developments, health reform, funding and the transformation of the Title V Block Grant, which bring new hurdles that impact the public health system's ability to engage families.

There are many ways families can be involved in Title V programs (MCH and CYSHCN). Family engagement, as discussed here, is broadly referred to in the context of a continuum which ranges from family input on specific issues to family partnership in leadership activities.

When states and communities engage families in a meaningful way in the planning, development, implementation and evaluation of programs and policies, the result is a strengthened system of care which meets the needs of children and families.

From late 2014 to early 2015, AMCHP conducted a survey about family engagement policies and practices in Title V MCH and CYSHCN programs with funding from the Lucile Packard Foundation for Children's Health and the Division of State and Community Health in the Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services. The survey findings provide a snapshot from the perspective of Title V Directors of current strategies to support meaningful family involvement, effective and innovative practices and areas of need for improvement and technical assistance. The information in this case study comes from the survey and follow-up interviews with the states profiled.

One of the struggles highlighted by the survey is how to reach and engage families from diverse populations and cultures. When we engage families we want to ensure that we are reaching, engaging and partnering with as many as possible and are including the voices representative of all those served by MCH programs and policies. This document identifies some ways that states are engaging diverse populations. The examples included are not requirements of family engagement and partnership and may not work for every state.

Engaging Diverse Populations in Texas



Texas has a long history of collaboration with families and consumers. Through the incorporation of family- and person-centered strategies into Maternal and Child Health (MCH) programming, staff

provides assistance and support to diverse populations and cultures.

Due to its large and diverse geography and population, Texas implemented a variety of strategies to ensure ongoing family and consumer engagement. For example, as part of the Title V Five Year Needs Assessment, MCH staff members solicited input from parents across the state in small and large rural and urban communities, including parents of CYSHCN. Data from the needs assessment shows that, of 923 responses received to a survey developed specifically for CYSHCN, 312 were completed in Spanish. In eight cities, 16 focus groups with consumers were held in both English and Spanish to ensure stakeholders could participate in their preferred language and in their local communities. A total of 11 focus groups for parents of CYSHCN were held in each of the eight Health Service Regions. Spanish focus groups took place in El Paso, Dallas and Laredo. Of the 102 focus group participants, 44% were identified as being primarily Spanish-speaking.

MCH staff members use several methods to obtain input and feedback from the public throughout the year, including surveys, webinars, conference calls, trainings and in-person meetings. This feedback informs programming and serves as an opportunity for ongoing evaluation. The Texas AMCHP Family Delegate and Texas' Family Voices State Affiliate Organization, Texas Parent to Parent, are included in program activities to ensure the family voice in MCH planning. Additionally, families who are directly served by MCH programs are surveyed yearly regarding the services they receive.

Staff actively engage and collaborate with families on an ongoing basis through numerous forums including work groups, committees, councils and collaborative groups to address ongoing and emerging issues. Family members and consumers participate in resource development and distribution with program staff. Texas MCH staff members collaborate internally to share successful program-specific initiatives and spread them to other programs within MCH.

Finally, Texas staff have embarked on a new initiative to develop a strategic plan to strengthen and expand family-professional partnerships statewide to align with MCH Block Grant transformation efforts. A key component includes identifying a team to collaborate with

representatives from each MCH population domain and operationalize a process of gathering input from families and consumers to guide Title V program development.

Engaging Diverse Populations in Kentucky



In Kentucky, efforts aimed at engaging families began around 1999 when the Kentucky Commission for Children with Special Health Care Needs (CCSHCN) had a "Healthy and Ready to Work" grant. The state began trying to engage

families more and support them in transitioning their children to adulthood. As a result of these efforts, Kentucky developed a transition checklist. Based on the realization that it needed to get families and youth involved, two councils were formed – one for parents and one for youth. Membership on the youth council is currently representative of male, female, African-American, Asian-American and white youth.

While the CCSHCN always supported the engagement of diverse populations, broader efforts began around 2005-2006 when the parent and youth councils were formed. The Commission also hosted a training on cultural diversity in 2014. There has been a focused effort to reach out to the Hispanic and refugee populations in the state. Kentucky's CCSHCN has been working with the Hispanic community; it funded efforts through a local physician and the Hispanic Center to form a support group for families in 2015. In addition to these efforts, refugees can come to any of 12 clinic centers across the state, where they receive help throughout the life course and at various stages of need/transition.

Since 2009, efforts to reach and engage diverse populations have included the Family to Family Health Information Center's program to teach parents to become trained support for other parents in the state. Within the past year some members of the Hispanic support group were trained as support for members of their community.

When engaging diverse populations in Kentucky, the major challenges have been language differences and engaging families in rural areas. Current efforts in Kentucky include arranging for interpreters, using video-conferencing equipment, scheduling parent and youth advisory group meetings after business hours, reimbursing mileage, providing a child care stipend, and soliciting input; both parent and youth advisory councils provide input on the Block Grant report and needs assessment, as do the two co-directors of the Commission Family to Family Health Information Centers, who are both parents. The chair of each council is invited to attend the strategic planning for the commission. The strategies the CSHCN used to address these challenges most directly are video- and tele-conferencing and the use of interpreters. These strategies have proven successful; however, the CSHCN is always looking for ways to improve upon its efforts and reach as many families as possible.

Along the way, Kentucky officials learned some valuable lessons in reaching and engaging families of diverse populations. Some of the key tips they can share with others are:

- Be flexible.
- Sometimes what you think will work, does not.
- Parents with CYSHCN and youth can't participate during regular business hours; if you want them at the table, offer times that make it possible for them to participate and provide incentives/stipends for participation.
- Families should be compensated for their time and feel valued to the same degree as anyone else being asked for his expertise.

For more information on family roles within AMCHP: amchp.org/programsandtopics/family-involvement/Pages/default.aspx

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