

AMCHP Case Study

Family Engagement: 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 engaged in Title V programs (MCH and CYSHCN). Family engagement, as discussed here, is referred to broadly 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 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.

This document serves as a resource to highlight some ways that states are engaging families. The examples included are not requirements and may not work for every state.

Engaging Families in Louisiana



The Louisiana CYSHCN program welcomes and values the involvement of families in their state. Children's Special Health Services' (CSHS) family engagement began in the early 1990s with two parent liaisons and has

grown ever since. Now, families are involved in the development of all policies and activities of the state's four Title V CYSHCN Programs.

Louisiana contracts with Families Helping Families to hire parent liaisons housed within clinics in eight out of nine of its regions to help identify family needs and to link families with state and local resources. In addition to the 22 CSHS Clinics, parent liaisons attend 10 genetics clinics and two sickle cell clinics. Local to his or her region, each of the parent liaisons is familiar with the area and the resources available to families. In 2011, when New Orleans clinics were closed due to budget cuts, a Family Resource Center (FRC) was established with a full time parent liaison, youth liaison and advisory council comprised mostly of parents who advise on activities and the strategic plan. The FRC is located in the state's only children's hospital in an effort to help link families with resources nearest to their homes. In all nine regions of the state, parent liaisons are looked to for their input and expertise.

Louisiana is one of the poorest states in the nation, with provider shortages throughout the state but most severely in its large rural areas. In recent years, Louisiana has experienced additional challenges such as budget cuts and health care reforms that reduce direct services. In the last five years, the number of CSHS clinics decreased from 60 to 22. The remaining clinics are largely focused on neurology, orthopedics and chronic conditions such as cleft lip and palate and spina bifida. As closures progressed and Louisiana Medicaid began transitioning to managed care, Louisiana CYSHCN leadership increased its emphasis on infrastructure building and policymaking. As a result of the program's parent participation in an AMCHP Action Learning Collaborative, Medicaid mandated its managed care organizations to include parent representatives on all of their regional advisory committees.

In addition to the Children's Special Health Services Program, parent consultants are hired for the state's Early Hearing Detection Intervention (EHDI) program, which is also under the Title V CYSHCN umbrella. The national Guide by Your Side program trained six Louisiana parents to assist parents of children with newly diagnosed hearing loss. Multilingual parent consultants also assist with follow-up of infants with positive hearing screens. Through the extensive use of parent consultants and guides, the program reduced its

loss-to-follow-up rate to approximately 30 percent, which is below the national average.

Louisiana values family input for all block grant activities, starting with the writing of the block grant itself. One long-term challenge the state experienced was getting families to complete Title V Block Grant surveys. The lack of response was due in part to families not receiving information about how their input was being used. To address that challenge, Louisiana began publishing the information in its newsletter, Family Matters; sharing it on its website and posting it in clinics so parents would know what the survey responses were and how the information would be used. The survey was also transitioned to an online survey tool, which has made it more accessible and efficient for families to complete.

The two parent consultants in the central office participate in all staff meetings and Title V planning meetings to ensure continual parent input in all Needs Assessment and Block Grant activities. Family input is taken into consideration at all levels of decision making, from what program brochures should look like to what programs/services are helpful and how they can be improved.

One lesson learned through the use of parent liaisons is the importance of training. Louisiana has two parent consultants who provide ongoing training for parent liaisons that includes topics such as advocacy, professionalism, HIPAA, medical homes and resources for families. Parent liaisons are reimbursed for their transportation for training activities.

Thinking back on lessons learned, Louisiana shares that it would have given parent liaisons more training and more opportunities to be a part of the process from its onset in the early 1990s, so that they would have been as engaged then as they are now. Louisiana is mindful that trainings must be continually developed on a variety of topics and that having well-trained parent liaisons is critical. The Louisiana Title V CYSHCN Programs realize that family engagement has been critical in shaping policies and activities that truly meet family needs. Families will continue to be included at all levels of decision making.

Engaging Families in Michigan



Michigan's CYSHCN program is Children's Special Health Care Services (CSHCS). CSHCS is housed in the Medical Services Administration of the Michigan Department of Health and Human Services. The Family

Center for Children and Youth with Special Health Care Needs (Family Center) is the statewide parent-directed center within CSHCS.

The primary role of the Family Center is to offer emotional support, information and connections to community-based resources to families of children and youth with special health care needs. This includes all children who have, or are at an increased risk for, physical, developmental, behavioral or emotional conditions. The center also provides parental perspectives and input on policies and health care matters, focusing on families' access to coordinated systems of care. The center operates from a family-centered care approach and promotes family/professional partnerships at all levels. This ensures that families participate in the decision-making process and are satisfied with the services they receive.

In 1988, when Michigan CSHCS launched the Parent Participation Program (PPP), it was innovative to employ a parent of a child with special health care needs to represent families on the Title V administrative team. Since then, numerous programs nationwide have adopted the concept.

Over the past 28 years, the Family Center has only had three directors. This speaks to the level of meaningful involvement and the longevity of engaging families throughout Michigan's Title V programming. All Family Center staff (nine positions) are parents or caregivers of a child with special health care needs.

Michigan is proud of its history of engaging families. CSHCS ensures that policy and program changes include family members at the table as equal partners. The CSHCS director promotes this collaboration and partnership, and supports family engagement at all levels. The Family Center has

become a credible resource for families and other areas of the state health department.

Michigan's family engagement efforts center on family needs. It is important to focus on programming based on what is in place and utilizing family input to evolve and improve those programs and identify where the gaps may be. The Family Center proudly offers small grants to local health departments to increase parent involvement and feedback into programming and services at the community level. This collaboration and parent engagement between the local health departments, the CSHCS Division and the Family Center have been instrumental in supporting all families.

Michigan has faced challenges during its years of engaging families. For example, a role of CSHCS and the Family Center is to ensure family participation on advisory committees within the CSHCS Division. However, participation on committees dropped over the past few years. Keeping families supported and involved can be challenging for many different reasons. Recently, the Michigan CSHCS reached out to several partners to identify parents to serve on these advisory committees. The state looks to ensure a broad and diverse reach. Utilizing technology, CSHCS offers, through the center, alternative ways to participate and recognizes families for their participation through financial reimbursement.

Family Center staff have assessed what has been successful and gauged the program's impact and need. Efforts within the Family Center include strengthening the foundation of the center's policies, procedures and programs. The center is assessing whether it is meeting the needs of its staff. It is very important to the Family Center to look at all aspects of the infrastructure that is in place to support staff, engage families and ensure all programs are family-centered, although that means not always moving as quickly as staff would like. Staff members realize the importance of providing balance in the process of being able to listen and respond to questions and concerns of an individual family while keeping in mind that they might not represent the views of all families. While staff doesn't want to give preference to a specific view, it is important to balance broad input while also validating individual perspectives.

The Family Center has been fortunate to have many engaged stakeholders who assist in building

connections and supporting it on many different levels. The Family Center receives support from the top down, including from community-based organizations. A strategy to address obstacles builds on the strengths of the systems already in place and individualizes programming for families in Michigan. The Family Center does this by utilizing information from other local, statewide or national programs. For example, the Family Center has used information from AMCHP about engaging families and uses the P2P USA model on parent-to-parent support. The center also credits a strong relationship with the Michigan Family to Family Health Information Center (F2F), collaborating on multiple projects and promoting learning opportunities for parents and youth with special health care needs. An F2F leader serves on the CSHCS Advisory Committee.

Michigan's efforts have yielded some great results. For example, more families have engaged with its programs; more parents utilize the programs, supports and services (such as scholarships for educational opportunities or parent-to-parent matching); and more professional contacts have formed, which provide an entry point for families to the Family Center.

Along with challenges and successes come lessons. When times were tough and the Family Center was struggling to keep programming running, CSHCS continued to invest in engaging families and demonstrating the impact of the Family Center's work. Since then, the CSHCS has continued to invest in engaging families and demonstrate the impact of its work. The division learned that having parents at the table is necessary, but it is not sufficient to fully inform program and policy decisions. It is incredibly important that families are part of all programs and policy conversations and that work is done to ensure parents can broadly represent the voice of families. As part of this, families need to be connected to other causes. The Family Center staff realized the importance of being cognizant of parents on staff versus those who are volunteers. State employees might be more constrained because of the government infrastructure or might not share the same perspective as those parents who are not connected to a formal government system.

Having a supportive leader within CSHCS has been critical to the success of engaging families and the

Family Center. Looking ahead, the Family Center would like to focus on its need to commit more time to strategic planning and to developing a work plan. It would also like to focus on ensuring that institutional knowledge about family engagement is captured and that there is a process for knowledge management and documentation. The Family Center and CSHCS are extremely proud of this partnership and the work accomplished together throughout the state of Michigan.

Engaging Families in Washington



The 1990s presented a big transitional phase for Washington. Funding shifted from direct services and allowed for more systems development. As a result, the CSHCN Program was able to begin to formally partner with family

support organizations. Families were then engaged in the CYSHCN program from the mid- to late 1990s. Then, in the late 1990s, it created a staff position for family engagement, with the preference to have a family leader in the position. Despite financial threats during the recession and some roadblocks with the previous administration, Washington is once again engaging families. Family engagement has become more routine, and families are accepted members of the Title V program's partnerships.

Currently, Washington engages families in a variety of efforts. First, the family voice is included through a staff position. The state also works with contractors that either promote family engagement or offer training to family leaders. Washington contracts with P2P and uses MCH Block Grant funds for a parent-to-parent support program and to identify emerging family leaders. There are similar efforts targeted at reaching dads through a contract with the Fathers Network. In addition, it contracts with Seattle Children's Hospital to train family leaders, with mentoring included as an element of this. Finally, it has utilized the AMCHP Family Scholars Program (now the Leadership Lab), for training family leaders.

Washington is unique: parts of the state are very agriculturally-oriented and has a migrant workforce. The diversity presents cultural and lingual challenges. Washington has experienced some bumps along its journey to engage families. Due to some restrictions, it is unable to directly recruit a family member for their staff position. Therefore, it has had to find creative ways to get a parent of a child with special health needs into the position without directly asking.

Washington's CSHCN Program partners with many local community organizations to address the diverse needs of the state. With the state's diverse political, cultural and ideological climate, it can be challenging to engage family leaders from diverse populations and address the essential needs of all of the different stakeholders in Washington. Not only does the state have families from many different cultural backgrounds, such as agricultural migrant workers and refugees, but the program serves families across many rural areas where access to services and supports can be limited. Staff members strive to improve health equity by finding strategic ways to include the families with the greatest unmet needs in programs and systems designed for their communities. It has subcontracts with other organizations that have success in reaching diverse groups (Spanish-speakers, refugees, etc.). Washington consistently seeks new methods to reach families (for example, through social media). When it comes to compensation, staff learned that it is best to use a methodology outside of the state system that is more flexible for expenses like child care.

Through their experiences, Washington representatives learned some valuable lessons: institutionalized family engagement is possible, and it can be successful. To this end, they focus on modeling what they believe those in MCH should be doing to engage consumers and partner with other organizations and how CYSHCN programs/staff can help with this.

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

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