MODULE 5

How can you partner with other stakeholders to address inequities?

The Importance of Partnerships

Our health care landscape is very complicated – families need information and support from family leaders, providers, and others in the health care system to ensure that they understand the services to which they are entitled and how to navigate the system. However, it is also integral that professionals get input from families about their experiences with the system of care. Partnership means a two-way flow of information and collaboration between families and professionals (which includes providers, public and private payers, policy makers, and family leaders).

Who Can You Partner With?

This section provides information on national and state-based organizations that focus on partnerships to improve coverage and financing for children with special health care needs (CSHCN) and to reduce health inequities.[1] You may be able to partner with the organizations listed in this section to improve coverage and care for and reduce inequities among CSHCN in your state. In fact, you may already have connections with these organizations in your state that you can strengthen or draw from to create opportunities for reducing inequities.

Family Voices

Family Voices is a national organization that provides extensive information and support to families of CSHCN around their health care and other service needs. Family Voices also provides information and training to family leaders around the country to support them in working directly with families and advocates to improve local-, state-, and federal-level policies that impact CSHCN and their families.[2] For more information, visit the Family Voices website at http://www.familyvoices.org

National Center for Family/Professional Partnerships (NCFPP)

The National Center for Family/Professional Partnerships (NCFPP) is a project of Family Voices that provides technical assistance to families, family leaders, and other professionals around fostering family/professional partnerships to improve care for CSHCN.[3] NCFPP focuses on the importance of partnerships for improving outreach to diverse families of CSHCN, fully implementing provisions

You may already have connections with the organizations listed in this section to improve coverage and care for and reduce inequities among CSHCN in your state:

- Family Voices
  http://www.familyvoices.org
- National Center for Family/Professional Partnerships (NCFPP)
  http://www.fv-ncfpp.org/
- Family-to-Family Health Information Centers (F2Fs)
  http://www.familyvoices.org/page?id=0034
- State Offices of Minority Health
  http://www.nasomh.org (National Association of State Offices of Minority Health)

of the Affordable Care Act (ACA), and strengthening the primary care workforce to be more family-centered. Among a variety of other organizations, NCFPP provides technical assistance to Family-to-Family Health Information Centers (F2Fs) throughout the country.[3] For more information, visit the NCFPP website at http://www.fv-ncfpp.org/

Family-to-Family Health Information Centers (F2Fs)

Each state and the District of Columbia (DC) has an F2F, which provides information and outreach to families of CSHCN to help them make informed health care-related decisions. F2Fs also partner with health care and other organizations as well as government agencies to advocate for collaboration between families and professionals.[4] F2F staff members are family members of CSHCN who have first-hand knowledge about how to navigate complex health care systems.[4]

From 2013-2014, F2Fs throughout the country served more than a million families and almost 400,000 professionals.[4] F2Fs serve a racially diverse array of families, with about 40% of those served being families of color.[4] Additionally, 65% of F2Fs are involved in initiatives around cultural and linguistic competence and 55% are involved in initiatives around immigrant families and families of diverse cultures.[4] F2Fs represent an opportunity in each state to ensure collaboration among diverse families of CSHCN and organizations, state agencies, policy makers, and providers to ensure that the needs of diverse CSHCN are being met. For more information, visit the F2F section of the Family Voices website at http://www.familyvoices.org/page?id=0034

State Offices of Minority Health

The Federal Office of Minority Health (OMH) focuses on health policies and programs to reduce racial and ethnic health disparities throughout the U.S. OMH provides funding to community-based organizations, distributes information to improve awareness about health disparities, and fosters partnerships that help improve health and reduce disparities.[5] Additionally, each state has its own Office of Minority Health. These offices perform many of the same tasks as OMH, but at the state level, and often have more direct connection to their state's health care workforce and may have fostered partnerships within communities throughout their state.[5] For more information, visit the National Association of State Offices of Minority Health website at http://www.nasomh.org/

Partnerships to Address Inequities

This section provides examples of state-based organizations that have utilized partnerships to create or strengthen programs that address inequities among CSHCN. These examples may provide inspiration for new or innovative programs that could be created or expanded in your state. Contact information available in the links in the "Your Turn" section of this module on page 44 can also help you connect with other organizations with whom you may partner to create similar innovative programs to address inequities among CSHCN.

Arkansas Disability Coalition

The F2F organization in Arkansas, the Arkansas Disability Coalition, partnered with two elementary schools in the Little Rock School District to provide cultural competency training to better equip the school district to provide support to Latino families.[6] This program has reportedly increased awareness of available health care services and supports among Latino families and has increased the school district's understanding of the needs of local Latino communities.[6] By increasing awareness and improving support for Latino families, this partnership may help address the high uninsurance rates among Latino CSHCN.[7]

Oregon Family-to-Family Health Information Center

The Oregon F2F conducts regular family gatherings with diverse families of CSHCN – specifically with Latino families and those from rural areas. Oregon F2F partners with other community-based organizations to host these gatherings at local venues that are familiar to and comfortable for diverse families.[5] At these gatherings, Oregon F2F staff members share information with families about the extensive network of family groups and professional organizations within the state. These meetings allow Latino families and those from rural areas, who may be more secluded from other families and services, to connect with one another and to learn about

services and supports that are available in their county.[5] Thus, this program helps address inequities by expanding outreach and information to some of the most vulnerable groups of CSHCN. Because Latino CSHCN are more likely than other CSHCN to be uninsured,[6] this increased outreach may help increase insurance rates and close racial gaps in coverage.

Alaska Title V CSHCN Program

The Alaska CYSHCN program staff received reports from health care providers in some of the rural villages that some children were entering school with limited language competency and were demonstrating behavioral challenges such as self-regulation, cooperative play, and following directions. They found that within the tribal communities, especially in rural locations, parents are not readily alarmed when their children do not speak fluently by school age. This is because, within the Alaska Native culture, adults oftentimes will talk for their children, and as long as a child is participating in cultural activities, parents are not as concerned. As a part of the neurodevelopmental and autism screening clinic, the Title V parent services manager offered community education sessions in the rural villages and talked about autism spectrum disorders as well as other common elements of developmental delays. These community sessions continue to be offered in each community with every Neurodevelopmental/Autism Screening Clinic. The community work helped to normalize the screening process and increased the understanding of what it meant to have a possible autism or developmental delay diagnosis. With a better understanding in the community, there was a sharp increase in the number referrals to the screening clinics with a notable increase in the number of children 0-3 years. This resulted in an increase in the number of referrals to the early intervention program. The ongoing outreach clinics are offered in 8-10 communities annually and help to facilitate ongoing communication and collaboration between the health provider community, the early intervention programs, public health nursing, early head start and the Title V/CYSCHN program. This collaboration has resulted in a decrease in the age of children who need to be referred to the diagnostic clinic in Anchorage, an increase in the number of children identified prior to kindergarten, and an increase in the number of qualified children receiving intervention in the early intervention program in their home community. The improved outcomes helped to inform the legislature who passed a law to annually appropriate dollars to support intensive intervention services for children diagnosed with autism. Regulations and development of licensing and credentialing procedures for Applied Behavior Analysis (ABA) therapists are underway in Alaska to support this new service.

Minnesota Title V CSHCN Program

The Minnesota CSHCN program hires staff that is representative of the populations to whom they provide services. Currently, they are working with the Somali population around autism and connections to services including insurance coverage. They have formed a Somali public health advisors group that helps Title V staff identify emerging health issues in the Somali community. These advisors also connect with families to identify their needs and build trust between the health department and families in underserved populations.

In addition, to facilitate connections to families from diverse communities, Title V staff has partnered with the Minnesota Family-to-Family Health Information Center to identify other new family leaders. Prior to the Affordable Care Act, the Title V program also had partnerships with community-based organizations that provide services to culturally diverse families and those who speak languages other than English. Many of these organizations now serve as navigator or consumer assistor entities. So while Title V does not have a direct partnership with the Minnesota Health Benefits Marketplace, their partnerships with these community-based organizations helps ensure that underserved families raising CSHCN have access to information and benefits counseling around insurance coverage.

Michigan Title V and CSHCN Program

Beginning in 2010, the Michigan Department of Community Health, Bureau of Family, Maternal and Child Health made a commitment to examine their work through a "health equity lens" in response to disparities in infant mortality rates among Whites, Blacks, and American Indians. The PRIME (Practices to Reduce Infant Mortality through Equity) initiative, funded by the W.K. Kellogg foundation, is an intra- and inter-agency effort to raise awareness of institutional racism, increase cultural competence, and build the capacity of the state health department, including the Children's Special Health Care Services (CSHCS) program, to reduce health disparities. The

CSHCS program engaged in these efforts by taking self-assessments, participating in health equity learning labs, developing and implementing health equity plans, and working with Medicaid to remove barriers to covered services.

North Dakota Medicaid

In order to ensure Native Americans are aware of Medicaid and CHIP program eligibility for their children, the North Dakota Healthy Steps program contracts with a vendor that specializes in Native American outreach. Good Health TV is one of their outreach initiatives. Good Heath TV is a health and wellness network that broadcasts in the Indian Health Services and other tribal clinics across the state, and promotes health-related topics specific to Native Americans. This specialized vendor has produced two creative video segments to air on the network promoting Medicaid and Healthy Steps. They also employ a Native American woman who provides, “boots on the ground” outreach to the community, specifically to tribal employers. In addition to her work with employers, she conducts outreach and helps families enroll in coverage at job fairs. She also assists schools with outreach and enrollment as part of their back-to-school campaigns.

Conclusion

Partnerships are important for reducing inequities among CSHCN for several reasons. Professional partnerships between Title V and Medicaid programs may help ensure that the information families receive is coordinated, while partnerships with policy makers can ensure that the needs of CSHCN are addressed in federal- and state-level health policies. Partnerships among F2Fs, community-based organizations, and informal networks, such as faith-based organizations or schools, may facilitate outreach to more vulnerable families who do not already have strong connections to the health care system. These partnerships can also help promote cultural competency when they include organizations or family leaders who can make sure that communication is provided in families’ preferred language(s) and is accurate and trustworthy. Finally, organizations that partner directly with families ensure that the real needs of families are heard and met. Innovative partnerships can be a vehicle for providing outreach and information to the most vulnerable families, who may not receive the services and supports they need using traditional outreach methods.[1]

WORKSHEET TO ADDRESS INEQUITIES IN YOUR STATE - MODULE 5

YOUR TURN: How can you partner with other stakeholders to address inequities?

Module 5 provided you with some information about family/professional partnerships to address inequities among CSHCN. The examples from Arkansas, Oregon, Alaska, Minnesota, Michigan, and North Dakota may inspire similar initiatives in your state. There are various opportunities for partnerships that may help address the specific needs of CSHCN and may support innovative strategies to reduce inequities. Use the table below to explore organizations with whom you may partner to improve coverage and financing of care for CSHCN in your state.

Opportunities for Partnerships in ____________________
(your state)

Family Voices (national)	National Center for Family/Professional Partnerships	Family-to-Family Health Information Center (F2F)	State Offices of Minority Health	Other Organizations in Your State
More information on Family Voices[1]	More information on the National Center for Family/Professional Partnerships[2]	Use this list of F2F organizations[3] to identify the F2F in your state. **Your state's F2F:** ____________________	Use this interactive map[4] to identify the state office of minority health in your state. **Your state's office of minority health:** ____________________	

[1]http://www.familyvoices.org/
[2]http://www.fv-ncfpp.org/
[3]http://www.fv-ncfpp.org/f2fhic/find-a-f2f-hic/
[4]http://minorityhealth.hhs.gov/omh/browse.aspx?lvl=2&lvlid=6

Now, take a look back at the "Your Turn" section for Module 3: *How can policies and programs improve inequities in your state?* on pages 30 - 31. Were there any policies or programs to reduce inequities that your state has **not enacted**? If so, you can use the below table to fill those in and think about which organizations or stakeholders you might partner with in your state to get these or similar programs enacted.

Policies and Programs Enacted/Not Enacted in ____________________

(your state)

Policy	Enacted	Not Enacted	Potential Partners for Planning/Future Enactment
State Earned Income Tax Credit (EITC) Program			
Increased Medicaid Income Eligibility	Every state (including DC) must provide Medicaid to children, age 0 to 19 at income less than 138% FPL. Many states have higher income eligibility. Your state's income limits for Medicaid: Ages 0-1: ______% FPL Ages 1-5: ______% FPL Ages 6-18: ______% FPL		
TEFRA/Katie Beckett State Plan Option			
The Legal Immigrant and Children's Health Improvement Act (ICHIA) Option			

References

1. Catalyst Center. (2015). *Improving access to coverage for children with special health care needs in the face of health inequities: Strategies reported by family leadership organizations.* Boston, Massachusetts: Catalyst Center. Retrieved from http://cahpp.org/improving-access-to-health-coverage-for-children-with-special-health-care-needs-in-the-face-of-health-inequities/

2. Family Voices. (2013). *About us.* Retrieved from: http://www.familyvoices.org/about

3. National Center for Family/Professional Partnerships. (2015). *What we do.* Retrieved from: http://www.fv-ncfpp.org/ncfpp/about/

4. National Center for Family/Professional Partnerships. (2015). 2013-2014 *Data report of activities of Family-to-Family Health Information Centers.* Albuquerque, NM: Family Voices.

5. Office of Minority Health. (2015). *About the Office of Minority Health.* Retrieved from: http://minorityhealth.hhs.gov/omh/browse.aspx?lvl=1&lvlid=1

6. Family Voices. (2014). *Activities and accomplishments of Family-to-Family Health Information Centers.* Albuquerque, NM: Family Voices.

7. Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved from http://www.childhealthdata.org

This document, *Health Care Coverage and Financing for Children with Special Health Care Needs: A Tutorial to Address Inequities,* is available in its entirety on the web at http://cahpp.org/resources/inequities-tutorial

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