

## **New Jersey Families as Partners in Medicaid and Managed Care Organizations: Increasing Access for Families of Color and Immigrant Families**

Access to quality healthcare services can be difficult for underserved families, particularly for those with children and youth with special health care needs (CYSHCN), and is often compounded by factors like race, class, immigration status, and ability to pay. These factors can leave parents and families of children needing care feeling helpless and without support. In New Jersey, the Statewide Parent Advocacy Network, an organization which houses the state's Family to Family Health Information Center (F2F HIC), trains parents and families to become advocates for their own health, support and engage their communities, and break down the assumptions and anxieties that serve as barriers to high quality care. The network works to reach immigrant families with and without CYSHCN to expand care networks. This state story highlights the impact family advocates have on Medicaid and managed care organizations in providing access to comprehensive care.

### **Access Challenges for New Jersey**

New Jersey is racially, ethnically, linguistically, and culturally diverse. The state faces significant challenges to ensuring access to quality healthcare, particularly for immigrant children, children of color, and those with public insurance.

Achieving more diverse representation on consumer advisory boards of the state's Medicaid managed care agencies is one approach for addressing barriers to insurance access and quality healthcare for immigrant children, children of color, and CYSHCN. When families of color, immigrant families, and non-English speaking families are at the table to share their experiences and provide their recommendations for improvement, their issues and concerns are more likely to be addressed.

### **Families as Partners in Medicaid and Managed Care Organizations: New Jersey's Story**

Staff at New Jersey's F2F HIC are active participants in training and supporting diverse parent leaders of CYSHCN and immigrant families of non-CYSHCN with an interest in serving on Medicaid HMO consumer advisory councils. Additionally, a representative from New Jersey's largest Medicaid HMO serves on the board of the Statewide Parent Advocacy Network (SPAN). This participation strengthens the relationship between the two organizations and provides ongoing exchange of information and opportunities for collaboration on specific projects and issues.

[F2F HICs](#) are federally-funded entities found in every state and the District of Columbia and are designed to assist families of CYSHCN and the professionals who serve them. F2F HICs are uniquely positioned to serve this population because they are staffed by family members who have experience navigating healthcare services and programs for CYSHCN. This intimate understanding of the issues families face

There are an estimated 294,346 children and youth with special healthcare needs (CYSHCN) in New Jersey. Though programs often refer to CYSHCN as a single population, this is a diverse group, with diverse needs. Of the CYSHCN in New Jersey:

- 15.9 percent are Non-Hispanic Black.
- 15.3 percent are Non-Hispanic White.
- 7.9 percent are Non-Hispanic Asian.
- 8.0 percent are Hispanic and live in a Spanish language household.
- 18.6 percent are Hispanic and live in an English language household.
- 14.4 percent live below 100 percent of the federal poverty level.
- Only about half have adequate private or public insurance to cover needed services.
- Nearly a third have families who pay \$1,000 or more out of pocket per year for the child's medical expenses.

Source: [NS-CSHCN Chartbook 2009-2010](#)

makes F2F HIC staff exceptionally qualified to help other families navigate health systems and make informed decisions.

In addition to operating the health information center, SPAN also serves as the Family Voices state affiliate organization. Family Voices is a national nonprofit, family-led organization promoting quality healthcare for all children and youth, particularly those with special healthcare needs. Working with family leaders and professional partners at the local, state, regional, and national levels since 1992, [Family Voices](#) brings a family perspective to improving healthcare programs and policies and ensuring that healthcare systems include, listen to, and honor the voices of families. Family Voices, through its National Center for Family and Professional Partnerships, provides technical assistance and support to the nation's 51 F2F HICs.

### **SPAN's Steps to Success**

The Advocacy Network has long understood the importance of family professional partnerships and the need to have families of CYSHCN engaged in designing and improving support systems. For almost 30 years, SPAN has informed policymakers in state systems and Medicaid about the importance of including families at all levels of decisionmaking. The network supports and encourages families to share their stories and perspectives to enhance and improve the quality of service delivery. For example, SPAN engaged immigrant parents in discussions around cultural and language barriers that exist when following up with the appropriate systems after their children do not pass a developmental screening. After identifying barriers, one New Jersey HMO provided SPAN with resources to provide a family resource specialist, a trained bilingual parent, at Quick Peek Screening Programs that are frequented by immigrant and non-English speaking families. After introducing the specialists, New Jersey saw an increase in follow-up care after screening among non-English speaking families. Furthermore, there have been more opportunities for families to provide input to HMOs, indicating HMOs understand consumers have choices and grasp the importance of consumer satisfaction. Molly Auciello, manager of community relations at WellCare Health Plans, Inc., stated:

*“Member and community partner participation is imperative to the success of our Community Advisory Committee, Comprehensive Health Evaluations for Children, and Medicaid Long Term Services and Supports committees. It is an opportunity for them to give us—the [health] plan—feedback on operations improvements, issues or concerns, and positive commentary on what they want to see more of. Many times our members and partners have issues with a health insurance carrier and do not have a platform to voice their concerns beyond the confines of an 800-member service number. Even using a member service hotline will only resolve a standing issue and not get to the root of an operational flaw the plan may have. This allows everyone to comfortably come together and voice their perspectives on how WellCare is doing by the member, provider, and community.”*

Through periodic evaluations and focus groups, SPAN provides families with an opportunity to express what is working well and provide input on agenda topics and logistical changes being proposed. Families, and the professionals with whom they partner, benefit from training, helping to understand and appreciate each other's roles. SPAN provides training to HMO members and coordinates and facilitates meetings between HMOs and families to explore ways to engage family leaders. New Jersey's HMOs made the following changes to ensure family participation:

- When New Jersey's largest HMO wanted to learn about barriers for immigrant and Spanish-speaking families, the plan's administrators reached out to SPAN. They held quarterly Spanish

Advisory Meetings to ensure that they captured the needs and barriers of families served by Federally Qualified Health Centers (FQHCs) and others in underserved communities. Through these meetings, the HMO representative documented and followed up on their concerns and responded to everyone individually with the assistance of SPAN’s resource specialists.

- Another HMO now holds its meetings in locations accessible to public transportation for people with disabilities and specifically invites families to participate.
- A third HMO now offers a translator at its advisory meeting so that the non-English speaking parent members can participate. Previously, the HMO did not offer translators and attendees were unable to contribute due to language barriers.
- A fourth HMO funded family support and engagement activities at one of the FQHCs in its catchment area. As a result, the town funding an inclusion and integration initiative for families of CYSHCN and hired a bilingual parent leader from the community to run the after-school program and weekend intramural sports leagues to provide greater opportunities for immigrant CYSHCN to be physically active.

*“WellCare care managers work with WellCare’s Advocacy Program to identify and connect their members to needed programs, services, and resources. Having a seat at the table allows for an exchange of information, recommendations for improvement, and resolution to areas of concern.”*

**Rosemarie Stern, RN, CCM**  
 Manager, Quality Improvement  
 WellCare Health Plans, Inc.

**Successful Outcomes**

The network is part of a healthcare coalition, NJ for Health Care, which focuses on policy changes and advocacy. SPAN’s policy director works with families to implement changes with their needs in mind. SPAN increased the number of parent guides and other materials translated into other languages, especially Spanish, which came about as a direct result of parent testimony and advocacy. SPAN also undertook a successful advocacy effort to maintain zero co-pay for Medicaid enrollees. The coalition successfully advocated for the expansion of Medicaid in New Jersey by meeting with policymakers and developing grassroots advocacy efforts. The coalition has worked to maintain the zero co-pay policy and Medicaid expansion.

SPAN participates in an HMO and a community of care consortium consisting of the New Jersey Department of Health, HMOs, the hospital association, and other partners, where families and staff have an opportunity to discuss and address barriers to enrollment access. This collaboration has resulted in funding for SPAN to assist with trainings, outreach, and enrollment for diverse families under CHIPRA grants. SPAN’s approach of partnering with racially, culturally, and linguistically diverse parents to identify and overcome barriers to enrollment, including providing stipends to parents to facilitate outreach and enrollment in their communities, led to an invitation to train all of the Centers for Medicare and Medicaid Services (CMS)-funded navigators, FQHCs, and other enrollment assistors on effective outreach to and enrollment of diverse constituencies and healthcare financing options for CYSHCN. The Region II CMS office [noted](#) New Jersey’s work: “Your planning and support helped our enrollment assistors to more effectively reach faith-based partners, while providing great assistance to individuals with language barriers who would have otherwise had great difficulty enrolling.”

In addition, SPAN has created and reviewed patient and family outreach materials from Medicaid, HMOs, as well as state agency websites, and provided input and advocated successfully for shortening the Medicaid online and paper applications. SPAN provided factsheets including a seven-part Medicaid Managed Care Factsheet Series, a Healthcare Financing for CYSHCN Guide, and a Managed Long-Term Services and Supports factsheet, as well as materials on cultural competence and nontraditional outreach to HMO members.

SPAN staff work across the state with HMO health educators to deliver topical training to families with a focus on covered services, early screening, prevention services, nutrition training, disease awareness, disability management, mental health awareness, and blood pressure screenings. HMOs have sponsored conferences and partnered with SPAN in other ways. One such partnership with WellCare led to funding for a family resource specialist to provide support, training, and resources to families and CYSHCN served by FQHCs. This collaboration was a continuation of a county-based effort to integrate CYSHCN into their communities through a focus on health, wellness, and fitness.

As a network of professionals, advocates, and consumers, SPAN has benefited from conducting needs assessments to understand the needs and gaps in program service delivery, which has led SPAN to create resources and tools to fill those gaps. SPAN developed [resources](#) including healthcare financing factsheets and blogs to address information gaps and to ensure diverse consumers have information on all healthcare options. Medicaid advisory meetings provide excellent networking and information sharing opportunities like delivering and participating in training to the HMO staff. Likewise, SPAN staff learn from HMO staff about Medicaid program changes, trends, and what is happening in different areas of the state.

### Lessons Learned

To engage and retain family leaders in advisory roles, it is important to:

- Work with a trusted family organization that has relationships with diverse family communities to identify, prepare, and support parent leaders to participate.
- Provide travel expense and childcare reimbursements or stipends, as needed.
- Provide advance notice about meetings.
- Ensure meaningful opportunities to contribute and communicate any resulting changes back to participants.
- Hold meetings at times conducive to family and school schedules.
- Meet in locations that are served by public transportation and can be accessed by participants with disabilities.
- Not use acronyms or jargon that families may not understand.
- Have interpreters present to facilitate interaction as needed.
- Translate materials and resources.

SPAN advocates for these strategies for engaging families successfully. A report [prepared](#) by Community Catalyst, "Consumer Engagement in Medicaid Community Care Organizations," describes similar strategies in six states: "State policymakers and health care organization leaders can improve the efficacy of consumer engagement by: being mindful about meeting times and locations; providing adequate time in advance of meetings for consumers and consumer advocates to review materials and provide their input, ensuring that recommendations have impact; and ensuring appropriate support such as funding and training for consumers and consumer advocates."

### **Opportunities for Including Parents in HMO Advisory Committees**

Meaningful participation on HMO advisory committees requires ongoing training for both parents and professionals about the dynamics of partnerships and collaboration. Collaboration is more successful when the HMO understands the value of consumer representation in its policies and programs and views the advisory committee as a partner in the process. Having a designated coordinator is essential to performing outreach to families and ensuring all the steps needed for meaningful engagement occur before, during, and after the meeting. Coordinator duties include sending out the committee meeting invitation and agenda, translating meeting materials, securing a translator or facilitator, providing compensation or a stipend for participation, and following up with members to share the outcomes resulting from their input.

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