

## Oklahoma Engages Families as Partners to Strengthen SoonerCare Program

Families are important stakeholders and should be engaged early in family and community health policy and program development. Programs and policies developed without family input may prove impractical or place an undue burden on those they are intended to serve. Families provide a unique perspective and can speak to what components of the program are being implemented and working efficiently. Family-focused organizations and their members bear the collective voice and expertise from working directly with families, contributing a wealth of knowledge to policy and programmatic discussions. Successful partnerships with families require planning, training, support, and funding.

To identify opportunities to improve the state's Medicaid program and the services it provides, the Oklahoma Health Care Authority (OHCA) established a SoonerCare Member Advisory Task Force (MATF) to gather input and feedback from members and their families. Oklahoma recognized that the first step to gauging how effectively SoonerCare met its beneficiaries' needs was to garner input from them directly. With the goal of enhancing family engagement, the SoonerCare program partnered with the Oklahoma Family to Family Health Information Center (F2F HIC), a program of the [Oklahoma Family Network](#), to form the MATF steering committee, which held its first meeting in January 2011.

### One State's Story: Oklahoma

The decision to seek families' input on the Medicaid program began with the joint efforts of SoonerCare and the F2F HIC program. The Oklahoma F2F HIC program assists families of children and youth with special healthcare needs (CYSHCN) and the professionals who serve them. The program is staffed by family members who have firsthand experience navigating healthcare services and programs for CYSHCN. F2F HICs are federally-funded and exist in every state and the District of Columbia.

In 2006, the Oklahoma State Department of Health's (OSDH) maternal and child health director and the director of the Children with Special Health Care Needs program at the Oklahoma Department of Human Services (OKDHS) collaborated to invite a team from [Family Voices](#), a national, nonprofit family-led organization which promotes quality healthcare for all children and youth, to provide technical assistance on family involvement for the Title V and CYSHCN programs. Health department leadership wanted to involve families more consistently and meaningfully, beyond just the Title V block grant process, inviting other state agencies and families from multiple advocacy organizations to participate.

As a result of this technical assistance meeting, the Oklahoma Family Network (OFN)—also the Family Voices state affiliate—held its first annual Family and Professional Partnership Conference in 2006, inviting representatives from Oklahoma's state health, social services, and Medicaid agencies. Keynote speakers participated in early planning, served on the conference committee, and provided technical assistance to key Oklahoma program directors and state staff (e.g., Title V directors, special education directors, director of developmental disabilities services) on engaging families at a systems level. Technical assistance included how the speakers' states and their governmental agencies engaged families. These planning meetings and conferences laid the foundation for what would become the SoonerCare MATF.

### First Steps

The MATF initially struggled to engage families in meetings. Families faced significant hurdles to participation, including long travel times, travel costs, and childcare expenses. Recognizing this, OHCA

issued a Request for Proposal to fund an organization to identify, train, and support families involved in the MATF meetings and to provide food and stipends for participating parents. The OFN was awarded a contract to coordinate the task force meetings six times per year. The OHCA advertised the MATF in its member newsletter and invited SoonerCare families to attend meetings and provide constructive feedback on how to improve the program. It was important that the MATF membership be representative of SoonerCare users and reflect the cultural and ethnic diversity of the state, including its tribal population. As the state-designated F2F HIC, OFN's primary focus is CYSHCN, but its mission also values the perspectives of all families.

The OFN outlined several considerations for families interested in participating, including:

- Required individual or family member enrollment in SoonerCare Choice (primary care case management program).
- Availability to participate in most MATF meetings.
- Ability to speak about personal experiences and issues affecting other SoonerCare families.
- Ability to review information and share the viewpoint as a recipient of SoonerCare services.
- Maintain respect for others' viewpoints.
- Demonstrated ability to communicate with a variety of individuals in a positive way.
- Ability to consider different opinions and support common ground.

### Setting the Stage

The task force provided initial guidance on SoonerCare's operational issues and problems that warranted immediate attention. Prior to the first MATF meeting in January 2011, members were unaware of key provisions and benefits, such as the Member Helpline, the "SoonerRide" program (providing transportation to medical appointments), or SoonerCare's coverage of some over-the-counter medications. SoonerCare's Member Handbook was not widely used, and participants were not aware of which topics the handbook covered. Their knowledge of the medical home model was also limited. The MATF meetings provided a venue for clarifying key provisions and benefits for members.

MATF members also play several roles, including:

- Providing the OHCA with information on important issues and members' healthcare needs.
- Educating the OHCA staff to assure services are delivered according to members' preferences.
- Recommending potential changes to current services and/or policies.
- Offering new ideas for services and/or policies.

### Partnership Accomplishments

Since 2011, MATF has demonstrated its value by reducing state costs, clarifying the issues that families face, and increasing beneficiaries' trust in SoonerCare. MATF's key accomplishments include:

- **Making the member handbook "family-friendly."**

Prior to convening the MATF, the SoonerCare Member Handbook was long, difficult to understand, and underutilized. Members called the helpline rather than consulting the handbook.

MATF spent two meetings reviewing the handbook and looking for ways to shorten and simplify the information and make it more user-friendly. The task force reduced the size of the

Trimming the member handbook and providing an online version saves Oklahoma more than \$100,000 per year in printing and mailing costs.
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handbook by nearly 66 percent and created a “Quick Start Guide” with basic information and phone numbers to call.

- **Making the SoonerRide program work for families.** Families use the SoonerRide program to get to medical appointments, but seats in the vehicles were limited to only the parent and the child. This was a challenge for families with other small children or if the mother was pregnant and utilizing the transportation for prenatal care visits. The MATF asked how often the vehicles had empty seats and discovered that additional seats were often available. Thanks to the MATF’s suggestion, up to three children can now accompany a sibling or a pregnant mother when the visit is for an illness for no additional cost.
- **Streamlining, systematizing, and significantly overhauling the TEFRA process and policies.** The [Tax Equity and Fiscal Responsibility Act of 1982 \(TEFRA\)](#) is a law that allows Medicaid eligibility and waives parental income requirements for some 18-year-olds who have significant health conditions and intellectual disabilities. The process for enrolling in TEFRA benefits was revamped as a result of several MATF recommendations. The MATF recommended that the application process to become eligible under TEFRA be streamlined and long wait times for the application process be eliminated. Thanks to this input from task force members, OHCA moved TEFRA’s program administration to the member services department, which employs more staff and has a greater capacity to review and process applications. The agency also streamlined the application review and approval process, provided family advocates to assist OHCA staff, and trained Medicaid staff to ensure workers were clear on eligibility and qualification guideline. Finally, OHCA [developed](#) a parent instructional document and posted it to the agency’s website to help families navigate the application process. As a result, the TEFRA program grew from serving 70 people to over 600 people.
- **Assisting members by identifying after-hours providers.** MATF members raised concerns about not being able to find an in-network provider when their usual physician’s office was closed for the day, causing many to visit the emergency room. Upon the recommendation of the MATF, OHCA [developed](#) *After Hours*, an app to help families find providers with extended hours. The MATF also recommended that Oklahoma University physicians allow families to cancel appointments by text to increase ease and convenience.
- **Organizing regional focus groups.** OHCA contracted with OFN to hold focus groups throughout the state to ask members what services were difficult to access and what, if anything, they wished to change about the SoonerCare program. OFN provided a report to OHCA’s administrators, who shared it during the agency’s annual strategic planning meeting.
- **Making incontinence supplies (briefs, wipes, etc.) available through EPSDT for children.** Task force members shared with OHCA administrators that incontinence supplies for older children were not being covered by Medicaid as was the practice in some other states. As a result of this feedback, OHCA changed the policy to provide briefs and wipes under the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) benefit in Oklahoma.
- **Developing new publications and educational materials.** MATF helped revise publications and provided videos to reduce stigma affecting SoonerCare members and to educate legislators.

## Conclusion

The MATF partnership has created an effective vehicle for learning about families’ needs, developing recommendations for improving the SoonerCare program, and elevating members’ voices to the program agency to catalyze change. Collectively, these efforts have led to a greater awareness and knowledge of Medicaid services; creative ideas for improvement; cost-effective programs, including

innovative solutions to budget concerns; updated publications and website content; and ongoing staff development. This grassroots effort began because of good partnerships, and continues as those partnerships grow and strengthen.

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