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*The mission of the Institute for Medicaid Innovation is to improve the lives of Medicaid enrollees through the development, implementation, and diffusion of innovative and evidence-based models of care that promote quality, value, equity and the engagement of patients, families, and communities.*

# LISTENING TO FAMILIES: UNDERSTANDING EXPERIENCES FROM PARTICIPATION IN MEDICAID CHILDHOOD OBESITY PREVENTION AND TREATMENT INITIATIVES

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*Rates of childhood obesity are significantly higher for those covered by Medicaid compared to those receiving coverage through private insurance. For every 100,000 children in Medicaid, 1,115 have obesity compared to 195 for those in private insurance.<sup>1</sup> The average cost for children with obesity covered by Medicaid exceed \$6,700 compared to \$3,700 for private insurance.<sup>1</sup>*

*Examination of obesity by socioeconomic status and race/ethnicity demonstrates that rates are disproportionately higher for African Americans, Hispanics, and low income households.<sup>2,3,4</sup> Approximately 38 percent of African American children under 18 years of age and over 43 percent under age five live in poverty.<sup>5</sup> For Hispanics, 30 percent of children under 18 and 33 percent under five live in poverty.<sup>6</sup> Among these populations, social determinants of health influence overall health status and may contribute to obesity. In particular, food insecurity and fewer safe, community spaces for physical activity disproportionately affect minority children.<sup>7,8,9,10</sup> Tomayko and colleagues reported that economic hardship was positively associated with childhood obesity prevalence with significant racial/ethnic disparities.<sup>11</sup>*



## Introduction

To date, most childhood obesity initiatives in the literature have been designed as a single approach.<sup>12</sup> However, under the Early Periodic Screening, Diagnostic and Treatment (EPSDT) program, Medicaid managed care organizations (MMCOs) have been implementing multi-pronged approaches that address social determinants of health to prevent and treat obesity. As part of the EPSDT program, Medicaid-enrolled children receive regular well-child exams and medically necessary services, treatments, supplies, or devices, including nutritional assessments and counseling.

The CHildhood Obesity Prevention and Treatment Program (CHOPT) for Medicaid project was launched in 2016 with the purpose of understanding initiatives that MMCOs were implementing to address childhood obesity. The project included several components including a national survey, submission of innovative best practices, interviews with families that participated in the innovative initiatives to capture their experience with the program, and the development of a toolkit.<sup>13</sup> This report highlights findings from the interviews conducted with families and children.

## Methods

Grounded theory methods guided the study design and analysis, providing a framework for capturing the voices of families, including children, who participated in Medicaid managed care childhood obesity initiatives chosen for their innovative best practices.<sup>14,15</sup> Initiatives submitted by MMCOs were reviewed, scored, and identified as innovative best practices by the CHOPT for Medicaid National Advisory Committee consisting of clinical, research, and policy experts in childhood obesity. The committee identified five innovative Medicaid childhood obesity initiatives (Table 1).



Table 1. Overview of Innovative Initiatives

Program Name	Location(s)	Number of Participants	Highlights of Initiative
<b>Food Smart Families</b>	Arizona Florida Louisiana Mississippi* New York Nevada Tennessee Wisconsin	26,809	A community-based approach targeting low-income areas that help youth and families improve eating habits through evidence-based educational programming. Initiatives are in partnership with community and recreational centers, public housing, and schools.
<b>Keep Fit</b>	Texas*	731	A program led by health plan staff that focuses on areas with high concentrations of health plan membership with obesity. Utilizes group sessions to provide children and parents (or caregivers) with education about physical activity, healthy snacks and drinks, goal setting, and appropriate screen time.
<b>Kids Healthy Living Program</b>	Washington*	124	A program that offers interactive learning (e.g., exercise classes, cooking classes) and classroom events (e.g., nutrition education) led by community health professionals to create a collaborative and sustainable environment around healthy living for children and parents.
<b>Healthy Lifestyle Clinic</b>	Colorado*	323	A partnership with a pediatric obesity and comorbidity clinic that offers children and their families' access to evidence-based weight and comorbidity management services and interventions.
<b>Join for Me</b>	Kansas* Minnesota Rhode Island Texas	50,000	A weight management program that works with local health care providers in community settings (e.g., community centers, Young Men's Christian Associations (YMCAs), Boys and Girls clubs, Federally Qualified Health Centers (FQHCs)) to offer extended health education. Utilizes evidence-based tools and strategies to promote healthier lifestyle and behaviors for the entire family.

\* Indicates the state in which family interviews were conducted.

After institutional review board approval, the selected MMCOs invited families and their children from their initiatives to voluntarily sign-up for one-on-one family interviews. All families that participated and completed one of the five innovative initiatives were eligible to participate. A total of 27 families volunteered and consented to participate in the interviews (Table 2). The interviews included a total of 28 parents or caregivers (e.g., grandparents) and 36 children ranging in age from 5 to 16 years.



Table 2. Overview of Family Interview Participants

Program Name	Food Smart Families	Keep Fit	Kids Healthy Living Program	Healthy Lifestyle Clinic	Join for Me
<b>Number of Interviews</b>	6	6	5	6	4
<b>Number of English Speaking Interviews</b>	6	3	0	2	2
<b>Number of Spanish Speaking Interviews</b>	0	3	5	4	2
<b>Race/Ethnicity of Families Interviewed, (n)</b>	AA, 6	H, 3 AA, 2 A, 1	H, 5	H, 5 A, 1	H, 4
<b>Total Number of Adults</b>	7	6	5	6	4
<b>Total Number of Children in Attendance</b>	10	6	7	6	7

key | AA African American H Hispanic A Asian

## Procedures

The interviews took place in a private space at the clinic where they received care or community center where they had participated in the initiative. All of the interviewed families self-reported that they were of African American or Hispanic background. An interpreter was provided for Spanish speaking families. The interviews (Table 2) lasted between 40 to 60 minutes and families received a \$50 gift card for their time and participation. Semi-structured interview questions were directed primarily to the parent or caregiver (Table 3). Children were encouraged to participate to their degree of comfort. There was no attrition. Saturation was achieved after the twelfth family interview. Despite reaching saturation, all scheduled interviews were honored, recognizing that many families had altered their work schedules and were excited to participate.



Table 3. Semi-Structured Interview Questions and Probes

Interview Questions	Example Probes
1. Please help me understand how you learned about the program.	What were the reasons for choosing to participate?
2. Tell me about your experience participating in the program.	No further probes.
3. On a scale of 1 to 10, with 1 being poor and 10 being excellent, how would you rate the program?  Tell me more about why you would rate it as XX?	Tell me more about what you like about this program?  What would you add to the program [to make it a 10]?
4. What changes have you made since starting the program?	What would assist you in maintaining these changes?  What changes have been made for your child/children and family?
5. What was hard for you about this program?  Tell me more about the program in regards to activities you did not find helpful?	What changes were difficult for you, your child or your family?
6. Overall, help me understand what matters most to you about your family's health?	No further probes.
7. What will you remember most about this discussion?	Is there anything else that you wish I had asked?

The family interviews focused on three primary objectives: 1) capturing the voices of families by highlighting their experiences, perspectives, and preferences; 2) identifying social determinants of health that affect the families' ability to access and maintain their participation in the program; and, 3) identifying opportunities to improve upon initiatives from the perspective of families.

The qualitative technique of member checking was conducted to validate data, analytic categories, interpretations, and conclusions.<sup>15</sup> During the interviews, the researcher restated or summarized information and asked the families to determine the accuracy of the statement. The information collected from each interview was recorded, transcribed verbatim and reviewed. If applicable, interviews were translated, reviewed again, and compared with the other interviews.

## Data Analysis

Data were analyzed using the constant comparison method with three levels of coding.<sup>16</sup> First, data collected from each individual interview underwent open coding (Level I) consisting of sentence-by-sentence examination with substantive codes assigned. Codes that were similar were clustered into concepts that were assigned to categories (Level II). The categories were composed of coded data that formed patterns and were compared with other categories to ensure they were mutually exclusive.<sup>14</sup> Categories were compared to determine fit within a higher-order category (Level III) to identify the thematic codes. The interview data for each family was coded independently and compared. Standard techniques to ensure credibility of the analysis included use of peer debriefing and research team meetings to confirm consensus of the analysis process.

## Results

Six major themes emerged from the interview data based on the families' experiences participating in the childhood obesity initiatives offered by MMCOs. The themes included time, motivation, access, support, approach, and recommendations.

### Major Theme I: Time

Time was a major theme identified in almost every interview conducted. Families shared that the dates, times, and locations of group sessions impacted their ability to participate in the initiatives, requiring them to consider work schedules and child care coverage.

*My schedule [made it difficult to get to the program]... 'cause of my job schedule and they only had two places [to participate in the initiative activities]. - Parent of child participant.*

*The difficulty is the timing. Sometimes, we have one car. - Parent of child participant.*

However, other families felt that the day and time worked for them.

*It was really good timing and it was right after school. - Teen participant.*

*The rest of the group was willing to change the time to make it able for me to come. I was very thankful that everybody in the group was willing to help me move the time. - Parent of child participant.*

Demands and responsibilities impacted families' ability to find time to participate in the healthy activities that they were being taught.

*One other thing that is hard for me is to actually sit down and actually prepare a healthy meal because I'm always on the run. – Parent of child participant.*

*It was hard to keep track at school. Because trying to put an exercise routine in the day and also having to do homework was hard. So, sometimes I would miss days of exercise. – Teen participant.*

Additionally, families indicated that the duration of the initiative was influential in their learning, adopting, and maintaining healthy lifestyle changes. They acknowledged that if the initiative had a shorter duration, the impact of the program would have been less successful.

### *Major Theme II: Motivation*

Of the families interviewed, motivation, within a variety of contexts, was identified as a major theme.

*There's lots of program they always offer but it really just comes down to if you want to attend. If you have a discipline and you want to be here. I really wanted to be here. – Teen participant.*

Those with a family history of chronic conditions (e.g., diabetes) expressed their motivation in leading a healthy lifestyle and changing habits.

*I was afraid that she would get diabetes. That was my major wake-up call, that we were doing something wrong at home. That's my only reason I started to go there because of her. – Parent of child participant.*

*...both sides of my family are big...because I know that from my family's history; from high blood pressure, to cancer, to diabetes. I know that I have to do what I gotta do because if I don't I'll be another one of those statistics just like the rest of them in my family. – Parent of child participant.*

Families discussed overcoming temptations to return back to old behaviors and remain motivated to stick to the program.

*It's just been really hard to substitute that TV for exercise (laughter). – Child participant.*

*At first, it was hard because we had those bad habits. Like with the sodas and the things that I would buy at the grocery store. After awhile, when the kids were putting things in the cart and they'd say, "can we get this, can we get this?" I would be the one to tell them, "sorry, we're not getting it." They would say, "but we used to get it before." I told them, "well, it's different. Now, we know." – Parent of child participant.*

Parents and caregivers frequently identified self-efficacy as a motivating factor to participate in the initiative. They wanted to gain the tools and information needed to affect change in themselves and empower other family members to be more involved in their own health.

*If I don't take care of myself, who will? And then who will take care of my family? – Parent of child participant.*

*My husband and I are very interested in having more information and being healthier and having our kids healthier; especially so that they don't develop any chronic issues. – Parent of child participant.*

Finally, families spoke about their positive feelings associated with the results of participating in the initiatives as a motivating factor to maintain a healthy lifestyle.

*They would say, "whoa, she's losing weight. Is she on a diet? What have you been doing?" I would just tell them, "no, she's just really being careful with what she's eating and she's watching what she's doing." It feels really nice when other people can tell you, "wow, look at her. She's thinner and she looks good." That feels good. – Parent of child participant.*

### *Major Theme III: Access*

Issues around access emerged as another major theme from the perspective of barriers (e.g., money to pay for healthy behaviors). The location of the group sessions impacted family attendance, especially for those with limited transportation resources. Access to healthy foods was also cited as a barrier. The cost of healthy foods made it difficult to select and maintain food choices that nutritional education provided as part of the initiative.

*...they took our food stamps away. So, it's hard trying to eat healthy. It's expensive to eat healthy because fruits and vegetables is not cheap. – Parent of child participant.*

Additionally, parents noted that unhealthy, free school lunches are a barrier for adopting healthy food choices and that the afterschool physical activities are expensive.

*[My son] always wants to do activities but [I don't] find a lot of free programs in the community or something low cost. – Parent of child participant.*

### *Major Theme IV: Support*

Support was identified as a major theme in determining the success of family participation in the initiatives. Support from the initiative educators and the availability of local community resources gave families the extra boost needed to improve the health of their entire family.



*[The instructor] was awesome. She'll call you, even when the class stops. She'll still call you once in a while to ask how you're doing and stuff like that. She asked about how school was. Our conversation doesn't just have to be about losing weight and fitness. – Teen participant.*

Interacting with other families in the initiative provided support and a sense of community.

*I really liked the fact that I had the opportunity to meet other families who are going through the same issues with children. – Parent of child participant.*

Parents also noted that their children felt supported by participating in a group with their own peers.

*You know how big kids are prone to being bullied...he would come home and tell me. With this program, he saw the other kids and was like, "I'm not the only one with this problem." – Parent of child participant.*

Families also felt that they received support in adapting cultural norms that were not aligned with healthy living.

*We're Mexican so we either eat a lot of corn or flour tortillas. And we would just through them very quickly. Now, we've learned to eat without tortillas. They taught us how to make our food without the tortillas. – Parent of child participant.*

Finally, families consistently spoke about their desire to continue the program. They believed that ongoing support would be helpful for staying on track in reaching their goals and facilitating continued learning.

*I would like to have those classes throughout every month, like they continue, not only the sessions that we had. So, she (daughter) could eat, continue, encourage to attend, continue. – Parent of child participant.*

## **Major Theme V: Approach**

An initiative's overall approach in providing information and engaging families was identified in positive terms as contributing to the success of achieving healthy lifestyle goals.

*They make everything in a fun way to be able to remember it and to keep going. They should try making more families happier. – Child participant.*

*The videos were very educational and so was something valuable to me. The instructor that was teaching us how to make the fruits and vegetable recipes was really good too. – Parent of child participant.*

*The experience [keeps me going]. It's not pressuring me to lose weight but slowly persuading me to do good things and try new stuff. – Teen participant.*

The families also shared that the initiative's multi-intervention approach in providing information and tools increased their understanding and awareness of their own behaviors.

*The stuff I was cooking or I was buying...was not good choices and sometimes we think it is but it really wasn't until I got there and they teach us how the things was bad for the kids and how much sugar they have every stuff to show you. That was like a wake-up call for me. I'm like doing bad things at home then I need to do better. – Parent of child participant.*

## Major Theme V: Recommendations

All of the families participating in the interviews provided recommendations on how to increase the programs' capacities by addressing issues of accessibility, frequency, continuity, and location. Many of the families expressed the benefit of a higher frequency of classes to accommodate schedules and offering onsite childcare.

*When they tell you to stick with the food stuff, sometimes its like two months before another class and you slack off. – Parent of child participant.*

The families also suggested integrating technology into the program with phone apps and text messages that are targeted to the parents and kids who have cellular phones.

*Probably put in the phone a reminder and it reminds you every day, "come on. You're on a diet. And it's time to go running." - Teen participant.*

*Always having some kind of reminder...if it was something that could like follow her [daughter] through like monthly to kind of check in and say, "are you doing this? Are you doing that?" I think that would be helpful... something that would come in [to her phone] just kind of check on the progress and give her support. – Parent of child participant.*

## Discussion of Findings

The major themes from interviews provided important insight from families that participated in childhood obesity initiatives offered by MMCOs. The schedule in which the initiative activities were offered, the underlying motivation of the families, their access to affordable foods and physical activities, the support that families received in helping to achieve their goals, the multi-intervention approach, and recommendations to improve the initiatives offered valuable information.

Families from all five initiatives praised the programs and expressed appreciation for the effectiveness of the instructors or clinicians and the inclusive, supportive environment. Almost every family identified several, very

specific examples of changes that they made to their eating, cooking habits, or physical activity. Families conveyed how the initiatives increased their self-efficacy to implement positive changes for themselves and their families.

Families indicated that several factors contributed to the success of the initiative. First, MMCOs that worked with respected community organizations were viewed as credible and trustworthy. Second, it was important that the classes and resources were available in multiple languages for the entire family. For example, several children that participated in the initiatives were bilingual; however, their parents only spoke Spanish. The final contributing factor was the ability of the initiative to teach healthy eating that was adapted to the participant's culture. Repeatedly, families expressed the importance of learning how to adapt their favorite cultural foods with healthier choices rather than completely eliminating them.

Social determinants of health played an important role in a family's ability to participate in the initiative. Lack of reliable access to transportation and availability of childcare were oftentimes barriers that families had to overcome. Through the project's national survey of MMCOs, it was found that addressing social determinants of health (e.g., providing transportation vouchers) increased participation rates in the obesity initiatives.<sup>12</sup> The MMCOs recognized that, to be successful, they needed to identify what was important to families and address the barriers they were facing. Furthermore, listening to families to identify what they needed to initiate and sustain their engagement was an important element in achieving overall success of the initiatives.

## Conclusion

Families who participated in the childhood obesity initiatives found them helpful and endorsed the provision of knowledge and skills in a culturally appropriate manner. Barriers of transportation, access, childcare, and time were identified by families and acknowledged by MMCOs. MMCOs have the ability to provide case management, access to a number of coordinated health services and treatments, utilize clinician referral networks, and complex data analytics to identify high-risk enrollees with obesity. Frequent collaboration with community organizations was a prominent feature of the initiatives highlighted in this project, including partnerships between the MMCOs and local health departments, community organizations, and schools. This level of integration and coordination provided by MMCOs extends the influence beyond what clinicians and stakeholders are currently providing in the childhood obesity prevention space.<sup>17</sup>



## Clinical Priorities

### ***Provide clinician training on motivational interviewing.***

Clinicians, program staff and community providers should have training on motivational interviewing and in recognizing individual and family motivators for lifestyle change. Increasing self-efficacy and acknowledging family progress should be incorporated into program goals.

### ***Provide information and education on the importance and variation of culturally appropriate initiatives.***

Clinicians, community organizations, health plans, and other stakeholders should have access to standardized, evidence-based information and education on how to be culturally appropriate and responsive to the needs of individuals and families when developing, implementing, and refining childhood obesity prevention and treatment initiatives.

### ***Develop patient- and family- centered initiatives.***

Stakeholders should acknowledge that patients and families are a key partner in the successful development and implementation of childhood obesity prevention and treatment programs. Families and patients should have an opportunity to provide ongoing feedback and information based on their experiences, preferences, and values.



## Research Priorities

### ***Explore which program(s)- and system-level contexts support and enable opportunities for feasible scaling-up of these initiatives.***

Additional research is needed to identify programs that are able to be scaled-up beyond local communities to regional areas or nationally. Understanding the context in which programs can and cannot be expanded will support these efforts.

### ***Conduct research on relational, structural, and peer supports.***

Additional research should be conducted on the specific relational, structural and peer supports that families feel are most effective in initiating and maintaining healthy lifestyle change.

### ***Continue to explore the relationship between family- and patient- engagement in the development and refinement of initiatives.***

Additional research is needed to further explore the relationship between family- and patient- engagement in the development and refinement of initiatives specific to culture, language, socioeconomic and educational status, and social determinants of health.



## Policy and Advocacy Priorities

### ***Increase access to healthy food.***

Increase access to healthy food through school lunch programs and programs that reduce overall cost of purchasing healthy food.

### ***Support and expand existing programs that address social determinants of health.***

Reducing barriers associated with social determinants of health will enhance the overall success of childhood obesity prevention and treatment initiatives and improve the overall health and well-being of children and families.

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Prior to publication of the final issue brief, the Institute for Medicaid Innovation sought input from the CHOPT for Medicaid National Advisory Committee as independent clinical, scientific, and policy experts as peer reviewers who do not have any financial conflicts of interest. However, the conclusions and synthesis of information presented in this issue brief do not necessarily represent the views of individual peer reviewers or their organizational affiliation(s).

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