Center for Health Care Strategies

Engaging Youth with Special Health Care Needs and Families of Children with Special Health Care Needs:
Recommendations for Medicaid Agencies

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Contents

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ABOUT THE CENTER FOR HEALTH CARE STRATEGIES

The Center for Health Care Strategies (CHCS) is a policy design and implementation partner devoted to improving outcomes for people enrolled in Medicaid. We support partners across sectors and disciplines to make more effective, efficient, and equitable care possible for millions of people across the nation. For more information, visit **www.chcs.org**.

Introduction

Across the country, Medicaid agencies serve children and youth with special health care needs — two distinct age groups with unique and often challenging health and social needs. To meet those needs, it is critical for Medicaid agencies to meaningfully partner with youth with special health care needs (YSHCN) and families of children with special health care needs (CSHCN).

In recent years, the concept of engaging consumers to guide Medicaid program decision-making has become more prevalent, with definitions of "engagement" varying broadly across organizations and individuals. Though some level of family and consumer engagement has become a growing expectation, how to do it, and the degree to which it could be done, is a ripe opportunity for exploration.[1] YSHCN and families of CSHCN can best speak to the challenges they face when receiving health care supports and services, as well as to the aspects of care that work well for them. Their lived experience can play an invaluable role in shaping policies and programs and in addressing health equity.

Identifying Medicaid Strategies for Effective Family Engagement

In 2019, the Center for Health Care Strategies (CHCS), through support from the Lucile Packard Foundation for Children's Health (LPFCH), sought to explore engagement strategies undertaken by Medicaid agencies in order to identify best practices and opportunities to strengthen family engagement in policy and program development processes.

For this exploration, CHCS used LPFCH's definition of family engagement: *the intentional practice of working with families at all levels — individual, community, and policy — to achieve optimal outcomes in all aspects of health and well-being through the life course*.[2] CHCS conducted a survey of Medicaid agencies to uncover how YSHCN and families of CSHCN were being meaningfully engaged, where agencies experienced challenges with engaging families; how YSHCN and families of CSHCN received compensation for their time; and what strategies Medicaid agencies hoped to deploy in the future to strengthen engagement. In survey design and administration, CHCS sought data on youth with and without SHCN and families with and without CSHCN.

Survey analysis, however, focuses primarily on YSHCN and families with CSHCN in an effort to identify the range of meaningful engagement activities taking place across the country for those populations, as well as gaps that could potentially be filled in the future.

In addition to the survey, CHCS fielded interviews with Medicaid agencies and family-focused organizations specializing in CSHCN to gain a deeper understanding of the agencies' survey responses and the family perspective on meaningful engagement.

This report gleans insights from the survey and interviews to guide Medicaid agencies, families, and funders in strengthening family engagement strategies. The report:

1. Highlights key strategies Medicaid agencies are using to meaningfully engage YSHCN and families of CSHCN;
2. Describes challenges Medicaid agencies face when working to engage YSHCN and families of CSHCN, both before and during the COVID-19 pandemic;
3. Provides recommendations to Medicaid agencies for bolstering and improving engagement mechanisms targeting YSHCN and families of CSHCN; and
4. Offers suggestions for YSHCN, families of CSHCN, and funders for advancing meaningful engagement.

Methodology

To ensure the integration of the family voice throughout this work, CHCS recruited a seven-member Advisory Committee as the first project activity. Committee members included representatives from Family Voices, Family Run Executive Director Leadership Association, YouthMove National, Vermont Agency of Human Services (Medicaid), as well as one YSHCN and two families of CSHCN. The Advisory Committee provided valuable insights throughout the project, helping to shape the survey as well as offering helpful feedback on post-analysis recommendations.

In February 2020, CHCS distributed the survey via email to all 50 state Medicaid directors (see Appendix A for survey questions). Surveys were completed by a range of staff at each agency, including Medicaid directors, deputy Medicaid directors, and policy specialists. Twenty-five of 50 states submitted completed surveys; unfortunately, follow-up to request completed surveys was suspended due to the onset of the COVID-19 pandemic.

Survey Logistics

The survey included 15 questions and took approximately 20-30 minutes to complete. It included a combination of multiple choice and open-ended questions. Survey sections included: Introduction, Demographics, Survey Terminology, Defining Family and Youth Engagement in Your State, and Barriers to Engaging with Families and Youth.

Outreach was conducted to all 50 state Medicaid agencies via email. The email was sent to state Medicaid directors, and asked that they share the survey with staff who oversee consumer engagement within their state's Medicaid program.

To dig deeper into the survey responses, CHCS completed follow-up interviews with six states — **Colorado**, **Connecticut**, **North Dakota**, **Ohio**, **Oklahoma**, and **Rhode Island** — and the **District of Columbia**. Most interviews were conducted with the Medicaid staff member who completed the survey. Additionally, CHCS conducted separate interviews with family-focused organizations in eight states — **Colorado**, **Connecticut**, **Delaware**, **North Dakota**, **Ohio**, **Oklahoma**, **Rhode Island**, and **Texas**. Interviewees

included staff members who are CSHCN family members themselves, work closely with families, and were most familiar with family engagement activities and experiences.

In terms of interview structure, CHCS provided highlights of key survey findings and reminded interviewees that the responses were submitted pre-pandemic. Medicaid interviewees were asked to elaborate on their survey responses, including if any significant changes to those responses had occurred due to the pandemic. Family-focused organizations were asked if the summary of survey responses aligned with the experience of families' engagement with Medicaid in their state.

Interviewees

Medicaid Agencies:
Colorado, Connecticut, District of Columbia, North Dakota, Ohio, Oklahoma, and Rhode Island

Family-Focused Organization:
Colorado, Connecticut, Delaware,[3] North Dakota, Ohio, Oklahoma, Rhode Island, and Texas [4]

For Medicaid agencies, the interviews consisted of questions that gathered additional information on the ways in which YSHCN and families of CSHCN are engaged, effective strategies for engagement, and challenges to engagement (see Appendix B for state Medicaid agency interview questions). Family-focused organizations responded to similar questions and were asked to reflect on whether families with CSHCN feel that their voices are heard (see Appendix C for family-focused organization interview questions).

The interviews with YSHCN and families of CSHCN offered an opportunity to better understand how states were engaging these populations pre-pandemic, and how strategies had changed in response to the pandemic environment. The interviews added a richness to the survey data, creating a more complete picture of: (1) the meaningful partnerships Medicaid agencies and YSHCN and families of CSHCN are aiming to build; (2) how these partnerships were occurring in practice; and (3) the challenges these partnerships are confronting in a post-COVID environment.

Survey Findings

The survey findings help paint a clearer picture of Medicaid engagement of YSHCN and families of CSHCN among a diverse set of states. Findings, outlined below, explore goals for engagement, methods of engagement, engagement challenges, and strategies for improvement. Stakeholders can use these findings to strengthen current engagement activities, guide policymaking that will better meet patient needs, and work toward more equitable health outcomes.

Practices for Engagement

When asked to describe their agency's goal in engaging enrollees, some Medicaid agencies noted providing an opportunity for enrollees to be a part of the decision-making that ultimately impacts the coordination of services and care that they, or a family member, receive. Respondents reported employing a range of practices to achieve this goal. While responses pertaining to specific engagement practices varied by state and population type, three-fourths of respondents indicated that their agency participated in a formal engagement process. Agencies were most likely to have systematized engagement with families of CSHCN, while processes for engaging YSHCN were less common. This theme, prioritizing family over youth engagement, prevailed throughout the survey.

Exhibit 1. Medicaid Practices for Enrollee Engagement, by Population

ENGAGEMENT PRACTICE	FAMILIES OF CSHCN	YSHCN
Enrollees serve in a general advisory capacity on boards/bodies that address broad issues beyond issues specific to CSHCN populations. Enrollees represent issues and concerns beyond their own personal experiences.	76%	45%
Enrollees serve as representatives on select advisory committees and task forces related to specific issues, conditions, or CSHCN populations. Enrollees primarily share their own personal experiences.	71%	45%
Enrollee engagement is part of the program culture — it is expected and institutionalized with clear guidelines.	59%	34%
Enrollees are in leadership roles to partner with program staff in decisions related to program planning and policymaking.	48%	21%
Agencies obtain input from enrollees through general surveys or satisfaction surveys, but families do not participate directly in any program activities.	7%	10%

Engagement Strategies

State Medicaid agencies typically target their engagement efforts to reach YSHCN and families of CSHCN, using a variety of high- and low-touch strategies to connect and recruit participation. Many of the activities, described below, are delivered in partnership with family organizations, managed care organizations, and/or sister agencies (e.g., other state government agencies).

Exhibit 2. Medicaid Strategies to Engage Enrollees, by Population

ENGAGEMENT STRATEGY	FAMILIES OF CSHCN	YSHCN
Public notices with opportunities to provide input	85%	63%
Representation on general Family Advisory Committee	74%	41%
Surveys/satisfaction surveys	70%	33%
Representation on advisory committee specific to CSHCN	67%	41%
Partnerships with family or youth organizations	63%	41%
Focus groups	59%	37%
Provide input through agency website	56%	37%
Provide input through social media	52%	33%
Representation on advisory committee specific to children	52%	26%
Medicaid staff who are representatives of YSHCN	37%	15%
Structured interviews	26%	7%
Enrollment representatives as external consultants	22%	11%

Challenges in Engaging Families and Youth

While agencies reported ongoing engagement activities, they also expressed significant challenges in maintaining their engagement processes. The most cited challenges fell into two categories: (1) recruitment, representation, and retention; and (2) agency resource constraints. Medicaid agencies indicated similar challenges in engaging both youth and family, with or without SHCN.

Exhibit 3. Engagement Challenges Identified by Medicaid Agencies

CHALLENGE	FAMILIES OF CSHCN	YSHCN
Difficulty recruiting representation across geographic areas and/or remote areas	67%	56%
Lack of resources/methods to pay participants for time/expense	67%	63%
Participant time constraints	56%	48%
Difficulty identifying participants	52%	52%
Difficulty recruiting culturally diverse families	52%	41%
Limited staff resources for engagement	48%	48%
State budget limitations for consumer activities	41%	41%
Lack of staff time to train and/or supervise participants	41%	41%
Limited access to participants – no direct services provided	33%	33%
Difficulty recruiting youth or families to participate in committees	33%	33%
Difficulty providing flexibility for participants' schedules	33%	26%
Lack of training for enrollees to support them in their roles	30%	30%
Difficulty keeping participants involved over time	26%	22%
Consumers unable to use technology and/or social media for engagement	26%	26%
Difficulty recruiting enrollees to participate in more general issues beyond population or condition-specific committees	26%	22%

Strategies to Address Engagement Challenges

Medicaid agencies use a range of strategies to alleviate engagement challenges for YSHCN and families of CSHCN. Forty-eight percent of responding agencies reported implementing at least one strategy at the time of the survey to overcome engagement barriers. Reported strategies varied, as shown below, and informed our recommendations.

Exhibit 4. Strategies to Address Engagement Challenges, Ranked by Usage (Highest to Lowest)

RANK	STRATEGIES
1	• Creative use of technology and/or social media to engage target population (48%)
2	• Payment to participants for time/expense (40%)
3	• Targeted efforts to recruit enrollees to participate in committees (36%)
4	• Targeted efforts to recruit culturally diverse enrollees (32%) • Targeted efforts to recruit representation across geographic areas and/or remote areas (32%) • Targeted efforts to increase knowledge/support of leadership about the value of engagement (32%)
5	• Providing increased flexibility for enrollees' schedules (28%)
6	• Training for participants to support them in roles (24%)
7	• Use of staff time to train and/or supervise participants (16%)
8	• Addressing legislative or administrative oversight limitations in entering contracts with other agencies or non-state agencies (12%)
9	• Addressing state budget limitations (4%)

Benefits of Engagement

To better understand the impact of engagement on improving policies and programs, CHCS asked state Medicaid agencies how they evaluate the impact of involving enrollees in agency program design and decision-making. Over half of responding states do not employ any evaluation method. Of the states that evaluated engagement activities, the most common tools were: (1) internal self-assessments; and (2) enrollee satisfaction surveys. Even with few to no formal evaluation methods in place, Medicaid agencies anecdotally shared that they benefitted from enrollee engagement, as listed below.

Exhibit 5. Benefits of Enrollee Engagement as Experienced by Medicaid Agency, Ranked by Agency Identification of Benefit (Highest to Lowest)

RANK	BENEFITS
1	• Increased awareness and understanding of issues experienced by enrollees (96%)
2	• Improved planning and policies resulting in services more directly responsive to enrollee (81%)
3	• Increased focus on evaluating program goals, objectives, and performance measures (63%) • Improved relationship that elevates partnership with enrollee (63%)
4	• Increased understanding by legislature and state officials of the impact of programs and issues on enrollees (59%)
5	• Increased health literacy among general public in understanding programs and issues (52%)
6	• Increased availability of enrollees to engage in training, public awareness, and policy development activities (48%) • Increased agency responsiveness to federal requirements (48%)

Opportunities to Improve Engagement

Finally, CHCS wanted to understand how Medicaid agencies would change engagement strategies if all barriers were removed. Respondents generated a list of changes to improve engagement, centered around establishing a strong framework and process for relationships, feedback, and evaluation. About half of states indicated an interest in improving engagement with both YSHCN (52%) and families of CSHCN (56%). Sixteen percent of states responded that even if engagement challenges lifted, they would not make any changes to their programming.

Exhibit 6. Proposed Changes to Engaging Enrollees if Barriers were Removed, by Population

STRATEGY FOR IMPROVEMENT	FAMILIES OF CSHCN	YSHCN
Increase enrollee feedback in specific areas or related to specific issues or conditions	64%	68%
Establish/strengthen relationships with family organizations in the region/state	56%	48%
Establish evaluation methods for extent, impact, and effectiveness of enrollee involvement	48%	52%
Develop other methods to support enrollee consultants for participation on advisory groups, committees, task forces, and work	40%	44%
Seek out or provide training and/or technical assistance for enrollees	36%	36%
Explore methods to financially compensate enrollee consultants for participation on advisory groups, committees, task forces, and work	32%	32%
Seek out or provide training and/or technical assistance for Medicaid leadership and staff on the importance of enrollee involvement in the program	28%	28%
Include enrollees in program evaluations	28%	36%
Include requirement for enrollee engagement in contracts or grants for service provision with other agencies	24%	28%
Hire one or more enrollees as staff in the program	16%	20%
None at this time	12%	16%

Interview Findings: Key Themes

Several themes emerged for fostering meaningful engagement between state Medicaid agencies and YSHCN and families of CSHCN through CHCS' interviews. Medicaid agencies reported that engaging in these activities leads to stronger policymaking to meet the needs of YSHCN and families of CSHCN, and results in better and more equitable health outcomes. The following section explores these themes.

Effective Medicaid leaders, as perceived by family-focused organizations' staff, have a firm understanding of the value of youth and family engagement, are committed to incorporating family voice at all junctures, and participate in meetings where family voice is central.

Families noted that highly involved leaders from Medicaid often had a personal connection to working with families. In one instance, a past Medicaid director participated in a residency that required him to do a home visiting and advocacy rotation. The family representatives noted that this rotation shaped the Medicaid director's understanding of what parents, especially those with CSHCN, go through daily, which spurred him to be more attentive to families' needs and concerns. In another state, the Medicaid director called for an in-person meeting in response to negative feedback from families, and when some were unable to attend the in-person meeting, the Medicaid director conducted home visits.

Truly understanding a parent/caregiver's day-to-day life can help Medicaid agencies more effectively value and prioritize family voice and family engagement opportunities.

When families feel as though their voices are truly valued and heard, they are more likely to attend family advisory meetings and provide their insights. At one family organization, representatives stated that parents/caregivers appreciate the opportunity to share personal stories with Medicaid leadership. In turn, they feel Medicaid is more responsive to families' needs and requests.

> **"A balance of empathy and understanding of parents' daily realities comes from truly hearing families' day-in-the-life stories.**
>
> *- Family Representative Interviewee*

Medicaid leadership indicated that hearing families' day-to-day experiences impacted their work positively. Several states explicitly make time to learn about YSHCN and

families of CSHCN. In one state, Medicaid leadership incorporated new opportunities for families to share their care maps after being inspired by one mother's story. The mother had shared her child's care map, which showed the complexity of care that she manages daily to keep her child healthy. Medicaid leadership found this so impactful that they now encourage families to share care plans during family advisory meetings to deepen leadership's understanding. During those meetings, Medicaid representatives listen to the family's story, which is followed by a question-and-answer period and an opportunity to seek suggestions from others.

By carving out time for families to share their personal journeys, Medicaid agencies learn more about what YSHCN and families of CSHCN face each day, and youth and families can voice their needs and concerns. Enrollees and Medicaid agencies both benefit from this intentional, dedicated time. As one interviewed family organization noted, "empathy is key" to building and sustaining productive, authentic relationships.

Medicaid can signify the value of family engagement by providing compensation to family advisory members.

Compensation, whether in the form of a stipend, childcare, meals, or otherwise, enables enrollees to engage when they otherwise may not be able to and demonstrates that their time is valued. According to the survey, 40 percent of responding Medicaid agencies offer some form of compensation to families of CSHCN for their participation, but 67 percent of Medicaid agencies surveyed face challenges in adequately compensating families for their time. In addition, 63 percent of Medicaid agencies lack resources for fully compensating YSHCN and families of CSHCN.

A reliable feedback loop between Medicaid agencies and family representatives encourages prolonged engagement and mutual trust.

Family representatives stated that if their feedback and needs are heard and they subsequently see policy changes, however small, they feel motivated to continue providing their input. During early stages of engagement, family representatives reported feeling hopeful about providing Medicaid with their feedback and sharing their needs. Unfortunately, due to bureaucratic barriers or resource constraints,

"[Medicaid staff] can hear it and it might touch them, but if they don't do anything on Monday morning, when they go back to work … then it is a waste of everyone's time.

- Family Representative Interviewee

states often are not able to take immediate action in response to families' feedback. As a result, states often see families' enthusiasm for engagement begin to wane. Medicaid agencies can help prevent a breakdown in trust by being transparent about barriers. A representative from a family organization noted that if a Medicaid representative can explain why a policy is in place and cannot be changed, families are more understanding and experience less frustration with the engagement process.

Families also indicated appreciation for opportunities to influence policy. In one state, Medicaid directly seeks out family feedback related to policy at Family Advisory Committee meetings. In turn, families feel that they have had a significant positive impact in this area. In another state, family organizations provide specific trainings on understanding state policy to empower families and encourage them to offer input.

Communication is key to maintaining a successful relationship between families and Medicaid.

States with comprehensive communication plans seemed to be able to better maintain engagement with families of CSHCN. Some states had success with emailed newsletters while others had a consistent presence on social media. Regardless of the chosen platform, interviewees indicated that the effort to develop a successful pipeline of communication with enrollees and their families was greatly appreciated, especially by those who were not able to attend meetings with Medicaid.

> **We should be at the table from the very beginning, not when they develop a program and need help … It should be all the time, across the board when things are good, when things are bad.**
>
> *- Family Representative Interviewee*

In conversations with family organizations, representatives noted that having a point person at Medicaid whom youth and/or families may call in the event of a question or concern helped maintain trust in the Medicaid team. Families of CSHCN reported that turnover within state Medicaid agencies caused frustration but knowing a specific person who would consistently answer or return their call was helpful. Two states highlighted the success of having peer-to-peer support models or having peer representatives employed by Medicaid who are responsible for fielding questions from family members, since families are more confident in their peers' understanding of their situation.

Amid a public health emergency, Medicaid agencies learned a lot about the usefulness of virtual family engagement.

Family organizations indicated that families benefitted from Medicaid's swift transition to a virtual platform for family engagement. Some family representatives highlighted the increased ease of access for those from rural communities who would have otherwise had to travel long distances. Families with medically fragile children could participate in family advisory meetings without having to leave their child. In some cases, Medicaid agencies noted that attendance increased significantly when family advisory meetings were offered online due to COVID. One state saw attendance of its Spanish-speaking advisory meetings increase in attendance size and duration. This served as an opportunity for Spanish-speaking families to contribute during advisory committee meetings while also finding community among each other during a particularly isolating time. As a result, this state's Medicaid agency has hired additional bilingual staff to fulfill this increased desire for engagement.

One drawback to virtual family advisory meetings noted by Medicaid and family representatives alike is that the more formal structure of virtual engagement decreases opportunities to bond, network, and engage on a personal level. The example below, however, indicates that the ability to pivot based on family feedback can help ease these concerns.

At the beginning of the pandemic, one Medicaid agency received significant pushback from its family advisory group around the format of virtual family advisory meetings. The meetings had changed to a webinar format and did not allow family members to participate in the conversation — leaving them to receive one-way communication only. After receiving the feedback, the agency restructured the family advisory meetings to 10 small work groups instead of a larger webinar. Families shared they feel heard in this restructured virtual set-up.

In addition to family advisory meetings moving online, Medicaid agencies have responded to other needs during the pandemic, which has helped build trust. Several state Medicaid agencies began to host special calls where they answered families' questions related to coverage during these uncertain times. When interviewed, family and Medicaid representatives both indicated new appreciation for telehealth visits as well. While some families do not intend to use telehealth once it is safe to visit their

providers in person, other families, particularly those with CSHCN or multiple children, welcomed the opportunity to meet with a provider from home. When balanced with in-person visits, families have indicated that Medicaid should continue to honor telehealth visits in certain circumstances.

Challenges

While many states are committed to meaningfully engaging YSHCN and families of CSHCN, common challenges still exist. Following is a synthesis of challenges described in survey responses and follow-up interviews.

Lack of a standardized understanding of the term "engagement."

As noted previously, the term "engagement" can have different meanings depending on the audience. Even with the best of intentions, there is often a disconnect between how state Medicaid agencies define engagement and what it means to YSHCN and families of CSHCN. YSHCN and families of CSHCN are more likely to operate with a broader and more inclusive definition of engagement, where they see themselves being able to thoughtfully partner with Medicaid agencies at all levels (e.g., policy level, governance level, community level). Most Medicaid agencies, however, currently use Advisory Committees as the main vehicle for engagement and do not necessarily take the more advanced step of engaging family members in actual policy discussions.

Difficulties recruiting and engaging YSHCN and families of CSHCN from culturally diverse backgrounds.

Many states reported challenges in recruiting and engaging YSHCN (41%) and families (52%) of CSHCN from culturally diverse backgrounds as well as remote and rural locations. The majority are deeply aware of the need to be more inclusive in recruitment and avoid drawing from the same small pool of YSHCN and families of CSHCN. States, however, struggle to identify effective recruitment strategies. As noted earlier, some states took advantage of the new virtual opportunities amid the pandemic and reported being able to reach individuals they could not interact with in person prior to the pandemic — such as enrollees living in rural communities and enrollees who are primarily Spanish-speakers.

> **Family engagement is much more successful when there's a community worker assisting the family. They need to feel supported, prepared, and engaged.**
>
> *- Family Representative Interviewee*

Turnover of Medicaid agency staff and leadership who champion family engagement.

Some state Medicaid agencies and family-focused organizations reported changes in momentum around engagement due to staff and/or leadership turnover at the Medicaid agency. If a staff member who had been the driving force behind engagement activities moved on, it could be challenging to identify another staff member to take those efforts on and hiring for new personnel could take time. Engagement activities with YSHCN and families of CSHCN often occurs in silos, making it difficult for someone to simply step in because staff in other departments do not necessarily know details about the work.

Lack of adequate funding to support family engagement activities.

Some Medicaid agencies indicated a desire to increase the number of staff responsible for engagement work but noted a lack of funding to support additional positions. Additionally, some agencies noted challenges in providing YSHCN and/or family representatives of CSHCN with adequate compensation for their time and expertise (e.g., stipends, travel reimbursement, meals during meeting times), again because of funds not being allocated for this purpose.

> **In a perfect world [family representatives] would have a full team of folks; to some degree, families would probably rather reach out to a community group…rather than reaching out to the state for assistance.**
>
> - *Medicaid Agency Representative Interviewee*

Recommendations

Survey data and interviews demonstrated that state Medicaid agencies have a strong desire to engage YSHCN and families with CSHCN. Furthermore, states have made progress in strengthening their meaningful engagement practices over the years by partnering with and listening to YSHCN and families of CSHCN.

The data, however, also show that more improvements need to be made to work toward fully integrating YSHCN and families of CSHCN into the fabric of the agencies. The following recommendations — for Medicaid agencies, YSHCN and families of CSHCN, and funders — offer opportunities for all three groups to come together to further advance engagement strategies, shape policies and programs, and ensure that both health outcomes and engagement practices are equitable and inclusive.

Recommendations for Medicaid

Establishing and maintaining more meaningful engagement processes will support policies that are more person- and family-centered and have a positive impact on quality, costs, and enrollees' well-being. Medicaid agencies have made significant strides in recent years in effectively engaging YSHCN and families of CSHCN but could make further changes, that are not extremely resource intensive. For example:

1. ***Establish a collaborative environment for YSHCN and families of CSHCN that is intentionally structured to build mutual trust.***

It is imperative for Medicaid agencies to work with YSHCN and families of CSHCN to establish a collaborative environment where relationships are nurtured, mutual trust is present, and YSHCN and families of CSHCN feel valued. If that occurs, the partnerships will become natural and authentic, and will lend themselves to long-term, sustainable engagement. That sustainable engagement will inform the development of more person- and family-centered policies. Medicaid agencies can build trust by systematically checking in (e.g., establishing a consistent feedback loop) with youth and family advisors and representatives and refining engagement strategies based on their input. Additionally, offering training, onboarding, coaching, and compensation will ensure that representatives of YSHCN and families of CSHCN understand their roles and are able to participate effectively, further ensuring sustainability.

2. Place diversity and equity at the center of engagement strategies.

It is critical to have representation from populations of color on advisory committees, working groups, task forces, etc. It is worthwhile to dedicate staff time and resources to do the more intensive recruitment needed to identify a rich and diverse group. Notably, many states reported being able to leverage virtual opportunities created by the pandemic environment to reach more individuals and have been encouraged by the uptake. For some states, conducting outreach and providing a virtual option for participation can yield much more diverse and rich representation. In addition, it is important to consider cultural and linguistic competencies when partnering with youth and families. Understanding deeply rooted cultural needs and preferences can help Medicaid agencies better connect with YSHCN and families of CSHCN and will lead to more sustainable and meaningful engagement.

3. Partner with community-based and family-focused organizations (e.g., Family Voices and other advocacy groups) to strengthen connections and build relationships.

These important organizations help Medicaid agencies better understand and reach YSHCN and families of CSHCN in communities of color, rural communities, and other geographic areas that are often untapped, such as tribal communities. Additionally, they can support Medicaid agencies to onboard and train YSHCN and families with CSHCN so they can participate effectively and confidently on advisory boards.

Community-based and family-focused organizations could also partner with Medicaid staff in the design of trainings and development of resources that may help build capacity around engagement and enhance understanding of the value of the family voice.

4. Consider opportunities to build more significant partnerships with YSHCN.

The findings in survey responses and interviews revealed that YSHCN are largely left out of engagement activities, resulting in a missed opportunity and an untapped resource. Therefore, Medicaid agencies could review their Advisory Committee membership to ensure that there are YSHCN representatives and seek out their unique perspectives and experiences. Community-based groups such as YouthMove could support Medicaid agencies in identifying YSHCN representatives to participate, and in developing youth-

specific trainings to build their capacity around effective participation, policy development, storytelling, etc.

5. Prioritize evaluation of engagement strategies.

Meaningful and sustainable engagement requires evaluation. In partnership with YSHCN and families of CSHCN, Medicaid agencies could work to establish consistent process and dashboard measures that help determine how outcomes of engagement strategies and activities are shaping and changing policies and practices within the agency, as well as impacting Advisory Committee recruitment and retention. Developing clear benchmarks for what successful engagement will look like (e.g., number of YSHCN and families of CSHCN sitting on advisory boards, number of new partnerships formed with community-based organizations, number of activities completed in partnership with YSHCN and families of CSHCN, types of changes and improvements made as a result of input from YSHCN and families of CSHCN) will be useful for comparing progress from year to year, as well as for explaining the return on investment to leadership, funders, and other stakeholders.

6. Integrate engagement into strategic plans and mission/vision/value statements.

Medicaid agencies can demonstrate a high level of commitment to engaging youth and families by integrating a focus on engagement into strategic plans and mission/vision/values statements. In doing so, they could partner with YSHCN and families of CSHCN to create a shared understanding and refine language that is included in these foundational state documents. Incorporating a clear commitment to family engagement into agency guidance can serve as a roadmap for these efforts well into the future. Publicly committing to these values can help ensure that family voices are heard and can create a consistent platform to support family engagement at the state level, regardless of staff turnover.

7. Assess policies and practices in partnership with youth and families.

Even with the best of intentions, it can be challenging to take a step back and examine policies that have been in place for years and consider alternatives. Medicaid agencies could partner with YSHCN and families of CSHCN to review policies that may create unintentional barriers to meaningful engagement and reshape them to be more open and inclusive.

Recommendations for YSHCN and Families of CSHCN

YSHCN and families of CSHCN have a vital role to play in shaping policies within Medicaid. The recommendations below may make the partnership with Medicaid staff more effective, and lead to more person- and family-centered policies:

1. Be collaborative and flexible.

Advisory Committee meetings are a time to have conversations about services provided by Medicaid agencies, and an opportunity to think about growth and change. The work will be most productive if everyone is open to looking for solutions and being flexible.

2. Remember that meaningful change takes time.

When working in partnership, progress may seem slow at times. Significant changes — especially when they involve shifts in culture and long-standing processes — do not happen overnight.

3. Be honest about your needs, preferences, and experiences.

It is important for YSHCN and families of CSHCN to speak up if something is not working for themselves or their family and know that their perspectives are valuable and needed.

4. Request a peer mentor.

Pairing new YSHCN and families of CSHCN representatives with current Advisory Committee members to serve in a peer mentor role is valuable. A peer mentor can help new Advisory Committee members better understand their role, responsibilities, and expectations. Mentors could also be tapped to offer training and coaching to new members. Family-focused organizations, such as Family Voices, can serve as a resource for identifying peer mentors and also for training, coaching, and other tools to support effective participation.

Recommendations for Funders

Survey data and interviews revealed that Medicaid agencies often cannot take engagement activities as far as they would like due to staffing and resource constraints. Therefore, there is a role for funders to play in supporting Medicaid agencies in their efforts, especially through community-based organizations. For example, funders could provide grants to community-based organizations to:

1. ***Support YSHCN and families of CSHCN in efforts to partner with Medicaid through stipends and other forms of compensation.***

Offering transportation reimbursement, childcare, and meals at meetings are essential to ensuring that YSHCN and families of CSHCN can fully participate in engagement activities.

2. ***Recruit YSHCN and families of CSHCN for Medicaid Advisory Committees and ensure diversity and inclusion.***

Community-based organizations have a deep understanding of the cultural needs and preferences of YSHCN and families of CSHCN and are well positioned to identify and recruit individuals from diverse communities.

3. ***Coach and support YSHCN and families of CSHCN to help them effectively participate in engagement activities.***

Community-based organizations are equipped to offer the time and attention needed to coach and support YSHCN and families of CSHCN, which is essential for them to feel comfortable in their roles.

4. ***Develop tools to help YSHCN and families of CSHCN build capacity to contribute to engagement activities.***

Community-based organizations can help YSHCN and families of CSHCN strengthen and refine their roles as partners by providing education and training resources.

Conclusion

Medicaid agencies across the country are considering ways to improve engagement with YSHCN and families of CSHCN. Family organizations also report a strong desire to improve communication with their state Medicaid agencies. In some states, these processes are standardized and functioning well, whereas others have a desire to improve their efforts but lack adequate resources and knowledge to foster engagement.

Despite the immense loss and difficulty that the COVID-19 pandemic presented, this time of social distancing provided an opportunity to increase virtual engagement between Medicaid, YSHCN, and families of CSHCN. Families and Medicaid agencies alike endorse their desires to continue virtual and phone engagement opportunities, even when groups are permitted to gather in person again.

The recommendations above, directed at Medicaid agencies, YSHCN and families of CSHCN, and funders can spur meaningful change for Medicaid, youth, and family partnerships, driving toward sustainable engagement and more person- and family-centered policies with a lasting impact on outcomes, quality, equity, and cost.

ENDNOTES

[1] J. Zhu and R. Rowland. *Increasing Consumer Engagement in Medicaid—Lessons from States*. December 2020. https://www.ohsu.edu/sites/default/files/2020-12/Increasing%20Consumer%20Engagement%20in%20Medicaid%20-%20Learnings%20from%20States%2012.14.20.pdf.

[2] Lucile Packard Foundation for Children's Health. Webinar "California Children with Special Health Care Needs and Their Families. Current Issues and Challenges Facing Our Most Vulnerable Population." March 2019.

[3] Note that Delaware Medicaid did not complete the survey. However, an Advisory Committee member recommended CHCS talk to Family Voices Delaware given the organization's successful history of partnering with Medicaid to discuss best practices and lessons learned.

[4] Texas Medicaid completed the survey, but CHCS was unable to secure an interview with a Medicaid staff member.

Appendices

Appendix A. Medicaid Survey: Meaningfully Engage Families of Children with Special Health Care Needs in Medicaid Policy Making and Program Design

CHCS Center for Health Care Strategies, Inc.

Medicaid Survey: Meaningfully Engage Families of Children with Special Health Care Needs in Medicaid Policy Making and Program Design

Section I: Introduction

We invite you to complete this survey to help identify how state Medicaid agencies are engaging beneficiaries and families, especially those that have children with special health care needs (CSHCN). The survey is administered by the Center for Health Care Strategies (CHCS) on behalf of the Lucile Packard Foundation for Children's Health.

Meaningful and ongoing youth and family engagement within Medicaid can lead to: (1) greater patient and family satisfaction with health care; (2) increased consumer understanding of how health care benefits and coverage works; (3) improvements in health outcomes; and (4) consumer-driven enhancements in health service design. Engagement can include consumer input on specific issues, representation on groups, and/or partnership in leadership activities. Through this survey, CHCS will get a rich picture of how Medicaid agencies across the nation are approaching consumer engagement, with a focus on best practices as well as challenges. After survey results are synthesized, CHCS will nationally disseminate a summary of findings distilling state trends and opportunities to strengthen consumer engagement activities.

***Survey notes*:**

Audience: Medicaid staff who oversee consumer engagement within their state's Medicaid program.

Contact Information: Individual survey responses are confidential; responses will be reported in the aggregate. If you are willing to participate in a phone interview to provide more detail and/or clarification, please provide your contact information.

Completion Time: Approximately 15-20 minutes.

Deadline: Please complete the survey by COB on 2/25/20.

If you have any questions, please contact Courtney Roman, CHCS Senior Program Officer, at CRoman@chcs.org.

Section II: Demographics

1. Please enter your contact information.

Name

Title

Department

E-mail Address

Phone Number

* 2. In which state Medicaid agency do you work?

State/Province -- select state --

* 3. The Center for Health Care Strategies will follow-up with a subset of states regarding survey responses. May we contact you after the survey?

- Yes
- No

Section III: Survey Terminology

Following are terms used throughout the survey:

Children with Special Health Care Needs (CSHCN; also SHCN): Children who have, or are at-risk for, a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (*Maternal and Child Health Bureau*).

Family Engagement: Working with families at all levels – individual, community, and policy – to achieve optimal outcomes in all aspects of health and well-being through the life course. Family engagement ensures that parents and caregivers are engaged as full-partners in the planning and implementation of health care policies, programs, and individual service plans (*Lucile Packard Foundation for Children's Health*).

Youth Engagement: Partnership between youth and adults whereby power is shared, respective contributions are valued, and young people's ideas, perspectives, skills and strengths are integrated into the design and delivery of programs, strategies, policies, funding mechanisms and organizations that affect their lives and their communities. Youth engagement recognizes and seeks to change the power structures that prevent young people from being considered experts in regard to their own needs and priorities, while also building their leadership capacities (*Youth Power*).

Section IV: How Do You Define Family and Youth Engagement in Your State?

* 4. The following statements describe common ways that Medicaid agencies engage beneficiaries. Please check all that apply for how your agency engages with the beneficiary types listed.

Please note: For beneficiary types listed, "families" and "youth" refer to general beneficiary population, while "families of youth/children with SHCN" and "youth with SCHN" refers specifically to the special health care needs population.

	Families	Families of Children/Youth with SHCN	Youth	Youth with SHCN
Beneficiaries are in leadership roles to partner with program staff in decisions related to program planning and policy-making.	☐	☐	☐	☐
Beneficiary engagement is part of the program culture -- it is expected and institutionalized with clear guidelines.	☐	☐	☐	☐
Beneficiaries serve as representatives more broadly and in a general advisory capacity, beyond specific issues, conditions, or CSHCN populations. Beneficiaries represent issues and concerns beyond their own personal experiences.	☐	☐	☐	☐
Beneficiaries serve as representatives on select advisory committees and task forces related to specific issues, conditions, or CSHCN populations. Beneficiaries primarily share their own personal experiences.	☐	☐	☐	☐
We obtain input from beneficiaries through general surveys or satisfaction surveys, but families do not participate directly in any program activities.	☐	☐	☐	☐
We have no formal ways of including beneficiaries at this time.	☐	☐	☐	☐

Other/Please provide additional detail:

Section IV: How Do You Define Family and Youth Engagement in the Context of Your State?

* 5. What is your Medicaid program's goal in engaging beneficiaries? If you engage both family and youth, please provide your program's rationale.

* 6. What is your Medicaid program's goal in engaging beneficiaries with SHCN? If you engage both family and youth, please provide your program's rationale.

* 7. How does your state engage families and beneficiaries? This question provides a range of engagement activities. Please check all that apply for how you engage the beneficiary types listed.

	Families	Families of Children/Youth with SHCN	Youth	Youth with SCHN
Surveys/Satisfaction Surveys	☐	☐	☐	☐
Focus Groups	☐	☐	☐	☐
Structured Interviews	☐	☐	☐	☐
Methods to Provide Input Through Social Media	☐	☐	☐	☐
Methods to Provide Input Through Agency Website	☐	☐	☐	☐
Partnerships with Family or Youth Organizations	☐	☐	☐	☐
Beneficiary Representatives on General Advisory Committee	☐	☐	☐	☐
Beneficiary Representatives on Advisory Committee Specific to CSHCN	☐	☐	☐	☐
Beneficiary Representatives on Advisory Committee Specific to Children	☐	☐	☐	☐
Beneficiary Staff who are Representatives of Youth with SHCN	☐	☐	☐	☐
Beneficiary Representatives as External Consultants	☐	☐	☐	☐
Public Notices with Opportunities to Provide Input	☐	☐	☐	☐

Other/Please provide additional detail:

* 8. If your state's Medicaid agency is partnering with beneficiary representatives, please describe the methods used to recruit participants.

Examples: Advertising upcoming events via social media, asking providers for recommendations, holding public recruiting events, etc.

* 9. Does your state's Medicaid agency facilitate beneficiary participation in engagement activities through monetary or other supports? If so, please describe below.

Examples: Providing childcare at activities, transportation, gift cards, etc.

* 10. Has your Medicaid agency experienced any of the following benefits from beneficiary engagement? Please select all that apply.

	Select to indicate yes.
Increased Awareness and Understanding of Issues Experienced by Consumers	○
Improved Planning and Policies Resulting in Services More Directly Responsive to Beneficiary Needs	○
Increased Health Literacy in Understanding of Programs and Issues by Legislature and State Officials	○
Increased Health Literacy in Understanding of Programs and Issues by General Public	○
Additional Funding for Programs	○
Improved Relationship that Elevates Partnership with Beneficiary	○
Increased Availability of Beneficiaries to Engage in Training, Public Awareness, and Policy Development Activities	○
Increased Agency Responsiveness to Federal Requirements	○
Increased Focus on Evaluating Program Goals, Objectives, and Performance Measures	○
Improved Clinical Outcomes	○

Other/Please Provide Additional Detail:

* 11. How does your Medicaid program evaluate the impact of involving beneficiaries in agency program design and decision-making? Please check all that apply for the beneficiary types listed.

	Families	Families of Children/Youth with SHCN	Youth	Youth with SHCN
No Evaluation Methods at This Time	☐	☐	☐	☐
Comprehensive Approach to Evaluation with Standardized Indicators of Beneficiary Involvement Across Agency Programs	☐	☐	☐	☐
External Review/Assessment by Beneficiaries, Advisory Groups, or Family Organizations	☐	☐	☐	☐
Internal Self-Assessment	☐	☐	☐	☐
Data from Outside Organizations	☐	☐	☐	☐
Beneficiary Satisfaction Survey	☐	☐	☐	☐

Other/Please provide additional detail:

Section V: Barriers to Engaging with Families and Youth

* 12. Does your state's Medicaid agency face challenges in engaging beneficiaries?

○ Yes

○ No

Section V: Barriers to Engaging with Families and Youth

Please answer to the best of your ability.

* 13. What specific barriers or challenges to consumer engagement has your Medicaid program experienced? Please check all that apply for the beneficiary types listed.

	Families	Families of Children/Youth with SHCN	Youth	Youth with SHCN
Consumers Unable to Use Technology and/or Social Media for Engagement (Outreach, Input, Meeting Participation, etc.)	☐	☐	☐	☐
Difficult in Identifying Participants	☐	☐	☐	☐
Limited Access to Participants - No Direct Services Provided	☐	☐	☐	☐
Lack of Resources/Methods to Pay Participants for Time/Expense	☐	☐	☐	☐
Lack of Staff Time to Train and/or Supervise Participants	☐	☐	☐	☐
Lack of Training for Participants to Support Them in Roles	☐	☐	☐	☐
Participant Time Constraints	☐	☐	☐	☐
Difficulty Providing Flexibility for Beneficaries' Schedules	☐	☐	☐	☐
Difficulty Recruiting Representation Across Geographic Areas and/or Remote Areas	☐	☐	☐	☐
Difficulty Recruiting Culturally-Diverse Families	☐	☐	☐	☐
Difficulty Recruiting Youth or Families to Participate in Committees	☐	☐	☐	☐
Difficulty Recruiting Beneficiaries to Participate in More General Issues Beyond Population or Condition-Specific Committees	☐	☐	☐	☐
Difficulty Keeping Beneficiaries Involved over Time	☐	☐	☐	☐
State Budget Limitations for Consumer Activities	☐	☐	☐	☐
Limited Staff Resources for Engagement	☐	☐	☐	☐
Lack of Knowledge/Support from Leadership About the Value of Engagement	☐	☐	☐	☐
Legislative or Administrative Oversight Limitations in Entering into Contracts with Other Agencies or Non-State Agencies	☐	☐	☐	☐
State Employee Limitations Hindering Advocate Role	☐	☐	☐	☐

Other/Please provide additional details:

* 14. What strategies has your Medicaid program developed to address the above challenges, if any? Please select all that apply.

	Select to indicate strategies used.
Creative Use of Technology and/or Social Media to Engage Target Population	◯
Payment to Participants for Time/Expense	◯
Use of Staff Time to Train and/or Supervise Participants	◯
Training for Participants to Support Them in Roles	◯
Providing Increased Flexibility for Beneficiaries' Schedules	◯
Targeted Efforts to Recruit Representation Across Geographic Areas and/or Remote Areas	◯
Targeted Efforts to Recruit Culturally Diverse Beneficiaries	◯
Targeted Efforts to Recruit Beneficiaries to Participate in Committees	◯
Addressing State Budget Limitations	◯
Targeted Efforts to Increase Knowledge/Support of Leadership About the Value of Engagement	◯
Addressing Legislative or Administrative Oversight Limitations in Entering into Contracts with Other Agencies or Non-State Agencies	◯

Other/Please provide additional detail:

* 15. If there were no barriers or challenges to consider, what changes related to engaging beneficiaries would you make in your agency over the next 12 months? Please check all that apply for the beneficiary types listed.

	Families	Families of Children/Youth with SHCN	Youth	Youth with SHCN
None at This Time	☐	☐	☐	☐
Increase Consumer Feedback in Specific Areas or Related to Specific Issues or Conditions	☐	☐	☐	☐
Hire One or More Beneficiaries as Staff in the Program (Directly or Through a Contract With Another Agency)	☐	☐	☐	☐
Explore Methods to Financially Compensate Beneficiary Consultants for Participation on Advisory Groups, Committees, Task Forces, and Work Groups	☐	☐	☐	☐
Develop Other Methods to Support Beneficiary Consultants for Participation in Advisory Groups, Committees, Task Forces, and Work Groups	☐	☐	☐	☐
Establish/Strengthen Relationship with Family Organizations in Our Region/State	☐	☐	☐	☐
Include Requirement for Beneficiary Engagement in Contracts or Grants for Service Provision with Other Agencies	☐	☐	☐	☐
Establish Evaluation Methods for Extent, Impact, and Effectiveness of Beneficiary Involvement	☐	☐	☐	☐
Seek out or Provide Training and/or Technical Assistance for Beneficiaries (e.g. How to Be Effective Partners with CSHCN, How to Participate in Policy-making, Leadership)	☐	☐	☐	☐
Seek out or Provide Training and/or Technical Assistance for Medicaid Leadership and Staff on the Importance of Beneficiary Involvement in the Program	☐	☐	☐	☐
Including Beneficiaries in Program Evaluations	☐	☐	☐	☐

Other/Please provide additional detail:

Appendix B. Interview Guide: State Medicaid Agencies

OVERVIEW

Through funding from the Lucile Packard Foundation for Children's Health, the Center for Health Care Strategies (CHCS) is developing a paper that will identify how state Medicaid agencies are engaging beneficiaries and families, especially those who have children with special health care needs, and ways in which they can strengthen their consumer engagement activities.

To inform the paper, CHCS disseminated a survey to all fifty state Medicaid agencies (in February 2020) with a series of questions regarding engagement activities and agencies self-reported on their efforts. In conjunction with the national survey, CHCS intends to interview several state Medicaid agency representatives in addition to family-focused organizations to provide perspective on both delivery and receipt of family engagement activities. Upon completion of the survey and interviews, CHCS intends to disseminate a summary of findings to a national audience distilling state trends and opportunities to strengthen consumer engagement.

INTERVIEW QUESTIONS

Current Engagement Process

- In what ways do you engage beneficiaries and families with children with special health care needs?
- Do you feel that you have been successful in engaging both families and beneficiaries?
- What has been the most effective strategy to engage beneficiaries and their families? (For example, through social media, advisory committees, etc.).
- What challenges and barriers have you faced in engaging beneficiaries and their families?
- How has COVID changed strategies or outcomes of engagement?
- Can you share a story that highlights the benefit of engaging beneficiaries or families?

Reflections and Recommendations

- What resources would you say you need to help you do more in terms of consumer engagement, particularly for children with special health care needs and their families?
- Do you have any relationships with family organizations in your state who deal specifically with children with special health care needs and their families? Have you ever partnered with those organizations to think through additional strategies of engagement?
- Have you had any opportunities to speak with other states about their engagement strategies for this specific population?
- Are there particular activities or strategies you would like to try in the future?

Appendix C. Interview Guide: Family-Focused Organizations

OVERVIEW

Through funding from the Lucile Packard Foundation for Children's Health, the Center for Health Care Strategies (CHCS) is developing a paper that will identify how state Medicaid agencies are engaging beneficiaries and families, especially those who have children with special health care needs, and ways in which they can strengthen their consumer engagement activities.

To inform the paper, CHCS disseminated a survey to all fifty state Medicaid agencies (in February 2020) with a series of questions regarding engagement activities and agencies self-reported on their efforts. In conjunction with the national survey, CHCS intends to interview several state Medicaid agency representatives in addition to family-focused organizations to provide perspective on both delivery and receipt of family engagement activities. Upon completion of the survey and interviews, CHCS intends to disseminate a summary of findings to a national audience distilling state trends and opportunities to strengthen consumer engagement.

INTERVIEW QUESTIONS

Discussion of State Survey Results

- First, we will provide a broad overview of the ways that your state Medicaid agency indicated (through our survey process) that they engage with beneficiaries and families with children with special health care needs.
- How does that align with your experience or what you hear from family members that engage with Medicaid in the ways described previously? How do the families you work with describe their experiences with your state Medicaid agency?

Reflections and Recommendations

- What seems to be working well in terms of Medicaid's engagement with beneficiaries and families with children with special health care needs—specifically from your perspective representing a collective family voice? Where are the gaps?
- How has the COVID-19 pandemic impacted engagement? Are things better or worse in that regard? Has your state's Medicaid agency been innovative or creative in terms of reaching beneficiaries and families as a result?
- Do the families you work with feel that their voices are heard and that they are able to provide input surrounding their needs? If not, what would you suggest that your state's Medicaid agency do to improve the flow of information from beneficiary/family to state Medicaid agency?
- Are the families you work with able to drive policy that reflects their needs at your state's Medicaid agency?
- What do you or the families you work with wish Medicaid knew?
- Can you provide an example of a time where a beneficiary or their family truly felt that their voice was heard or their needs were met through engagement with the state Medicaid agency?