

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

TAKEAWAYS

- Meaningful partnerships with youth with special health care needs (YSHCN) and families of children with special health care needs (CSHCN) can help Medicaid agencies better support youth and families in meeting their goals for improved health and well-being.
- With support from the Lucile Packard Foundation for Children's Health, the Center for Health Care Strategies (CHCS) sought to understand the range of engagement strategies being used by Medicaid agencies across the country to support these populations.
- CHCS conducted a 50-state survey and interviews with select states and family-focused organizations to identify benefits of engagement, strategies used to meaningfully engage YSHCN and families of CSHCN, and challenges states face when trying to engage YSHCN and families of CSHCN.
- Themes from the survey and interviews point to clear opportunities for Medicaid agencies, YSHCN and families of CSHCN, and funders to strengthen and sustain engagement.

LEARN MORE

To read the full report, visit:

www.chcs.org/family-engagement.

Medicaid agencies across the nation are considering ways to improve engagement with YSHCN and families of CSHCN. Family organizations similarly want to improve communication with their state Medicaid agencies. Following are select themes from a survey of states and interviews with state and family organizations that uncovered current engagement practices and opportunities for improvement.

Survey

- 75% of Medicaid agencies participate in a formal engagement process. Agencies are most likely to have systematized engagement with families of CSHCN, while processes for engaging YSHCN are less common.
- 74% of Medicaid agencies include families of CSHCN on general Family Advisory Committees and 41% include YSHCN representatives on general Family Advisory Committees.
- 63% of Medicaid agencies have established partnerships with community-based family and youth organizations, yet 67% of Medicaid agencies report a lack of resources/methods to pay families of CSHCN for their time and 56% lack resources/ methods to pay YSHCN.
- The top two benefits of meaningful engagement with families of CSHCN and YSHCN for Medicaid agencies are increased awareness and understanding of issues experienced by enrollees (96%) and improved planning and policies resulting in services more directly responsive to enrollees needs (81%).

Interviews

- State agencies report that robust engagement leads to stronger policymaking to meet the needs of YSHCN and families of CSHCN, and results in improved and more equitable health outcomes. In addition, understanding a parent/caregiver's day-to-day life can help Medicaid better value and prioritize family voice and engagement opportunities.

- 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.
- Medicaid can signify the value of family engagement by providing compensation to family advisors.
- Consistent communication and a reliable feedback loop between Medicaid agencies and family representatives encourages prolonged engagement and mutual trust.

Recommendations for Strengthening Youth and Family Engagement

The following recommendations — for Medicaid agencies, YSHCN and families of CSHCN, and funders — offer opportunities for all three groups to advance engagement strategies, shape policies and programs, and ensure that health outcomes and engagement practices are equitable and inclusive.

Recommendations for Medicaid

- Establish a collaborative environment for YSHCN and families of CSHCN focused on mutual trust.
- Place diversity and equity at the center of engagement strategies.
- Partner with community-based and family-focused organizations (e.g., Family Voices and other advocacy groups) to strengthen connections and build relationships.
- Consider opportunities to build more significant partnerships with YSHCN.
- Prioritize evaluation of engagement strategies.
- Integrate engagement into strategic plans and mission/vision/value statements.
- Assess policies and practices in partnership with youth and families.

Recommendations for YSHCN and Families of CSHCN

- Be collaborative and flexible.
- Remember that meaningful change takes time.
- Be honest about your needs, preferences, and experiences.
- Request a peer mentor.

Recommendations for Funders

- Support YSHCN and families of CSHCN in efforts to partner with Medicaid through stipends and other forms of compensation (e.g., transportation reimbursement, childcare, etc.).
- Recruit YSHCN and families of CSHCN for Medicaid Advisory Committees and ensure diversity and inclusion.
- Coach and support YSHCN and families of CSHCN to help them effectively participate in engagement activities.
- Develop tools to help YSHCN and families of CSHCN build capacity to contribute to engagement activities.

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.