Meaningful Engagement in Medicaid: Strategies for Partnering with Youth with Special Health Care Needs and Families of Children with Special Health Care Needs

July 27, 2021
1:00-2:00pm ET (10:00-11:00am PT)

Made possible through support from the Lucile Packard Foundation for Children’s Health.
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Welcome and Introduction
Remarks from the Lucile Packard Foundation for Children’s Health
Medicaid Family Engagement: 50-State Survey and Interview Findings
Connecticut Medicaid and Family Engagement Efforts
Q&A
Meet Today’s Presenters

**Courtney Roman, MA**
Senior Program Officer
Center for Health Care Strategies

**Allison Gray, MA**
Senior Program Officer
Lucile Packard Foundation for Children’s Health

**Nanfi Lubogo, CCHW, CTC, YMHFA**
Co-Executive Director
PATH Connecticut

**Kate McEvoy, JD**
Director, Division of Health Services at Connecticut Department of Social Services
Remarks from the Lucile Packard Foundation for Children’s Health

Speaker: Allison Gray, MA, Senior Program Officer
Lucile Packard Foundation for Children’s Health

Allison Gray, Senior Program Officer
Family Engagement
Families as full partners at all levels
Family Engagement

Lived experience

Improved services & systems
Meaningful Family Engagement

- Recruitment and Selection
- Training and Orientation
- Mentoring and Support
- Networking
- Assessment and Feedback
THANK YOU.
About the Center for Health Care Strategies

A nonprofit policy center dedicated to improving the health of people with low incomes.
Goal: Understand how Medicaid agencies meaningfully engage youth with special health care needs (YSHCN) and families with children with special health care needs (CSHCN)

Funder: Lucile Packard Foundation for Children’s Health

Activities:
- 50-state survey to assess meaningful engagement of YSHCN and families with CSHCN
- Interviews with select states and family-focused organizations to better understand landscape
Project Interviews

- Medicaid agency interviews sought to gain a deeper understanding of the meaningful engagement strategies occurring in the states.

- Family-organization interviews compared their experiences with engagement to what Medicaid agencies reported in the survey.

**Interviewees**

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

**Family-Focused Organization:** Colorado, Connecticut, Delaware, North Dakota, Ohio, Oklahoma, Rhode Island, and Texas.
Survey Findings
## Top Engagement Strategies

<table>
<thead>
<tr>
<th>Engagement Strategy</th>
<th>Families of CSHCN</th>
<th>Youth with SHCN</th>
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<tbody>
<tr>
<td>Public Notices with Opportunities to Provide Input</td>
<td>85%</td>
<td>63%</td>
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<tr>
<td>Representation on General Family Advisory Committee</td>
<td>74%</td>
<td>41%</td>
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<tr>
<td>Surveys/Satisfaction Surveys</td>
<td>70%</td>
<td>33%</td>
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<tr>
<td>Partnerships with Youth or Family Organizations</td>
<td>63%</td>
<td>41%</td>
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Positive Impact of Meaningful Engagement

- **Increased awareness** and understanding of issues experienced by enrollees (96%)
- **Improved planning and policies** resulting in services more directly responsive to enrollees (81%)
- **Increased focus on evaluating** program goals, objectives, and performance measures (63%)
- **Improved relationships** that elevate partnership with enrollees (63%)
## Common Engagement Challenges

<table>
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<tr>
<th>Challenge</th>
<th>Families of CSHCN</th>
<th>Youth with SHCN</th>
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</thead>
<tbody>
<tr>
<td>Difficulty recruiting representation across geographic areas and/or remote areas</td>
<td>67%</td>
<td>56%</td>
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<tr>
<td>Lack of resources/methods to pay participants for time/expense</td>
<td>67%</td>
<td>63%</td>
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<td>Participant time constraints</td>
<td>56%</td>
<td>48%</td>
</tr>
<tr>
<td>Difficulty identifying participants</td>
<td>52%</td>
<td>52%</td>
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Key Themes and Effective Engagement Strategies

- Most states make a good-faith effort to meaningfully engage YSHCN and families with CSHCN.
- However, there are areas ripe for improvement.
- The following strategies were most effective:
  - Strong support and buy-in from Medicaid leadership around engagement
  - Authentic understanding of the value of the youth and family voice
  - Well-established feedback loop and mutual trust
  - Additional opportunities for engagement that arose from the pandemic
Connecticut Medicaid and Family Engagement Efforts

Speakers:
Nanfi Lubogo, CCHW, CTC, YMHFA, Co-Executive Director, PATH Connecticut
Kate McEvoy, JD, Director, Division of Health Services at Connecticut Department of Social Services
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Learn More


- Available on our website, [chcs.org/family-engagement](http://chcs.org/family-engagement)