

Q&A: Moving from Spending to Investment: A Research Agenda for Improving Health Care Financing for Children and Youth with Special Health Care Needs

Below are responses to questions the panel was unable to answer during the webinar.

Respondents

- Jeff Schiff, MD, MBA
- Christopher (Chris) Stille, MD, MPH

Q&A

Research Agenda

Where can we find potential research partners/funders in our state to explore possible research?

Jeff: Some states have health care foundations that may be interested. If Medicaid moves to a value-based payment model, they could be a partner in assuring that quality measures are implemented. Family Voices is a partner that could make sure research is geared to outcomes that are important to families.

Will the research also address the role of pediatrics, and specifically CYSHCN, in helping to reduce the overall total cost of care?

Jeff: Total cost of care is a challenge when looking at CYSHCN because some populations (e.g., those with technology dependence) will be more expensive. Some cost avoidance can be evaluated but cannot be the only driver towards improvements.

Alternative Payment Models

How do you bring health care organizations to the table with payors to talk about value-based payment options for CYSHCN when these patients often have frequent and protracted (and expensive) hospitalizations due to the complexity of their diagnoses?

Jeff: In any value-based payment (VBP) model for children with medical complexity, the relationship of the provider and insurer will need to be integrated to be successful – for both sides to understand each other. VBP should at a minimum offer CYSHCN families intensive care coordination including integration of outpatient and inpatient care. It is important to focus the conversation on the benefits for the family of care coordination and integration (in health care and across systems) and the benefits for the providers (e.g., less burn out, more satisfaction).

A VBP payment model could include full capitation but would involve creating a risk corridor for the capitated entity so that if a single child is very expensive, the vast majority costs switch back to the insurer. On the “lighter” side, a VBP with a fully integrated care coordination model that is paid on a per member per month basis could start with these payments to set up a system and measure outcomes (pay to play) and then move to making some of the outcomes (avoidable hospitalizations) a quality incentive process.

Our state is holding provider groups and health plans accountable to sustainable health care cost growth targets. In addition to value-based payments, do you see opportunities in reducing costs, specifically in the CYSHCN population?

Chris: There may be greater opportunities for small, individual cost reduction with higher prevalence conditions such as asthma and attention-deficit/hyperactivity disorder (ADHD). Episodic high-cost encounters are harder to predict and may require new insights incorporating human-centered design.

Jeff: In addition, 1) some costs are outside the health care sector and need to be considered – in a population with social and relational risk, early intervention may reduce costs, and 2) there need to be more opportunities to negotiate with insurers - calculation of health care growth targets must consider the costs that are within the control of the provider and those that are not. New genetic therapies, for instance, are not and should be taken out.

How do you account for the natural history of many children's diseases, which may be incurable and lead to deteriorating health status, within payment models--so you don't have unrealistic expectations around prevention of Emergency Room visits and hospital stays?

Chris: Medical complexity, which drives high cost, tends to be comprised of rare conditions with episodes of outlier costs from year to year. The proposed research examining financial data is likely best carried out with large data sets.

Jeff: The issues around hospice and palliative care should be researched and defined for this population. On a subpopulation level, children with life-limiting conditions should be analyzed differently than other children.

Do you have any new research that provides information on whether or not Patient-Centered Medical Home practices are improving health care financing for CYSHCN?

Chris: No new research that I am aware of, although Patient-Centered Medical Home literature has been heavily slanted to adult practices and stymied by considerable variation in definition and operations.

Jeff: This article might be helpful: [Costs and Use for Children With Medical Complexity in a Care Management Program](#).

Family Experiences

How will you address the changes families experience when moving between health plans? Children and youth with complex medical needs often move between private-only, private + public + education system services, multiple private plans + education system services, and multiple private plans only.

Chris: This is a very interesting question and would be good to investigate. Perhaps a case series and/or interview study would be a good way to start.

How do you address the challenges of transitioning to adulthood and navigating the thorough lack of understanding some providers have regarding the journey CYSHCN and their families have traversed?

Chris: For research ideas, I would refer to this article from the supplement: [Improving Health Care Transitions for Children and Youth With Special Health Care Needs](#).

Are we missing measuring the value of the families' contributions throughout the life course and the cost of not investing adequately in family support (e.g., poorer health outcomes for the parents/caregivers)? If so, how can we begin to address these experiences with measurement?

Chris: This is a very important but hard to study topic. Developing consistent, objective methods of measuring family contributions would be a good way to start.

Jeff: This article might be helpful: [Research on Family Health and Children and Youth With Special Health Care Needs](#).