

Q&A: A Conversation on Protecting Rights of Children with Medical Complexity in an Era of Spending Reduction

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

Respondents

- **Jane Perkins, JD, MPH**, Legal Director, National Health Law Program
- **Edwin Simpser, MD**, President and CEO, St. Mary's Healthcare System for Children

Q&A

What do you believe are the real barriers to having pediatric criteria from State/Federal Levels?

Dr. Simpser: I believe that the population of children with medical complexity is still relatively small and “flies under the radar” as compared to the numbers and costs of geriatric care. I have experienced, both at a State and Federal level, some interest in moving forward and both times the champions left their government positions and the dollars were not available to complete the process. I also think that service providers are so busy just trying to “stay alive” that they spend most of their state advocacy resources on reimbursement issues.

How can we get more oversight for states that mandate changes for our CSHCN that create unequal access to care?

Dr. Simpser: I think you will need to engage local legal advocacy practices/groups to assist in this process. However, at times this may end up at the level of the Federal Department of Justice, which may or may not be willing to “take on” the particular state.

What does one do if your state is non-responsive?

Jane: The state Medicaid director has the legal duty to make sure that that the Medicaid provisions and protections are enforced. If that is not happening, there are a number of steps you can take, including: (1) write a letter to the state detailing the problems and proposing solutions; (2) discuss the problems with the media; (3) discuss the problems with members of your state legislature, suggesting that they hold a hearing or commission a report; (4) ask that the subject be added to the agenda of the Medicaid Medical Care Advisory Committee (a committee mandated in each state by the Medicaid Act to provide policy advice to the state Medicaid agency); and (5) work with disability rights advocates who are representing children who need services to identify problems, propose solutions, and if necessary and proper file a legal action.

Are you leaving room at the table for pediatric private duty nurses to speak out?

Dr. Simpser: Almost all the advocacy and research efforts I have seen or participated in have integrated families and various providers including home care and private duty nurses. I believe the leaders in this field are very sensitive to the need to be family centered and multi-disciplinary

Are interpretation/translation services an EPSDT benefit?

Jane: Yes. Medicaid laws and policies identify language services as a covered benefit.

Is EPSDT a federally-protected funding (not affected by budget cuts) for children with special healthcare needs?

Jane: Yes. EPSDT is a mandatory Medicaid services for most children and youth under age 21. As such, it is part of the Medicaid entitlement, meaning that states are entitled to receive federal funding for the services rendered through the program and Medicaid-eligible children are entitled to coverage for the services and activities included in the benefit.

What are your thoughts on ways to engage physicians in the appeals process/advocacy process with Medicaid Managed Care companies? Often, physicians are either not willing to participate in the appeals process or do not feel comfortable doing so. Often these appeals involve a peer-to-peer (physician-to-medical director) conversation.

Dr. Simpson: This is a significant challenge. I do not have an adequate response to offer. The AAP is trying to educate physicians through its Section on Home Care and Council on Children with Disabilities, along with local efforts by many Districts and Chapters. Physicians need to be better educated on what is going on with their patient and these processes. Not every practice is set up to serve this population. Physicians with an interest in this population may utilize nurse care coordinators to help manage the needs of the kids and families. Those coordinators can play an integral role in helping physicians navigate the insurance process and ensure they are well informed during the appeal process. In terms of engaging physicians – I think we have to start during residency in training young physicians and stimulating their interest in this population.

Dr. Simpson referenced a recent HRSA grant working to establish evidence-based research on medically complex children. What is the name of the grant? Who are the participants? What is the timeline?

Dr. Simpson: The project is headed by Dr. Chris Stille and Dr. Jay Berry. It is called the “Children and Youth with Special Health Care Needs National Research Network”. Please see: cyshcnet.org for details.