

Q&A: A Conversation on Supporting Self-Management in Children and Adolescents with Complex Chronic Conditions

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

Respondents

- **Amy Houtrow, MD, PhD, MPH**, Chief, Division of Pediatric Rehabilitation Medicine and Vice Chair of Physical Medicine and Rehabilitation, Children's Hospital of Pittsburgh and University of Pittsburgh Medical Center
- **Avani Modi, PhD**, Professor of Pediatrics and Director, Center for Adherence and Self-Management, Cincinnati Children's Hospital Medical Center

Q&A

Can you give more information on the Shared Plan of Care?

Amy: I would use this publication by the Lucile Packard Foundation for Children's Health, "[Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs](#)".

Can Dr. Modi share what "barrier checklist/tool" she uses?

Avani: I can provide some examples of barriers checklists that we have used at Cincinnati Children's Hospital. These can be adapted based on disease/treatment. There are also some tools that we have used to address barriers, that families helped us create. These are based on the evidence-based literature for adherence.

- [Barriers to Immunosuppressants](#)
- [Barriers to Rheumatology Treatments \(Caregiver Version\)](#)
- [Barriers to Rheumatology Treatments \(Patient Version\)](#)
- [Barriers to Sickle Cell Management](#)
- [Remembering to Take Medication](#)
- [Learning to Swallow Pills](#)
- [Making Medication Taste Better](#)
- [Taking Medication in Public](#)

There are also several transition checklists online by disease that nicely spell out the skills that can be learned over time. Here is [one example](#).

How do you have inpatient teams accept that children and youth have a right to have a say, especially if they can understand their condition and finding a mental health provider who is experienced in medical trauma to be part of a multidisciplinary team?

Amy: This is challenging for sure. Skilled mental health providers are hard to find because they are in such short supply.

If you are a pediatrician in a clinic assessing a child with chronic health conditions, how are you able to assess and possibly find solutions to barriers in a 20-minute visit. Often find that we do not have enough time to address barriers. Do you have any suggestions?

Amy: I find asking about goals for the visit up front helps shape the visit. If I have a goal that the family doesn't mention, I offer it after they state their goals. This is a place where the rest of the clinical staff might be able help.

Do you have examples of one or two specific ways for a child to manage an aspect of a chronic medical condition? Are there ways to modify that tool for a younger child or one that has no fine motor ability, etc.?

Amy: I start asking my patients around the age of 5 to tell me their medications just like they learn their address and phone number. For children who have poor motor skills, I expect them to be able to guide another person in doing the task such as doing glucose checks. Breaking down the tasks into small steps that can be learned and mastered is key.