



FA Connect: Question & Answer Transcript

Session Title: Coloring Outside the Lines - Creative Solutions to Educational Barriers for Children with Chronic Illness

Invited Speakers: Sarah Steinke and Valerie Theile, Cincinnati Children's Hospital Medical Center

Session Air Date: October 7th, 2021

Access a recording of thier presentation by vising www.fanconi.org. The recording has been uploaded with Spanish subtitles.

Have additional questions for the speaker? Email Sarah Steinke directly at sarah.steinke@cchmc.org and Valerie Theile at vtheile@nwlsls.org

Q: What are your suggestions for helping children work through the social aspects of having these educational plans and do you suggest pushing a child to use these plans even if they don't want to?

A: Sarah: We always say that the parents know their child better than anyone else. It is very important that you advocate for what his best for your child and maybe don't push him into anything he isn't needing or ready for. Although if a child goes through a major medical event such as a transplant, they may need to learn to accept the extra help the school provides.

A: Valerie: I thought I would address if the child decides to go to college. The universities will offer similar plans to help students succeed. So the child will need to decide as they get older when they are ready to accept these plans and they might decide to create these plans for when they need them.

Q: Do you often see stigmatization in the hospital or as a liaison with teachers and classrooms?

A: Valerie: The key thing to remember is that everybody has something they are dealing with. I think helping kids understand that there are kids with various mental health disorders, speech issues or various health conditions.

A: Sarah: Often kids have a lot of anxiety about going back to school. It can be helpful to have a team get together to figure out what aspects of school are the source of their anxiety. Sometimes it can help to show the class an informational video on the medical event the child is recovering from, like a transplant. This way the class can ask questions before the child comes back to the classroom. Also putting together educational flyers can also give the classroom time to learn and ask questions before the child returns to the classroom.

Q: Would you recommend that parents set up these educational plans even if their child doesn't need them or should they wait till their child needs the assistance?

A: Valerie: I would recommend setting up a health plan with the school but would wait to establish the individual plan till the child needs that assistance. It is important to think about the least restrictive environment (refer to the slides). I do recommend having a conversation with the school up front about the child's situation even if you don't intend to set up any of the additional plans.

Q: Are kids at a certain age able to be part of the IEP planning process?

A: Valerie: We've seen kids start joining the process usually in middle school. I think it is important to have them be part of the conversation. Some kids might struggle to sit through the whole process and have to listen to adults talk about all their challenge. I think 14 is the legal age to start including them in the conversation. Adding them to the process can help with they start transitioning to adulthood too. Helping them learn about advocacy is also very important. We want people to grow up and be independent human beings and not be dependent on their parents for their whole lives.