

Questions, Responses:

Should trauma-informed care extend to families during transition?

- When an organization or your practice is trauma-informed, it will impact everyone who walks through your door. Families, patients, staff, and yourself. The values of trauma-informed care are Safety, Trust/Transparency, Peer Support, Collaboration, Empowerment, and Cultural/Historical/Gender Understanding. Supporting families in a trauma-informed way could look like being transparent with family members about what a typical healthcare transition has looked like in the past, creating a plan with them not for them about what that transition process will be and a timeline, etc., or finding ways to connect them to peers who are also going through the healthcare transition process
- Debbie Harris responded to this question verbally and talked about the need for psychological counseling care during the transition. You may have to re-listen to get her exact words, which can be found at minute 46:24 in the recording.

Early in the presentation information on surveys/research showing provider and individuals' perspectives on HCT. There were percentages of different disciplines' participation in the process -- I am wondering if there were child life specialists involved? Given the inherent developmental challenges of adolescence, I am curious why these protocols start at 12yrs and not 10yrs (as we seek to maximize a child's inherent curiosity)?

- To answer the first question, yes if a health system has child life specialists available, they are involved in the HCT process being developed.
- We have seen a study that 10-year-olds were not very interested in transition as 12-year-olds were. This study led us to starting this at the age of 12. However, you can start this at any age, and it is very individualized. Transition is a lot for families to handle, so even at 12 you say “congrats” to families. They made it here and over the next 10 years we are going to work on transition.
- Please see the references below from Patience presentation:
 - [White PH, Cooley WC; Transitions Clinical Report Authoring Group; American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians. Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. Pediatrics. 2018;142\(5\):e20182587 | Pediatrics | American Academy of Pediatrics \(aap.org\)](#)
 - [Outcomes of Pediatric to Adult Health Care Transition Interventions: An Updated Systematic Review - ScienceDirect](#)
 - [Outcome Evidence for Structured Pediatric to Adult Health Care Transition Interventions: A Systematic Review - ScienceDirect](#)

We worked on an organization-wide transition policy at our institution but now it makes her think about how she has a transition policy within her own department and how do you keep all those straight?

- It is very hard, the larger the system you work in the more you should have one, and everyone agrees on it.

If a patient is a chronic/complex care patient the first transition should be to an adult PCP so they can be aware and even assist with transitioning the other services the patient needs?

- Yes, ideally transferring to an adult PCP first is most helpful.
- From Tori Bahr, MD: I think there are really 2 ways that you can look at this one and it is dependent on the diagnosis and patient needs. I think most important is that you lay out what the options are to the family and make an informed decision about what makes sense.
 - For some disease processes there may be very specific places that they can get care or the needs are so specialized that the principal adult specialist for this condition may have built collaborative working relationships with PCPs. In that case, it could be beneficial to transition the specialty care first and then they can refer to those PCPs they work best with.
 - For most patients however, I find that transitioning the PCP first is preferable because adult PCPs are more familiar with the adult subspecialists than the pediatrician is. Then the adult PCP is able to curate a team around a patient that they work well with and that they communicate well with. The goal is not to just find the right adult providers. The goal is to find the right team of providers that work well together.

When you have a cognitively impaired patientt, do you recommend the transition assessments be done with the parent? Would you still start at age 14?

- In general, a young person with cognitive challenges and their family may need more time to move through the process so giving them the time and starting around age 14 to give them a chance to plan was recommended by the families we worked with youth who had cognitive challenges.
- From Tori Bahr, MD: The Got Transition Transition Readiness Assessment and many other types of Readiness Assessments have both an assessment for the child and an assessment for the parent. In that case I would still start at 14 to start the conversation and to identify those areas that maybe a child with cognitive impairment could learn or be a goal through their IEP.

There are so many barriers to youth accessing healthcare, and we need to build capacity for adult providers who are knowledgeable and ready to provide youth centered care. Are there any resources or strategies that are being implemented to help address bias youth may face when transitioning to an adult practice?

- By prioritizing trauma-informed care practices, this includes addressing cultural, historical, gender, racial bias. Understanding our own explicit and implicit biases is a critical component of trauma-informed care. If we do not start the process of addressing these biases in ourselves, our practices, and our organization, we are not fully engaged in trauma-informed care. Connecting with health equity leaders in your organization, if you have any, is a great first step. Also, encouraging healthcare providers to see themselves as less of a leader in their patient's care and

more of a collaborator with the family. This will help to uplift and center families' voices and experiences, as well as hopefully give less space for provider bias.

- From Tori Bahr, MD: agree wholeheartedly with the need to build capacity of knowledgeable adult providers. Some of our future sessions will address this need and build skills around it. We encourage you to promote this ECHO session to adult providers as well. As for addressing bias, there is an upcoming CME event at Gillette that continues this conversations: Disabled Not Disposable: <https://www.gillettechildrens.org/get-involved/attend-an-event/2023-disabled-not-disposable-a-health-equity-conference#:~:text=Disabled%20Not%20Disposable%20is%20a,care%20for%20patients%20with%20disabilities.>

Is there any professional/medical association that can or already work on developing a group of providers who are interested in providing care to young adults? Young adults with complex medical needs?

- Yes, we need this. Certainly, there is much discussion about this. The Chloe Barnes Rare Disease Advisory Council is looking at this as well.
- From Tori Bahr, MD: Many professional organizations do have a section or special interest group that addresses Healthcare Transition. Sometimes it is a Transition specific special interest group but sometimes it is part of another subset. For example, the Council on Children with Disabilities in the American Academy of Pediatrics.

Could you utilize my kids chart to send reminders?

- Using a patient portal to send reminders is an excellent way to remind folks about transition.

If we have any experts in our ECHO group that have expertise in the below questions, please let us know your thoughts!

Could you utilize a child's SSA through their developmental disability board?

Are there any insurance plan folks in this ECHO? If so, could you chime in on the availability of managed care, care coordination?

Sharing Chat Comments that may be helpful:

- The 6 Core Elements from Got Transition have been very helpful for our Agency. At Piedmont Health Services and Sickle Cell Agency we have built a transition program around the 6 Core Elements.
- I love the suggestion about talking about transition from the day that they are born. I strongly agree with this. In rehabilitation therapies we talk about "planning for discharge at the evaluation." I think that it is critical that we ensure that the pediatric patients we care so well for

so many years receive excellent care during and after medical transition. We have the duty as providers to help those kids "finish well" through their pediatric years and transition successfully into adulthood.

- The discussion spoke volumes on the importance of having one plan across a larger system (such as what Patience White recommended).
- I think it is much easier to find pediatric providers for youth who have chronic/complex needs vs adults and then if you add Medicaid it makes it even more challenging. That is why it is important to begin having these conversations early with caregivers and trying to help them understand that it is going to take time and won't be overnight.
- It's incredibly difficult to find a provider who is interested in this age group and even more so, post pandemic as systems seems to be more stressed
 - Not only is it difficult to find providers interested, but adult clinical systems don't seem to be set up to support young adults.
- Involvement with vocational rehab (through their IEP) might be a better route than the school IEP team
 - We had school nurses on the call and the school nurses are rockstars! School nurses are trying to figure out how to help our 18-22 years old with higher medical and mental health needs.
 - Connecting the school with additional support and services with the transition is helpful when looking at coordinating transition activities.
 - As a Transition School Nurse, I can see a strong role for school nursing, in helping families with this transition. Unfortunately, all districts do not staff Transition health in the same ways, so there is lots of variation in the ability of school nurses to aid students in this way with care management.