Q&A: A Family-Centered Research Agenda for Improving Health Care Transitions for Children with Special Health Care Needs

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

Respondents

- Megumi (Megie) Okumura, MD, MAS
- Ifeyinwa (Ify) Osunkwo, MD, MPH
- Mallory Cyr, MPH

Q&A

Can you talk about balancing the need to standardize care and have a "plan" in place for CYSHCN with the need to provide individualized, patient-centered care? What have your own experiences with that been like?

Ify: Providers need a guide to follow. If there is no plan in place for transition, then nothing is done. We recommend a broad, standardized template/approach/protocol for ALL CYSHCN that can then be individually modified for each patient as needed. This allows for programs to be evaluated for quality-of-care delivery. An example of a broad framework is the Six Core Elements of Health Care Transition. Providers may need to further define what "transition readiness assessment" tool should be used for the conditions they manage and what care plan template works well for their population.

Megie: As a primary care internist, understanding the "life course" and treatment preferences of the patient is critical to ensuring a continued, long-term, and healthy relationship with the patient and caregivers. Figuring out what the family goals are and ensuring that the team is supportive and available to actualize those goals ensures continuity and quality of care.

Other than large-scale system change, how do we get adult-focused providers on board with accepting medically complex young adults into their patient panels?

Ify: This is an easy ask, but hard to implement. Many adult-focused providers have never learned how to interact and work with youth and young adults with chronic conditions. Awareness of the challenges with transition and opportunities to learn how to manage complex medical conditions are critical for adult-focused providers so that they can provide better care. Skills around how to interact with youth and young adults with chronic conditions need to be incorporated into medical education and training.

Megie: Current incentive structures make managing medically complex patients difficult. These patients take additional time and the system doesn't reimburse physicians adequately to provide appropriate care for medical or social complexity. Having a system set up, getting families established with as many community resources and supports as possible, and having a clear care plan for what to do next allows adult providers a way to support their patients. We need to maximize the use of adult providers knowledge about the adult care system and adult disease management, and providers need to have a "lifeline" in case challenges come up. A lifeline could be a pediatric specialist that is available for consultation. Using sickle cell disease as an example, I have a relationship with our pediatric hematologist who is willing to be contacted for direct questions as we transfer patients to adult hematology. The worst-case scenario is a

nebulous transfer request of a patient who is "medically complex" and needs "a lot of help" without clear instructions of what they need and no care plan. That is a formula for a disaster for both the provider and the patient.

How do you get doctors and staff to buy into a structured plan? Many may think that just gathering medical records and sending them to adult providers entails transition.

Megie: On an individual provider level, the adult-focused provider can ask for a summary before accepting a patient into the practice. There are many resources to help providers generate a transfer summary, including this [Transfer of Care tool from Got Transition](#). On a clinic level, having a policy in place to develop a plan is a first step, as this policy could also serve to build rapport between the adult-focused clinicians and the pediatric practice. On a policy level, incentive structures that would pay for care management and coordination that is provided because of the structured care plan may encourage doctors and staff to participate.

It seems like the most important roles being talked about in the health care system are ones that aren't paid for, e.g., peer mentor. How can doctors advocate for these other roles? Are doctors resistant to "losing power" in the health care system?

Ify: I think doctors have limited bandwidth to advocate for these roles. Patients and other stakeholders must also be involved in speaking up about the need for roles like a transition coordinator, community health worker, nurse care manager and/or peer mentor.

Megie: I often bring up the fact that patients don't live in clinics. Realistically, the provider has about 15 minutes with the patient and needs to fill out the chart and all the forms. They can spend about 30 min to 2 hours at the first visit just pouring through charts and case management. Most clinicians don't have the time or bandwidth to be able to work on every aspect, including advocacy. Many times, I am writing letters to landlords in clinic for reasonable accommodations. I tend to bring complex patients in regularly to address social needs, and vocational and school needs. For me, having community agency support (for example, our regional center patients can get health navigation services through the Arc) has been critical for allowing me the time to perform medical management, as issues taking place outside the clinic are often the number one barrier in accessing patient care. It is important to ensure that patients have health advocacy and community supports. Also, in pediatrics, many practices have social workers supporting families of the patients. Most adult practices don't have social workers with this level of expertise. It is more diffuse for adult social workers who are working on a myriad of issues and have much higher caseloads than our pediatric social work colleagues.

Are there any research groups looking at clinics that are using standard transition tools whose evidence we can cite and share as a justification to provider groups/systems that they should be using the tools as well to track process and progress?

Ify: The ST3P-UP study, funded by PCORI, supports establishment of the 6 core elements of transition across 14 sites with pediatric and adult clinics for sickle cell disease. The model has been published by [gottransition.org](#) and serves as a model for how programs should be set up. ST3P-UP will soon publish an article on using quality improvement to implement the 6 core elements. A good group to reach out to is Got Transition as they have deep expertise in this field. Some additional articles that could be helpful include:

- [Outcome Evidence for Structured Pediatric to Adult Health Care Transition Interventions: A Systematic Review](#)

- [Outcomes of Pediatric to Adult Health Care Transition Interventions: An Updated Systematic Review](#)

Tools are also often adapted to meet the needs of a specific clinic. The tools below are examples of tools that have been used to track populations engaging in transition:

- [The Transition Readiness Assessment Questionnaire (TRAQ): its factor structure, reliability, and validity](#)
- [STARX Questionnaire](#)

How will the CalAIM initiative affect care coordination during transition and care expectations from primary care providers?

Megie: I think this will depend highly on the definition of case management plans will be provided. Will case management entail coordinating referrals or will case management require risk-adjusted management that supports development and implementation of care plans? There have been really good demonstration projects with other diseases in Medicare populations (e.g., for congestive heart failure), that we could learn from, but it will depend on how support is laid out.

How does your health care transition model address who has the legal authority to make decisions for an individual?

Ify: This is part of any transition planning. The individual care plan and medical summary must address this issue upfront and document it clearly in the Electronic Medical Record (EMR) and across provider teams. As we advocate for alternatives to full guardianship such as supported decision-making agreements, we find that some healthcare providers don't understand this or make assumptions about who can or should make decisions for youth and adults with special health care needs. I encourage this to be addressed during the first visit or point of contact with a new provider team. Ideally, the nurse lead should be the champion for this information transfer.

Where were the 14 collaborative sites in your project located?

Ify:
1. Duke University
2. East Carolina University
3. Wake Forest Baptist Hospital
4. Atrium Health
5. Novant Health, North Carolina
6. Virginia Commonwealth University
7. Montefiore Medical Center
8. Prisma Health
9. University of Louisville
10. University of Miami
11. Johns Hopkins All Children's Hospital
12. University of Alabama at Birmingham
13. University of South Alabama Health System
14. Children's Healthcare of Atlanta/Emory University

What was the breakdown of stakeholders in the community input gathering phase of your project?

Ify: We spoke with patients, patient support groups, community-based organizations, community advisory boards for hospital/clinical programs that included medical doctors, advance practice providers, registered nurses, pharmacy, social work, case manager providers from emergency department/hospital/primary care and also administrators and sickle cell disease researchers.