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Successful healthcare transition for youth with special healthcare needs is a team effort

Abstract: NPs care for persons across the age continuum and transitions commonly occur. Some are unexpected, like hospitalizations for acute illness or injury. Others are an expected consequence of growing up, like moving from pediatric to adult care models. Understanding the factors impacting healthcare transition is critical for successful outcomes.

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The transition from child to adolescent to young adult is a period of immense physical and psychosocial change. As we age, our bodies change, regardless of our physical or mental health. The care needed to maintain health and the person who delivers that care also changes and this change is defined as healthcare transition (HCT). The HCT process involves moving from a pediatric/family-centered care model to an adult/patient-centered care model and requires planning, transfer of care, and integration into an adult health system.[1]

Healthy adolescents, or those without a chronic health condition, often begin the process of HCT between ages 12 and 15 during a well-child visit with their pediatric primary care provider (PCP), where the caregiver is asked to leave the exam room so the provider and adolescent can discuss their concerns in private. Depending on pediatric PCP licensure, appointment requests after the age of 18 are referred to an adult PCP. Data from the 2018-2019 National Survey of Children's Health (NSCH) indicate that only 17% of healthy adolescents receive services needed for transition to adult healthcare, which include changes in insurance, changes in providers and care systems, and a transition plan of care summarizing these changes.[2]

Youth with special healthcare needs (YSHCN) include adolescents with chronic health conditions, such as cystic fibrosis, sickle cell disease, chronic dialysis, childhood muscular

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dystrophy, cerebral palsy, spina bifida, and complex congenital heart disease. These adolescents often experience transition in the same manner as their healthy peers, with approximately 25% of YSHCN receiving needed transition planning and support services.[2] For all individuals, but especially YSHCN, an uncoordinated HCT can have negative consequences. Young adults with renal transplant or grafts have higher rates of failure than other renal graft populations, and the transition from childhood to adulthood has been identified as a high-risk period for this failure.[3,4] Young adults with spina bifida who did not complete HCT to adult care had significantly higher outpatient and emergency care use.[5]

In 2011, the American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, and Transitions Clinical Report Authoring Group jointly authored a clinical report supporting HCT from adolescence to adulthood in the medical home.[6] This report laid the groundwork for a multisite learning collaborative of pediatric and adult primary care practices to evaluate a core set of HCT processes and tools, referred to as the Six Core Elements of Health Care Transition™.[7] The Core Elements include discussing the clinic's transition policy with the adolescent and caregiver, tracking age-specific transition milestones, assessing adolescent and caregiver readiness for transition, developing a transition plan of care, using a transfer package to communicate the plan of care to adult providers, and ensuring care is established with an adult provider.[1,7,9] Got Transition®, a federally funded resource center for evidence-based healthcare transition emerged from the collaborative.[8] All Got Transition resources and tools, which include the Six Core Elements, are freely available and include transition toolkits for pediatric, family practice, and adult providers: transitioning from pediatric to adult provider, transitioning to adult care without changing providers, and integrating young adults into the adult care system.[1]

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A key driver of successful HCT transition is initiation within the pediatric medical home.[9] A critical first step is identifying all the pediatric providers and services used by the adolescent/young adult, followed by identifying, and ultimately transitioning, to appropriate adult providers and services. The YSHCN population is best served when the transfer of care occurs "one provider or specialty at a time" versus all at once, and leverages the adult PCP's knowledge and access to adult specialists.[9] Imperative to HCT success is communication and transfer of care information between existing pediatric and newly identified adult providers and services.[10] Implementing HCT as a process instead of a one-time discussion requires dedicated care coordination, but pediatric and adult primary care practices struggle to allocate clinic staff to support the HCT process.[9]

A health system that serves children and adults with childhood-onset disabling conditions (such as cerebral palsy, muscular dystrophy, spina bifida) assembled a team to identify gaps in the system's current HCT process. The team included pediatric and adult healthcare and service providers, and three caregiver advisors who were parents of young adults with differing special health needs. Initial meetings focused on understanding the HCT process from all team member perspectives. The caregiver advisors described a healthcare transition process that was often complex, frustrating, and stressful. They encouraged the team to think broader than just "healthcare or providers" when transitioning YSHCN. All services and supports needed for YSHCN must be transitioned and include insurance, equipment and supplies, home health services, waivers, vocational rehabilitation and work support services, independent living or group home, and when applicable, guardianship and social security income. With their permission, we are sharing their transition experiences, with the goal of educating a broader audience on the reality of HCT for YSHCN and their caregivers. The term "Med-Peds" is referenced below and is the acronym for physicians who have completed a combined internal medicine and pediatrics residency.[11] These providers are licensed to care for newborn to geriatric patients.

Cathy and Maggie's transition experience

My daughter Maggie is an articulate, independent, college-educated, and employed young woman who also happens to have Down Syndrome. Her transition journey began during an appointment with her pediatric PCP around age 18. The PCP was passionate about transition for YSHCN and recently published an article on the topic.[12,13] He mentioned the clinic policy on seeing patients until age 19 and asked if I had thought about who Maggie's adult PCP would be. I had not, primarily because I had hoped we had a few more years before transition occurred.

The pediatric PCP committed to helping us find the right fit, starting with the preparation of a transfer-of-care packet that could be shared with new adult providers. He recommended several adult PCPs that were Med-Peds-certified and each provided the option of a meet-and-greet appointment. Each adult PCP was easy to talk with but there were red flags. One was a half-time hospitalist and subsequently not available during those times, and the other provider was part of a practice that only saw pediatric-age patients, despite being Med-Peds-trained.

We decided to give the latter a try to find out more about their care philosophy. Maggie, being 19 years old and very capable, checks herself into clinic appointments, but I listen in, in case I need to step in. The receptionist at the new clinic was very disrespectful to Maggie. This experience illustrated the importance of not only the provider relationship, but the entire clinic culture. Is it welcoming to YSHCN? Do they have needed accommodations? I am well connected in the "disability community" and reached out to all my contacts for recommendations on adult PCPs.

My head said this is just about having a new doctor, but my heart was frightened, thinking about a new care team, a new clinic environment, and all the unknowns.

While finding an adult PCP seemed challenging, finding adult specialists was more difficult. Maggie's pediatric specialists viewed transition as her pediatric PCP's responsibility, but the pediatric PCP did not view this as his role since he was unfamiliar with adult specialists. Once again, we were on our own.

I am a DNP-level nurse who ran a successful case management business for 15 years and worked with healthcare and advocacy organizations to incorporate transition into their care guidelines. Despite my experience, HCT transition was a struggle, but so were other aspects of Maggie's transition to adulthood. The education/vocational rehabilitation system was more focused on "filling her day" (for example, sheltered workshops, day programs) than helping her develop useful skills to help her find meaningful work. Maggie was interested in data entry, so I found health literacy and computer skills courses, and when she completed them, I hired my own job coach to help her find work. All through high school, Maggie had friends that talked about going to college. She wanted the same experience and finally, at age 23, enrolled in a new, inclusive program at Bethel University in St. Paul, Minn. For 2 years, she was immersed in the college experience, sharing a dorm, making friends, going to school events, attending classes, and learning the skills of adulting. A decade later, Maggie lives independently and recently committed to her life partner. Her transition process is finally complete.

Debbi and Josh's transition experience

My son Josh was not expected to live past infancy, and here he is, a 28-year-old personable, handsome, and calm man. Josh cannot verbally communicate but understands everything that is happening around him and communicates with actions. He responds yes and no with movements of his mouth and hands. If we get him up but he wants to stay in his comfortable bed, he turns his head toward the bed. If he is watching TV with the family and gets tired, he tells us by closing his eyes.

Josh's pediatric PCP was the first person to mention healthcare transition. It felt very uncomfortable as we had been a part of this medical home clinic for many years. We had established relationships with a team who knew how to care for Josh. My head said this is just about having a new doctor, but my heart was frightened, thinking about a new care team, a new clinic environment, and all the unknowns. Would they know how to care for Josh in an emergency? Would Josh be safe?

During a hospitalization in Josh's early 20s, a provider mentioned a transition clinic service and asked if I would be interested. I hesitated because we had relationships with our pediatric providers as equal partners, and the adult care system would be different.

The NP who ran the transition clinic was very persistent, in a good way, and I agreed to an appointment. The visit lasted 3 hours and focused on helping me feel comfortable with the transition process. Looking back, I now understand why thinking about transition was uncomfortable. There is a huge chasm when it comes to transitioning a medically complex child. There are emotional, psychological, and practical barriers. When transition was discussed, I experienced all the anticipatory grief about what happens next that I experienced when Josh was born, along with posttraumatic stress disorder. I did not want to do this again.

Continuity of care is important for families of disabled children and presents a big challenge when trying to navigate the healthcare system.

Pediatric health systems have rules around "age eligibility" for care, and providers can feel stuck following these rules and meeting the needs of patients and families. Josh's pediatric PCP provided care for as long as possible but when Josh reached his early 20s, appointments were no longer possible because of clinic rules. I needed to find an adult PCP and started calling clinics to that end. A friend who recently experienced transition with her medically complex young adult recommended a clinic with Med-Peds physicians. When I brought Josh in for his first appointment, the Med-Peds physician was not surprised by Josh's condition and was very respectful of Josh and knowledgeable about his complex needs. Many years later, we continue to have an excellent working relationship, which greatly benefits Josh.

Tracy and Karley's transition experience

Karley is a 22-year-old, joyful, happy, and extremely social young woman. She loves being around friends and family, meeting new people, and experiencing new things. For Karley, there were two transitions: nondisabled to disabled and adolescent to adult. The first was by far the most painful and difficult, which made the transition to adulthood that much more challenging because we needed to find new providers and services.

Karley had an acquired anoxic brain injury due to a seizure 11.5 years ago and became nonverbal and nonambulatory. She has very acute hearing and understands and remembers everything that happens around her. She communicates with smiles and 7 years after her injury, made a breakthrough in communication and began "kissing." She is very intentional and purposeful in communicating her needs and is learning to use a Dynavox assistive technology communication device.

Karley's pediatric PCP since birth was willing to provide very limited care after her injury. I struggled for 5 years to find a new PCP, and fortunately with the assistance of a specialist at another clinic, I was referred to a wonderful, compassionate, caring med-peds trained PCP who was not afraid to take on a young, disabled woman. I also had a very knowledgeable and skilled county case worker. She helped with guardianship, insurance, social security income, and financial help for home modifications. For 8 years, she was my go-to person for any questions. She left the position 4 years ago. I learned to be a strong advocate for Karley and used this skill often due to the turnover in county case managers. We have had four different case managers over the past 5 years. This means following up continuously to get Karley's needs addressed. Continuity of care is important for families of disabled children and presents a big challenge when trying to navigate the healthcare system.

I discovered a specialty clinic just for children and young adults with complex health needs 3 years ago. Karley was 20, 9 years postinjury, and it was the first time a provider did a full-system check, head to toe, and developed a plan of care based on that assessment. This provider, who is not a primary care provider, was the first to talk to us about the transition to adult care and made up a list of recommendations and referrals. We were ultimately able to find the specialists we needed to help with Karley's complex care.

Karley moved to a group home 2 years ago and is very happy being on her own. I recently completed an assessment on her ability to make decisions from Charting the LifeCourse, a framework designed to help people of all abilities develop a vision for how they want to live.[14] Doing the assessment made me realize that Karley is very capable of making and communicating decisions about her daily routine, what she wants to do, who she wants to see, where she wants to go, and so on. Although nonverbal, she communicates through kissing, gestures, and other vocalizations. She is now able to practice walking with the assistance of a Rifton TRAM, a transfer and mobility device, and can move her legs, arms, and body upon command.

Conclusion

The transition experiences shared by our caregiver advisors provided clarity to the depth, breadth, and difficulty of HCT and helped our team understand why HCT is difficult, especially for YSHCN with complex health conditions. Despite well-intentioned pediatric providers, all three caregivers felt alone during the transition process and relied on their informal networks for support. This aligns closely with the themes of an integrative review of HCT experiences of young adults and their parents, which describes HCT as, "falling off a cliff, the paradox of independence, and it takes a village."[15]

The caregiver advisors experienced HCT in ways clinicians often do not understand or perceive. A possible explanation for this gap between caregiver and clinician perception of HCT could be implicit bias.[16] While this phenomenon is most commonly associated with race, implicit bias about the how caregivers "react" to transition may be embedded in providers' bias that moving to a new provider "is not a big deal." HCT is a big deal for YSHCN and their caregivers. Moving to a new health system with no coordination or support is complex, scary, and potentially dangerous, and is the reason why caregivers resist transition. They are not being "difficult" or "nonadherent" but acting as their young adult's advocate.

Clinician knowledge and use of available transition resources is key to addressing this gap. Got Transition is an evidence-based, HCT resource center for healthcare professionals, youth, young adults, and their caregivers.[7] Tools to develop and implement HCT programs based upon the Six Core Elements are freely available in English and Spanish.[1] All persons working with YSHCN need awareness of not only potential self-biases about transition, but also of available resources to ensure that the HCT experience for all YSHCN, especially those with complex health conditions, is successful and safe. NP

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