

## **Roles of Physical Therapists in Healthcare Transitions**

Children and youth with special health care needs (CYSHCN) are increasingly living well into adulthood, due to advancements in medical care and a growing awareness of what supports must be in place in order for these individuals to access and utilize healthcare services. Quality of life for adults with disabilities and/or chronic health conditions arising in childhood hinges on successful healthcare transitions (HCT) from pediatric to adult-centered systems. Despite international attention in the late 1980s to the challenges faced by CYSHCN as they move from child-centered to adult-centered models of healthcare, development of transition programs beginning in the 1990s, and establishment of policies and procedures based on aligned statements from multiple professional and governmental agencies in the early and mid-2000s, successful HCT eludes many CYSHCN and their families. Part of this 'disconnect' may be related to a lack of understanding of unique healthcare needs and HCT experiences of this population. In order to better understand 'first hand' perspectives, I developed a questionnaire and the followed up by interviewing two adults with special healthcare needs who experienced HCTs as young adults. Some of what I learned is incorporated in the following paragraphs.

The process of HCT has long been discussed in terms of:

- 1) policy-making
- 2) system infrastructures
- 3) training of healthcare professionals 'across the aisle' (i.e., in both pediatric and adult healthcare systems)
- 4) when and how implementation of HCT should take place, and
- 5) attitudes of healthcare professionals (often primary care physicians).

Little is known about the HCT process from the perspective of primary stakeholders themselves (i.e., CYSHCN and their families) with regard to their transition preparedness, access to and utilization of multiple types of services/resources, understanding about what to expect over time, and satisfaction with the HCT process as a whole. Furthermore, little information is available about how physical therapists (PTs) might play a role in helping patients and families navigate the HCT journey.

Why is successful HCT of CYSHCN so important? Well, it affords age-appropriate, self-determined provision of healthcare services and sets the stage for comprehensive delivery and utilization of healthcare throughout an individual's lifetime. Furthermore, successful HCT decreases morbidity and mortality risks, promotes adherence to treatment regimes, and correlates with improved health-related quality of life and overall patient satisfaction with the healthcare they receive.

Essentially, there are three phases involved in successful HCT:

- 1) planning and preparation
- 2) transference of care, and
- 3) full integration into an adult healthcare system.

A wide range of opinions exist about when and how each of these phases should be begin, who should be involved and what, specifically, should occur during any given stage. Despite a lot of dedicated time and resources devoted to creating guidelines and policies intended to streamline HCT, the process is often less than successful for many living with the challenges of chronic health conditions and disability arising in childhood.

Barriers to HCT commonly cited in the literature and echoed by my interviewees include:

- 1) resistance of pediatric physicians, their patients and families to 'let go' of the relationships forged from infancy or early childhood,
- 2) a distrust of adult providers' knowledge of pediatric conditions and how they might impact healthcare needs throughout life, and
- 3) whether or not HCT policies and procedures allow for 'customization', if they are even in place at all.

Certainly, one size does *not* fit all, when it comes to HCT for CYSHCN.

There is a tremendous spectrum of CYSHCN in terms of complexity of conditions and healthcare needs associated with them, educational levels of individuals and their families, support networks in place, and accessibility and/or availability of healthcare services. PTs can be well positioned to assist CYSHCN through the HCT process as they frequently interact with them in the course of providing interventions and developing solid relationships. Moreover, PTs may be found in supporting roles in a variety of healthcare delivery settings such as schools, private homes, and communities, in addition to the clinics and hospitals more often associated with primary care physicians. The combination of frequent and diverse opportunities to not only broach the subject of HCT to CYSHCN and their families but, also, to guide the process, is quite unique to situations in which PTs operate.

Not only do PTs have ample opportunity to assist with HCT, in fact, I would argue the PT profession has a *responsibility* to oversee portions of the process. A few simple ways in which PTs, as well as other healthcare professionals involved in the care of CYSHCN, can assist are:

- 1) Begin conversations early about the possible implications of specific conditions in terms of health and functioning over time to help 'paint a picture' of what the future may hold.
- 2) Help CYSHCN formulate questions about their health concerns and needs to ask various members of their healthcare team.
- 3) Based on the nature of those health concerns and needs, link CYSHCN to resources (e.g., medical specialists, support groups, websites, community services/programs, etc.).

I encourage the reader to keep this statement, made by one of my interviewees, in mind when working with CYSHCN:

*"Health care needs for people with disabilities do not go away just because they get older".*

As part of my process of learning about how I might assist in making HCT smoother for those I serve, I am beginning by raising awareness of the issues surrounding HCT. One step is to reach a wide audience through written articles, such as this one, in various publications. I have also written a similar piece for consideration for the American Physical Therapy Association (APTA) Magazine and plan to author at least one research article. For a list of references I drew upon to write this article, please contact me via e-mail.

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