

As more and more of the estimated 24% of youth with special healthcare needs (YSHCN) in the U.S. (Acharya, Meza and Msall, 2017) are living well into adulthood, the process of healthcare transition (HCT) from pediatric to adult healthcare systems warrants considerable attention. Definitions of what constitutes 'special health care needs' for children and youth is still often described in terms of those who have chronic conditions or an elevated risk for chronic developmental, behavioral and/or emotional impairments/disabilities that impact their functional status (McPherson et. al., 1998). Since life expectancies of YSHCN are increasing due to advancements in medical care and increasing awareness of the supports required, in order for this population to effectively access and utilize healthcare services, the number of YSHCN entering adult healthcare systems is growing: an estimated 750,000 are transitioning from pediatric to adult healthcare, annually.

The range of conditions presented by YSHCN is vast and complex, as is the list of healthcare services that may be required to improve or maintain the health and functioning of YSHCN before, during and after HCT. Despite international attention in the late 1980s, during a Surgeon General's conference, to the challenges faced by YSHCN as they move from child-centered to adult-centered models of healthcare (Magrab et., al., 1989), development of transition programs beginning in the 1990s (Blum, 1995), and establishment of policies and procedures based on aligned statements from multiple professional and governmental agencies in the early and mid-2000s (American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, American Society of Internal Medicine, 2002 and Maternal and Health Child Healthy People 2010), as well as extensive information available from national resource centers (White, et. al., 2020), successful HCT remains elusive. Based on the 2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN), only about 40% of YSHCN met transition core outcome criteria and *less than half* received adequate transition preparation. These statistics, sadly, were consistent with those reported on the 2009-2010 NS-CSHCN (McManus, et. al., 2013). Part of this on-going problem may be related to a lack of understanding of the healthcare needs and HCT experiences of individuals *directly* impacted.

The onus is on YSHCN facing the challenges of HCT, their families and the healthcare community to ensure the process goes as smoothly as possible and at optimal times along the way. However, there is little evidentiary literature that explores HCT issues from the perspectives of YSHCN. My viewpoint is that physical therapists (PTs) are uniquely situated to help YSHCN and their families navigate as their HCT journey unfolds. Successful HCT permits flexible, age-appropriate, developmental provision of services, as well as adequate, comprehensive utilization of healthcare throughout the course of an individual's lifetime, at times and stages that are customized to their health condition(s), situation(s) and needs. PTs frequently interact with YSHCN and their families in the course of providing interventions on a regular basis. Moreover, PTs operate in a variety of healthcare settings such as schools, private homes, and communities, in addition to clinics and hospitals traditionally associated with other healthcare providers (e.g., primary care physicians), allowing for multiple opportunities to broach the subject of HCT and assist in process guidance.

As a way to begin to understand how the experience of HCT might go for YSHCN and their families, I interviewed two adults with cerebral palsy who 'lived' the process, following their responses to a questionnaire I developed that was informed by questions on the NS-CSHCN. Based on information they provided, I have a few immediate suggestions about how PTs might effectively facilitate and advocate for a smooth HCT for YSHCN and their families:

- **Start HCT EARLY.** Currently, most resources recommend beginning HCT conversations at about 12-14 years old. The people I interviewed suggest opening up communication lines as early as preschool age. PTs might help form parental/family support groups and/or lead them to existing ones, in order to put families in similar circumstances in touch with each other. This may be done within school or community environments and requires becoming educated about and staying abreast of available resources.
- **Promote/provide education and training** of PTs and other healthcare professionals working with adults who have chronic conditions arising in childhood about the varieties and complexities of healthcare needs that may be encountered, specialists that may be involved, and trajectories health status courses might be expected to take.
- **Become involved in legislative processes** that support benefits, based on solid evidence, that cover adequate, necessary medical services not only during transfers of care but, also, that support on-going care required for optimum health-related quality of life at every stage of life. As one interviewee pointed out, ***“Health care needs for people with disabilities do not go away just because they get older”***.

Clearly, there is much more work to be done to bridge the gaps YSCHN and their families fall into as they move from a pediatric, child-centered model of healthcare to adult-centered systems. I would argue pediatric PTs are not only uniquely positioned to facilitate the HCT process but have a responsibility to do so, as members of a dynamic healthcare delivery team.

#### *References:*

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