

Guest Editorial

In the United States, there are approximately 13 million children with special needs and chronic conditions, such as cerebral palsy, spina bifida, and others, and over 90% of these children are expected to survive into adulthood. During this transition to adulthood children go through many major changes in their lives simultaneously. They may be moving on to college or a job and beginning to live on their own. Their legal status within our society changes, and with it our expectations of them. For youth with chronic illnesses, they also face the prospect of having to manage many aspects of their health condition by themselves and meeting a new set of adult providers, who may employ a different culture or style of health care delivery. For all the reasons above, health and social outcomes for transitioning youth across many different conditions can deteriorate if proper attention is not given to the challenges they face. From as early as the Surgeon General in the 1980s to the American Academy of Pediatrics and the Maternal and Child Health Bureau today, prominent organizations have discussed the best way for providers to help families through the process. While specific aspects of transition care may differ by condition, there are many opportunities and challenges that are common across conditions and systems of care. We hope that rehabilitation providers reading the articles in this issue can translate some of the findings described here to the care of their own patients within their specific setting.

A framework for studying the complex issue of transition is the focus of the first article in this issue. The framework developed here was put together by leaders of a collaborative network of healthcare transition providers and researchers. The group examines established models of care, and builds upon them to include the multitude of domains that are involved, from individual biology to socially developed systems of health care delivery. Once a framework is established, we can begin to understand our families' perspectives on transition care. Transition can be an exciting time for youth and their families. However, knowingly and unknowingly, many youth fear the idea of moving on and parents (and providers) very often fear "letting

go". One of the most important aspects of transitioning is instilling confidence and self-advocacy skills in our youth. Knowledge and proficiency with managing one's own health, along with confidence, can lead to independence. Parents often have different views of their child's level of independence and social participation than do the youth themselves. Parents who have seen their children perform these skills, and have seen their children respond to challenges and the unknown in a positive way, are more comfortable with "letting go". Understanding patient and parental views of the transition process is an important part of the next article, which groups barriers to transition into various themes. The next two articles contrast youth and parent views on capabilities, transition experiences, and barriers to transition. As expected there are surprising contrasts between the two views. Understanding these contrasts can help in developing a tailored and sensitive approach to transition care that attends to the most prominent needs of the youth and family.

A major barrier to transitioning reported by families of youth with childhood conditions and pediatric providers is finding willing adult providers. The barriers reported by adult providers themselves have been documented previously, and include lack of knowledge about pediatric diseases, lack of psychosocial supports, and lack of time and reimbursement for services. The next article examines various physician and patient characteristics that can influence adult physician acceptance of youth into their practice. Understanding these factors can help target efforts to help adult physicians accept and care for youth with chronic childhood conditions.

Beyond the ability to survive, the potential for these children to thrive in adulthood has greatly increased as well. New laws and opportunities regarding insurance and benefits, employment, education, and independent living for medically complex youth have been instrumental in strengthening their ability to live with hope, pride, and dignity. One of the most commonly asked about aspects of transitioning is the change in insurance and benefits that occur when a young adult turns 18. This is the focus of the next article in the issue.

As we all have heard, the health insurance marketplace is changing, and these changes affect youth between 19-26 greatly. These youth may have various options for health care coverage, and become eligible for benefit programs for which they were previously ineligible. Having a basic understanding of the concept and variety of programs that exist can serve the provider well in understanding the options available for youth and their families.

By understanding the challenges these youth and their families face during the process, transition programs can be designed to ease the main concerns and fears of our families. The last of these articles describe the development of transition initiatives in two large systems of care. By implementing a structured transition program in their practice, providers of all conditions can help adolescents with chronic conditions acquire the necessary skills to manage the various aspects of their care in the adult healthcare systems. The approach and process of developing these programs may be useful for those willing to start a transition program at their own setting. The importance of establishing community partners and sustainability of these programs are also discussed extensively.

Despite all of the above, we know our children have to and want to move on. We know that there are many benefits to entering the adult world, such as being treated with more respect, and having more autonomy over ourselves. As more and more youth with complex chronic conditions survive into adulthood, it becomes the responsibility of the healthcare system to fully prepare these youth for the adult world. A structured transition program based around the needs of youth and their families may help improve these outcomes. Such a program should help develop skills necessary to independently care for one's own health, as well as discussions around high risk behaviors, consent and confidentiality, employment, educational, and financial planning, and procurement of health insurance. In addition, ensuring a systematic transfer of care can improve the receptiveness of adult providers. As our youth survive longer into adulthood, we are in great need of understanding the challenges they face, and adapting our care from helping them survive to helping them thrive.

Parag Shah