



## HEALTHCARE TRANSITION IN THE SPINA BIFIDA COMMUNITY

Transition in healthcare refers to the process where adolescents and young adults with chronic medical conditions shift from pediatric-centered to adult-oriented care. This journey involves two main aspects: preparing individuals for adult responsibilities and facilitating the transfer of care to adult healthcare providers.

For those with Spina Bifida, this transition necessitates assembling a specialized care team including primary care physicians, urologists, neurosurgeons, physiatrists, and orthopedic surgeons. However, the United States faces a care crisis as the majority of Spina Bifida patients are adults, highlighting the urgent need for comprehensive adult care infrastructure. The lack of such infrastructure creates a “care cliff,” leaving patients without guidance as they transition out of pediatric care. This often leads to prolonged stays with pediatric providers or the challenge of locating adult providers, potentially in different geographical areas.

The challenges outlined in the transition of Spina Bifida patients from pediatric to adult healthcare systems are indeed significant and multifaceted. Let's address each of them.

### **Inadequately Trained Medical Providers**

The shortage of adult healthcare providers skilled in managing Spina Bifida poses a significant hurdle. To bridge this gap, specialized training programs tailored for adult physicians are essential. These programs should focus on the unique needs of adult Spina Bifida patients, covering long-term management, complications, and interdisciplinary care coordination.

Despite two-thirds of Americans with Spina Bifida being adults, healthcare infrastructure for them significantly lags behind the pediatric sector. While there are around 100 pediatric clinics dedicated to treating this condition in the U.S., only about 30 clinics cater to adults nationwide. This stark contrast highlights the urgent need to enhance adult care provisions for this population.

Medical education hasn't kept pace with this demographic shift, resulting in Spina Bifida primarily being taught as a pediatric condition with a focus on premature mortality. Most adult physicians lack adequate training to care for adult Spina Bifida patients, emphasizing the urgent need for updated and comprehensive clinical training tailored to adult healthcare providers.

As a result, adults with Spina Bifida face a disjointed medical system, struggling to find proficient physicians for treatment. Consequently, many resort to seeking care in emergency rooms or sticking with their pediatric care team until age-related insurance restrictions kick in.

### **Workforce Issues**

Addressing the shortage of healthcare providers for adult Spina Bifida patients requires systemic reforms. This may involve implementing incentives to encourage physicians to specialize in this field, improving reimbursement rates for complex care, and raising awareness about the importance of delivering comprehensive care for adults with Spina Bifida.

While pediatric Spina Bifida patients benefit from multidisciplinary healthcare teams, there is a significant lack of medical professionals equipped to care for the growing adult Spina Bifida population. Many patients struggle to find specialized adult care or physicians knowledgeable about their specific needs. Additionally, some physicians may be hesitant to accept these patients due to reimbursement challenges and biases toward disabilities.

## **Lack of Care Coordination**

Ensuring comprehensive and efficient healthcare for Spina Bifida patients requires seamless integration of care across specialties. This involves establishing specialized clinics or interdisciplinary care teams with experts from diverse fields and implementing effective communication protocols to facilitate smooth coordination among providers.

Collaborative efforts among healthcare professionals are essential for transitional care. However, the current landscape often lacks facilities tailored for adult Spina Bifida patients. It's crucial to involve urologists, orthopedic surgeons, neurosurgeons, and physiatrists in care, addressing various aspects of the condition. By integrating these specialized services, we can comprehensively address patients' needs and enhance preventive measures while reducing the likelihood of medical emergencies.

## **Research Challenges**

More research is needed to understand the specific needs and challenges faced by Spina Bifida patients during the transition to adult care. Funding agencies should prioritize research in this area to inform the development of effective transition programs and policies. Minimal research exists on the healthcare transition of youth Spina Bifida patients. It is unclear which agencies on the federal level, if any, are accounting for these common challenges experienced by medically-complex patients. The current gaps make it difficult to assess the efficiency of current transition programs.

## **Conclusion**

Addressing these challenges will require collaboration between healthcare providers, policymakers, advocacy groups, and patients and their families. New forms of medical innovation have allowed pediatric Spina Bifida patients to live long and fulfilling lives. These care advancements underscore the need for strong forms of infrastructure that help facilitate the transition of pediatric patients to the adult healthcare system.