

Medical Transition from Pediatric to Adult Care in Neurology

It is critical to see transition as a process not simply a moment in time when care is transferred.

By Lawrence W. Brown, MD



Pediatricians provide a medical home for most children in the US, and there is a common policy that care is transferred to practices focused on adult patients sometime in early adulthood, usually between age 18 and 23 years.

This is also generally true for specialty care of children, including those followed by pediatric neurology. All young adults, including those with special needs or intellectual disabilities are often best served by clinicians who are used to managing the problems of adults vs the constantly changing and maturing young patient. Historically, however, there has been very little attention to the distinction between transfer—a moment in time—vs transition—the long process of preparing youth and their families for independence, optimal disease understanding, and self-management skills. Medical transition for children and youth with neurologic disorders becomes even more complicated because many neurologic conditions include intellectual or physical disabilities that may preclude complete independence.^{1,2} Progress is being made with ongoing efforts to create best-practice models and develop tools to integrate transition into daily practice for clinicians, caregivers, and patients.

Although the fact that children eventually grow up is no revelation, it was not until 2011 that a publication first comprehensively addressed the issue of child-to-adult medical transition in pediatric practice.³ With the imprimatur of the American Academy of Pediatrics, the American Academy of Family Practice, and the American College of Physicians, the article outlined the key elements of transition preparation, transfer, and integration into adult primary care. It also challenged specialists to consider an individual's unique needs of to create a comprehensive care transition plan that would

lead to success.⁴ Other specialties led the way, but typically this meant disease-oriented programs such as cystic fibrosis, chronic renal disease, and diabetes. Child neurology was the first specialty to address an entire panoply of conditions as diverse as autism, epilepsy, migraine, and muscular dystrophy.

Challenges to Transition Planning in Neurology

Beyond the diversity of diagnoses and the additional challenges of intellectual disability complicating the ability to function without ongoing supervision, there are many reasons why barriers to the goal of successful transition have precluded the development of clear guidelines for the transition from child to adult neurologic care.⁵ These barriers involve both ideologic and practical issues. Child neurologists often have long-standing relationships that are hard to give up and they may feel that child neurology practitioners are more responsive to the complex issues that often extend beyond medical into educational, behavioral, emotional, and social areas than adult neurologists. There is also a dearth of colleagues in adult neurology who are willing to accept patients with developmental disabilities and behavioral complications. Patients and caregivers may be equally hesitant to move from the comfortable (and more holistic) pediatric environment to a more narrowly defined individual-oriented adult program with less support. This is further complicated by other transitions of early adulthood that make this a time when resources are becoming scarcer (eg, aging out of special education or having to enter different insurance models.) All of this is happening at a time when physicians are feeling, in general, beleaguered by having less and less time for direct patient care, insistence on more and more documentation, and ever-increasing financial constraints.

A Proposed Framework

Led by the Child Neurology Foundation (CNF), a broadly representative panel was brought together to address these issues. The initial committee was composed of child neurologists, child neurology nurses, adult neurologists, rehabilitation specialists, and patients and their families. The outcome was a set of principles of transition for youth with neurologic disorders that was evidence-based when possible and reflected expert opinion when data were lacking. These recommendations were published after input from multiple national organizations and endorsement by the Child Neurology Society, American Academy of Neurology (AAN), American Academy of Pediatrics, American Epilepsy Society and others.¹ Once the principles were outlined, the project was shifted to the Transitions Practice Advisory Committee, which could educate the medical and broader community, develop practical material to facilitate the process, support quality improvement projects, and encourage model programs reflecting neurology in general as well as the unique needs of specific disease states within neurology. This included work with interested advocacy organizations such (eg, the Lennox-Gastaut Syndrome [LGS] Foundation and the Tuberous Sclerosis Alliance).⁶

The principles of neurology transition are outlined in Box 1. The 8 steps were carefully worked out in recognition of the complexity of the process, but it is also possible to simplify these into 4 steps as follows.

1. Expectation of transition, in which there is a discussion of transition policy with youth and caregivers;
2. Joint development of a plan with youth and family (this may need evaluation for medicolegal competency);
3. Periodic review updated annually with increasing disease knowledge and assumption of self-care; and
4. Completion of process, including a transfer packet, full acceptance of adult responsibilities as reasonable, and first visit to an adult provider

▶▶▶ Box 1: Principles of Good Transition (2016)

1. Expectation of transition
2. Yearly self-management assessment
3. Annual discussion of the medical condition and age-appropriate concerns
4. Evaluation of legal competency
5. Annual review of the transition plan
6. Child neurology team responsibilities
7. Identification of adult provider(s)
8. Transfer complete when the provider accepts the patient and the first appointment is made and kept

Barriers to Overcome for Successful Transitions

There are many perceived barriers to accepting the responsibility of introducing transition in the practice of neurology. Many youth are not ready for the patient-centered vs family-centered model of care, adolescents may have an ignorance of consequences, and parents may be overprotective. Solutions include gradual introduction of individual office time beginning with visits in the early teens, providing training to meet the psychosocial needs of young adults, and using local resources (eg, Epilepsy Foundation camp) to encourage self-advocacy and independence.^{6,7} For youth with normal IQs, their evolving executive function needs to be considered because they may not appreciate the need for consistent adherence to the medical plan and their cooperation may be limited by psychiatric comorbidities. It can be helpful to have visits include time with a nurse or transition coordinator. Some practices provide a “Health Passport” on a flash drive or cell phone as a quick-reference resource as well. Screening for possible psychosocial problems is recommended.

For youth with intellectual disabilities, other approaches are needed. Beyond behavior challenges that can make blood work, EEG, and MRI difficult, there are cultural differences that must be taken into account. For example many adult specialists and emergency departments do not allow family members in the exam room. It may be necessary to negotiate with neuroradiology for MRI under anesthesia. It is important to avoid assumptions and consider individual capacity for self-management. In the hospital, staff should be trained to work with adults with neurologic conditions (eg, intellectual and developmental disabilities [IDD] or autism). The family should be encouraged to advocate for individualized person-centered care.

However, the practical differences that exist in how pediatric and adult health care is delivered go beyond the challenges associated with IDD, however. Often, care in pediatrics is better integrated between medical specialties compared to a more fragmented approach for adults.⁸ Therefore, it is essential to better prepare youth and caregivers for the adult model and to arrange as much as possible prior to transfer (eg, community living arrangements, vocational training and respite care). The limited resources of the health care system need to be acknowledged and accepted as parameters to handle. All neurologists feel the time pressure and will typically identify other more urgent issues than transition, especially with the current lack of compensation for these “nonurgent” services. But ideally, transition should be introduced in small increments gradually over the years. Child neurologists should be collaborating with primary care and supporting programs such as those cosponsored by the local advocacy organizations. A solution for the inability for both adult and pediatric neurologists to bill for a joint transi-

tion visit is to utilize the AAN coding initiatives (separate billing for pediatric follow-up and adult consultation).

Rapid progress in neurology has created other challenges; we are living in an exciting time with new advances in neurogenetic diagnosis and targeted treatments for children with neurologic disease. There is improved life expectancy into adulthood for what were formerly pediatric death sentences. Adult neurologists rarely had to care for patients with Duchenne muscular dystrophy and had never heard of Dravet syndrome. An obvious response if not a complete solution should be to provide a comprehensive medical summary and clear emergency plan for all patients and for the child neurologist to remain available as a consultant to the adult clinician. It should not be controversial to emphasize neurologic conditions as life-span disorders and to increase adult neurology training in neurogenetics.

Transition Planning and Care in Practice

How can a busy practitioner find time to incorporate the principles outlined by CNF into practice? Although this can be difficult, tools to make it easier are available (Box 2, Checklist). For example, the CNF website has open-source templates that include a model office-transition policy, transition checklist, and self-care assessment with separate forms for individuals with intellectual disability to be completed by caregivers. Sample transition packets are also available and have a sample transfer letter, plan of care, and medical summary. Local initiatives have introduced transition planning into the electronic health record (EHR). At the Children's Hospital of Philadelphia there is a Best Practice Advisory that appears in the EHR when a child turns 14; if accepted, the advisory includes a drop-down menu with a variety of resources.

Patient groups continue to advocate for more resources, such as transition coordinators and better education for nurses and social workers. There are practice codes in exist-

tence that could provide reimbursement for these services, although few insurance carriers actually offer coverage.

Current Results and Future Directions

The work is far from complete. A large survey polled clinicians in 2013 about their understanding of transition.⁹ Child neurologists still confused transfer with the transition and often delayed the process. More recent unpublished survey by CNF has shown little improvement:¹⁰ Although this is disappointing, the current perspective from caregivers of youth with complex neurologic conditions may be even more depressing. Focus groups from the LGS foundation largely agreed that transition discussions are not happening early enough, if at all. They felt that this vulnerable population feels unsupported by their medical team in the transitioning process. Many individuals with complex needs continue to see their pediatric neurologist well into their late 20s—or later. All agreed that there was need for more education targeted to caregivers regarding transition and the concept of a “medical home.”

(Continued on page 67)

Checklist: Practical Considerations throughout the Transition Period

- Have clear office transition policy
- Promote adolescent responsibility for self-care and self-advocacy
- Engage a team including transition coordinators, social workers, nurses, and others because transition care is not the sole responsibility of the neurologist
- Discuss transition readiness annually
- Discuss guardianship/power of attorney as indicated
- Emphasize importance of transition even if provider will not change
- Allow flexibility for times of transfer
 - High school graduation
 - Pregnancy
 - Independent living
 - College graduation
- Identify adult providers >1 year before expected transfer
 - Importance of primary care (medical home)
 - Consider medicine-pediatrics collaboration for complex or challenging patients
- Ensure the child neurology team remains responsible for continued care until the transfer is complete

▶▶▶ Box 2: Child Neurology Foundation Resources (www.childneurology-foundation.org/transitions)

1. Office transition policy
2. Transition checklist
3. Self-care assessment
4. Separate forms for individuals with intellectual disability
5. Transition packet
 - Transfer Letter Sample
 - Plan of Care
 - Medical Summary

(Continued from page 58)

The principles of good transition have been widely discussed for less than a decade, and the evidence base supporting the hypothesis that those principles lead to improved outcomes reduced health care costs, and better quality of life or satisfaction are few and far between. At this point even if one accepted that transition were essential, to borrow the language of politics, it would be an unfunded mandate. Still, there is something to be said for face validity. It is inevitable that children will grow up, and it is the goal of all parents and caregivers that their offspring will eventually become as fully responsible and independent adults as their abilities will allow.

It could be objected that the need for discussing, planning, and implementing care transitions for all patients is unnecessary because in some care models there is no mandated transfer of care. In many locales, the neurologic care of children and adolescents is provided by adult neurologists. In other cases, the child neurologist continues to manage care. However, even when there is no transfer from a pediatric to adult provider, it is essential to remember transition is a process over many years leading to full acceptance of expected adult responsibilities, not a moment in time when a young person “graduates” (or transfers) to an adult medical system. Therefore, the model must gradually shift, as youth take on the mantle of self-management with changing developmental imperatives and challenges be addressed. ■

1. Brown LW, Camfield P, Capers M, et al. The neurologist's role in supporting transition to adult health care: a consensus statement. *Neurology*. 2016;87(8):835-840.
2. Tilton AH. Transition of children with neurological disorders. *Curr Neurol Neurosci Rep*. 2018;18(4):14.
3. American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians; Transitions Clinical Report Authoring Group, Cooley WC, Sagerman PJ. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2011;128(1):182-200.
4. White PH, Cooley WC; Transitions Clinical Report Authoring Group; American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2018;142(5):e20182587. *Pediatrics*. 2019;143(2):e20183610.
5. Brown LW, Roach ES. Outgrowing the child neurologist: facing the challenges of transition. *JAMA Neurol*. 2013;70(4):496-497.
6. Camfield PR, Andrade D, Camfield CS, et al. How can transition to adult care be best orchestrated for adolescents with epilepsy?. *Epilepsy Behav*. 2019;93:138-147.
7. Andrade DM, Bassett AS, Bercovici E, et al. Epilepsy: transition from pediatric to adult care. Recommendations of the Ontario epilepsy implementation task force. *Epilepsia*. 2017;58(9):1502-1517.
8. McManus MA, Pollack LR, Cooley WC, et al. Current status of transition preparation among youth with special needs in the United States. *Pediatrics*. 2013;131(6):1090-1097.
9. Sonneveld HM, Strating MMH, van Staa A, Nieboer AP. Gaps in transitional care: what are the perceptions of adolescents, parents and providers? *Child Care Health Dev*. 2013;39(1):69-80.
10. Transition Practices Advisory Committee. From principles to practice: a survey of child and adult neurologists on transition. Unpublished.

Lawrence W. Brown, MD

Associate Professor of Neurology and Pediatrics
Children's Hospital of Philadelphia
Philadelphia, PA

Disclosures

LWB reports no disclosures