



TRANSITIONING TO ADULT NEUROLOGIC CARE: Where do we go from here?

BY DAVID ERVIN, JOAN HAHN AND MIYA ASATO, MD

For many individuals with IDD, epilepsy often begins in childhood and has a significant impact on children and families. As children with epilepsy and IDD reach adulthood, while principles have been developed by consensus to guide the child neurologist, no specialized guidelines have been created for the adult neurologist that speak to the unique transition of care needs necessary for successful transition from pediatric to adult care. This represents a critical period as individuals with IDD with health conditions often have complex personal, social, and physical challenges which historically have been associated with difficulty in accessing quality healthcare compared to their non-IDD peers, resulting in health care disparities.

Epilepsy is the number one health complication that occurs in individuals with IDD. In childhood, neurological care is most often delivered by pediatric neurologists and advanced practice providers (nurse practitioner, physician assistant) and epilepsy

nurse specialists. Pediatric neurologists have formalized training in pediatric and neurological medicine which provides a unique background to address the medical and psychosocial needs of patients and families.

Nursing has defined neurology as a specialty practice with certification of registered nurses. In the U.S., nursing programs that offer experience in the neurology specialty for AAPs are scarce. Care across the lifespan requires experience with the impact of cognitive impairments on daily life and understanding of the challenges around communication between caregivers and the medical team. Furthermore, family issues around adaptation, potential logistical and compliance difficulties for patients with IDD obtaining diagnostic testing, and risks of polypharmacy compound complexity of care. Unfortunately, neurologists trained in adult medicine do not typically have access to comparable training. They have limited exposure to adult patients with intellectual and devel-

opmental disabilities, and may demonstrate less familiarity with addressing quality of life and psychosocial issues compared to their pediatric neurology-trained colleagues.

Therefore, the transition to adult care from pediatric care settings can be challenging for patients, families, and team members. The so-called “cultural gap” between pediatric and adult neurology models of care is further compounded by other systemic factors. For example, despite increased need for longer visits to achieve effective communication between the patient, caregivers and medical providers, care can be compromised by time limitations, a limited selection of neurology providers, poor reimbursement for time, and resource intensive care management for individuals with epilepsy and IDD. Transition thus represents a vulnerable period where satisfaction with care may be compromised, which may ultimately result in poor care resulting from the mismatch of issues and agendas.

NEURO TRANSITIONS FOR PEOPLE WITH IDD ROUNDTABLE

On April 26 and 27 2017, experts from across the US convened for the first-ever Neuro Transitions for People with IDD Roundtable in Boston, Massachusetts. This event was sponsored by Eisai, Inc. and the LEND Program at the University of Pittsburgh, with support from the American Academy of Neurology Special Interest Group in Adult IDD, and the American Academy of Developmental Medicine and Dentistry (AADMD). Dr. Seth Keller, Co-Chair of the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) and AADMD President—and a neurologist—organized and led the Roundtable discussions. The primary purposes of the meeting were to identify barriers to successful transition from pediatric to adult neurology, and to identify actionable solutions to those barriers.

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“The Roundtable is a critical first step in improving the transition of youth with intellectual and developmental disabilities to adult neurology in order to improve continuity of care and health outcomes,” commented Dr. Keller. “We have transition guidelines for youth who are neurotypically developing, and we have transition guidelines for kids with IDD in primary care and even in some subspecialties—but we lack guidelines for those patients with IDD undergoing transition in neurology care. That has to change.”

The Roundtable participants were chosen in a fashion that would create a multidisciplinary broad range of perspectives and expertise in the care and supports of individuals with IDD. Key leaders were chosen from the fields of pediatric and adult neurology, specialty IDD primary care, community based and national advocacy, Pharma, managed care, as well as university disability leadership. The meeting was facilitated by a national IDD public health leader and, over the course of a day and evening, the participants all began to discuss and flesh out the inherent issues within the current national neurology transitioning of IDD care practices. Specific recommendations were then selected, followed

by the determination of action steps to enable this endeavor to be successfully implemented as a national effort to help make a real difference in neurology care.

Several key barriers were then determined as being significant impediments to care. These included:

Transition Barrier: *Lack of training and expertise in IDD and related education, and need for expanded education of providers, families about unique transition needs for patients with epilepsy and IDD.*

Transition Barrier: *Gaps in information availability about transition tools and resources to healthcare providers, patients, caregivers, families and advocates, other healthcare providers.*

Transition Barrier: *Inadequate healthcare financing/funding to ensure successful health care transition and coordination of care.*

Transition Barrier: *Lack of neurology transition guidelines tailored to the needs of people with IDD and other complex health care needs such as epilepsy.*

Transition Barrier: *The need for a unifying and team-focused health care model such as the Medical Home model which would be well-suited to individuals with IDD and other complex health care needs such as epilepsy.*

Roundtable participants committed to action items with specific deliverables, timeframes and goals. Dr. Keller said, “We have work to do, so our expectation is to leave the Roundtable itself with action plans in hand, hold ourselves accountable, and reconvene no more than a year from now to report out on our progress. Doing nothing is not an option.”

For more information on the Neuro Transitions for People with IDD and its work, Dr. Keller can be reached at sethkeller@aol.com •

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