

# **Transition of Health Care for Individuals with Intellectual and Developmental Disabilities: Building a Bridge from Pediatrics to Adulthood**

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Over the last several years, there has been a surge of interest in the phase of life that we now call the *transition to adulthood*, a period that has been defined as “moving from the protected life of a child to the autonomous and independent life of an adult.” The pediatric community has increasingly recognized that typical teens and young adults are unprepared to enter the adult health care system and to manage their own health care needs. For those with intellectual or developmental disabilities, families face even greater challenges as they strive to achieve the highest level of independence for their loved one, continue to provide the same protection that was required throughout childhood, and navigate systems of care that are not prepared to offer comparable supports found in the pediatric world.

According to the most recent CDC statistics, 1 in 6 children had a developmental disability in 2006-2008; the prevalence of autism alone increased almost 300% during that time, with NJ leading the nation in that trend. The increase in parent reported developmental disability translates to 1.8 million more affected children in 2008 than a decade prior. This means, of course, that those who were over 4 years old at that time are the teens that are facing the transition to adulthood today.

Pediatric health care systems are inherently different from their adult counterparts. Pediatric providers welcome a family-centered model, while adult providers are accustomed to patient-centered interactions. In fact, they are legally barred from communicating with family members unless they are granted explicit permission. In pediatrics, there is often organized assistance with coordination of care, whereas in the adult world independent coordination of care is expected. And, of course, pediatric providers are knowledgeable about diagnoses originating in childhood, while adult providers have limited experience with pediatric-onset conditions.

In October 2018, a study was published in the American Academy of Pediatrics' monthly journal, *Pediatrics*, that examined transition preparedness among U.S. youth. This survey of 20,708 individuals between the ages of 12 and 17, revealed that only 17% of youth with special health care needs met the defined transition performance measure. Other studies suggest that the responsibility for difficulties faced by families spans both the pediatric and adult sides. Pediatricians are not adherent to recommended transition guidelines, mainly due to inadequate time and lack of consensus regarding transition policies and procedures. But pediatricians also cite inadequate access to adult providers with sufficient expertise to manage complex patients, a pool that is further limited by insurance restrictions. Adult providers report

inconsistent health information received from pediatric providers, inadequate time for office visits and care-coordination between visits, and inadequate compensation for efforts outside of face-to-face encounters. They admit to lack of training and experience with childhood chronic conditions and lack of information regarding community resources.

It is no wonder that this multi-pronged failure leads to an unstructured transition and ultimately results in discontinuity of care, difficulties with treatment compliance, preventable emergency department and hospital visits, and family dissatisfaction and anxiety. Families report that as a child approaches transition age and they realize the loss of, not only their health care providers, but the social framework that the school system provided, they lose the solid foundation that took years to build. They are overburdened by the process of enrolling in government assistance and social service plans, guaranteeing insurance, assessing legal capacity and establishing legal authority, identifying new educational and vocational opportunities, addressing matters of sexuality, and contemplating adult living situations. The overall experience is compared to falling off a cliff. Families are wrought with panic and find themselves as overwhelmed as when they first received their child's diagnosis.

It is a tribute to the dedicated families of individuals with ID/D, as well as all of their advocates, that children with special needs are living longer, more productive lives, integrated into their communities. But the efforts cannot be considered a success if these children are brought to the brink of adulthood only to be left unprepared, unsupported, and unlikely to maintain the good health and well-being that has been celebrated along the way. Those that have been their champions throughout childhood clearly see the obligation to build a bridge to adulthood and deliver them safely across.

Got Transition, a collaborative effort between the Maternal and Child Health Bureau and the National Alliance to Advance Adolescent Health, has outlined strategies aimed to improve the transition from pediatric to adult health care and offers on-line tools to support the efforts of interested practitioners. They have also provided a platform for the advocacy needed to reach quality improvement goals. Integrated coordination of care programs, such as Children's Hospital of Philadelphia's New Jersey Transition to Adulthood Comprehensive Care (NJTACC), have been developed explicitly to guide teens and young adults with ID/D through this difficult stage and uphold the ideals inherent to an effective transition process.

NJTACC is a consultation service that sees patients with ID/D between the ages of 14-26 years. Our interdisciplinary team has significant experience providing medical coordination of care for this population and is available to assess medical concerns, review the plans of all involved specialists, and identify relevant screenings or problems that may have been overlooked. At the appropriate time, new providers in the adult system are matched to the family's needs, and patient information is assembled into a complete (but concise) medical record to assure that medical history is accurately conveyed. The physician and nurse practitioner communicate with other members of the individual's care team, as needed, to provide education and support to the new adult providers as they assume care. By initiating a

relationship while under the care of a pediatric team and remaining involved until adult providers are sufficiently confident to provide the expected quality of care, the NJTACC team provides the continuity that has been lacking in otherwise chaotic transitions. Our program manager and family consultant, along with a dedicated representative of the NJ Division of Developmental Disabilities, addresses additional needs of patients and families by identifying eligibility and accessing available governmental, residential and community services.

Information for NJTACC can be found at our website: <https://www.chop.edu/centers-programs/new-jersey-transition-adulthood-comprehensive-care-njtacc>, by calling (215) 590-1295 or by email to: [njtacc@email.chop.edu](mailto:njtacc@email.chop.edu).