

# Successful Transitions for People with Developmental Disabilities

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## Life Transitions Are More Complex for People with Intellectual and Other Developmental Disabilities (I/DD)

Transitioning from one life setting to another is a challenging, complicated event. For most people, moving from adolescence into adulthood, changing residences, or losing a parent are all difficult experiences. These transitions may be more complex for people with intellectual and other developmental disabilities (I/DD)—especially for those with more significant disabilities.

People with I/DD have an intellectual or other developmental disability that manifests before age 22, is expected to continue indefinitely, and leads to substantial functional limitations in at least three of the following areas: self-care, receptive and expressive language, learning, mobility, self-direction, the capacity for independent living, or economic self-sufficiency. North Carolina extends this federal definition of developmental disabilities to include people who have experienced Traumatic Brain Injury (TBI) regardless of the age of injury. People with I/DD require different types of services and supports. In addition to regular medical and dental care, people with I/DD may need housing, home modifications, assistive technology, educational supports, accessible transportation, personal assistance in activities of daily living, vocational services, and/or assistance in developing friendships and relationships.<sup>1</sup> More than 100,000 people in North Carolina have an I/DD.<sup>2</sup>

The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDAS) is the lead agency charged with overseeing services provided to people with I/DD. However, many other public and private organizations also provide services and supports. The complexity of the current delivery system and the fragmentation between agencies makes it difficult for many individuals with I/DD and their families to obtain needed services and supports, particularly during transition periods.

To address these issues, the North Carolina General Assembly directed the North Carolina Institute of Medicine (NCIOM) to convene a task force to study transitions for people with developmental disabilities. The Task Force on Transitions for People with Developmental Disabilities was co-chaired by James Bodfish, PhD, Director, Center for Development and Learning, Carolina Institute for Developmental Disabilities, University of North Carolina at Chapel Hill; Adonis T. Brown, Independent Living Consultant and Disability Peer-Advocate, EnVisioned Independent Living; and Leza Wainwright, Director, North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services, North Carolina Department of Health and Human Services. It had 40 additional Task Force and Steering Committee members. This issue brief summarizes the Task Force's findings and priority recommendations (in italics). A copy of the full report detailing the work of the Task Force and all of the recommendations is available on the NCIOM website at <http://www.nciom.org>.

## Students with I/DD Need Better Services, Programs, and Coordination to Successfully Transition to Postsecondary Education and the Community

Students need a high school degree to be competitive for work or eligible for postsecondary education, yet just under 50% of students with disabilities graduate from high school.<sup>3</sup> In-depth reviews have highlighted the need for both a larger array of services for students with disabilities and more detailed Individual Education Programs (IEPs) to improve educational outcomes for students with I/DD.<sup>a,4</sup>

Students with I/DD who graduate from or age out of secondary school need linkages to postsecondary education and vocational rehabilitation as well as to the Local Management Entities (LMEs) that provide other services and supports. Transition plans, required for all students with an IEP beginning at age 14, are supposed to identify and build

a Individualized Education Programs (IEP) are required by the Individuals with Disabilities Education Act (IDEA) to help ensure students with disabilities receive the individualized attention and supports to succeed in school.

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such linkages. However, data from a 2007 North Carolina Department of Public Instruction survey showed that only 50% of students with intellectual disabilities who left high school had been competitively employed, enrolled in postsecondary school, or both at some point in the past year.<sup>5</sup> These data indicate that North Carolina is not successfully linking students with I/DD to competitive employment or postsecondary education settings. Linking students with I/DD to postsecondary opportunities is difficult because there are very few opportunities specifically targeted for people with I/DD. *Therefore, the Task Force recommended that the North Carolina Community College System (NCCCS) contract for an independent evaluation of NCCCS educational and vocational programs available for people with I/DD, identify best practices, and develop a plan to provide more meaningful education and vocational opportunities for people with I/DD.*

Youth with I/DD in the foster care system may face additional barriers to a successful transition into adulthood. These children often do not have the supports—family, caring adults, mentors—that other youth have to help them through periods of transition. Therefore, it is important to identify children with I/DD in the foster care system early so they can be linked to their local LME. Once connected to an LME, foster youth with I/DD receive services while in foster care and continue to receive appropriate services and supports when they transition out of foster care.

### **When Offered Appropriate Supports and Services, People with I/DD, Families, and Advocates Generally Prefer Smaller Community Settings to Larger Settings**

Approximately 10% of North Carolinians with I/DD live in a state developmental center or private Intermediate Care Facility for Persons with Mental Retardation (ICF-MR)<sup>b</sup> with more than 16 individuals. While this percentage is comparable to the national average, North Carolina could

do more to help individuals with I/DD move to, and live more independently in, the community, when that is what they and their family members desire. Recent efforts to move people from the state developmental centers and large ICFs-MR to smaller integrated living arrangements in the community have met with only limited success. Barriers include the lack of community capacity, communication difficulties between state developmental centers and LMEs, insufficient planning and preparation time for local case managers to arrange for appropriate community services and supports, and payment systems that discourage community providers from accepting people who have more intensive needs.<sup>6</sup> To overcome these barriers, North Carolina needs strong leadership and a comprehensive transition plan that focuses on building community capacity (recommendation regarding a comprehensive transition plan is found in the section on leadership and expertise).

### **Older Adults with I/DD and People with I/DD Living with Aging Caregivers**

Adults with I/DD are living significantly longer than just a few years ago, and many adults with I/DD can now expect to live as long as the general population.<sup>7,8</sup> As individuals with I/DD age, their health care and other needs often increase. In addition, many people with I/DD live with their parents or other family members. As these parents or other caregivers age, their ability to provide services and supports often decreases.<sup>9,10</sup> However, many individuals with I/DD and their families have not engaged in advanced planning to ensure that the needs of the person with I/DD will continue to be met when their caregiver can no longer provide services and supports. Additional efforts are needed to help individuals with I/DD and their families develop appropriate plans to ensure a successful transition when the family member is no longer able to provide services and supports.

### **There Are Some Transitional Challenges That Are the Same Regardless of the Cause of the Underlying Transition**

In addition to the unique challenges that individuals experience during particular types of transitions, some issues are cross-cutting. Ensuring that people with I/DD transition successfully is dependent on strong and knowledgeable leadership at the state and local levels, appropriate and flexible financing, well-trained and supportive case managers, sufficient community capacity, and the availability of well-trained direct supports workers.

<sup>b</sup> Intellectual disability is the preferred term when referring to mental retardation. However, Intermediate Care Facilities for Persons with Mental Retardation is statutory language.

**Leadership and Expertise:** Leadership and expertise at both the state and local level is necessary for successful transitions. State and local leaders need to establish connections between community and family supports and services and public agencies that provide support services to ensure that the developmental disability system is responsive to the needs of people with I/DD. *Therefore, the Task Force recommended that the state develop a statewide transition plan, which identifies needed supports, services, and funding, as well as community services to support successful transitions. The state also needs professional leadership specific to I/DD. Therefore, the Task Force also recommended that the North Carolina General Assembly appropriate funds to hire developmental disability transitions specialists at the state and local levels.*

It will be hard for North Carolina to develop a plan to expand community capacity or to know what services and supports are most needed without adequate data. The state needs a waiting list system to capture information about the unduplicated number of adults and children waiting for services and the types of services needed. The state also needs to ensure that any new electronic health record system, developed as part of the American Recovery and Reinvestment Act funding, includes information about the support needs of people with developmental disabilities, mental health and substance abuse disorders, and those with other medical needs. *To address this issue, the Task Force recommended that DMHDDSAS create a waiting list system to identify the types of services needed and that the needs of people receiving mental health, developmental disabilities, and substance abuse services be incorporated into plans for an electronic health record system.*

**Financing Community-Based Services and Supports:** One of the biggest challenges the state faces is how to use its limited resources in the most equitable way possible to provide services and supports to people with I/DD. This is always an important consideration, but especially so during tight fiscal years. Some states have begun to use assessment instruments to determine the relative intensity of support needs. Data from these assessments can be used to set budget caps or tiered funding levels to match the amount of resources an individual receives to their support needs. Data from the assessments can also be used to establish provider payments that reflect the case-mix of the people they serve and to identify overall system needs. *Therefore, the Task Force recommended that DMHDDSAS adopt a validated assessment instrument to determine intensity of support needs and use this information, along with other relevant information to allocate resources.* In addition, the Task Force identified the need for more flexible funding to assist people in their transitions.

**Case Management:** Case managers play a central role in working with people with I/DD and their families to ensure that the needs of individuals with I/DD are being met. They must be properly trained and qualified to ensure that they are knowledgeable about developmental disabilities, the services and supports available in the community, available state and federal funding, and the legal rights of people with I/DD. While DMHDDSAS has identified certain case management competencies, it has not instituted a minimum training requirement (in terms of hours or standardized curricula), nor has it instituted a statewide competency-based exam. In addition, North Carolina only pays for up to 60 days of targeted case management services for people leaving state developmental centers as opposed to the 180 days allowed by federal law. *The Task Force recommended that DMHDDSAS and the Division of Medical Assistance (DMA) establish clear accountability standards for case managers. DMA should also develop an approval process to authorize payments for up to 180 days of case management transition services for people transitioning out of state developmental centers and large ICFs-MR.*

**“For successful transitions, people with I/DD need a comprehensive, coordinated, and accessible system of supports and services.”**

**Community Capacity:** Individuals with I/DD need access to appropriate services and supports in the community to help during transitions and to maximize independent living. However, many communities lack important services needed to facilitate successful transitions, including access to crisis services, employment opportunities, appropriate and affordable housing, assistive technology, trained health care professionals willing to treat people with I/DD, and other supports and services. The Task Force supported strengthening these community-based services. *In particular, the Task Force recommended that the state strengthen long-term vocational supports to enable more people with I/DD to engage in meaningful employment opportunities.*

**Direct Support Workers:** Aside from an individual’s family, direct support workers (DSWs) provide most of the day-to-day support for people with I/DD. In addition to providing direct services and supports, DSWs often facilitate connections to the community. DSWs are extremely important to the developmental disability system, yet there is no state-approved

training curriculum or certification. Unlike certified nurse aides, who provide services to frail adults, DSWs are not required to take a state established curriculum or pass an approved competency exam. The Task Force determined that the skills and retention rates of DSWs should be improved. *Therefore, the Task Force recommended that the state develop and implement a plan to improve the competencies, skills, and retention of direct support workers.*

## People with I/DD Need Access to a Comprehensive Array of Services and Supports to Help Them During Life Transitions

For successful transitions, people with I/DD need a comprehensive, coordinated, and accessible system of supports

and services. North Carolina can achieve this vision by increasing state and local developmental disability expertise and leadership, strengthening community capacity, and ensuring that case managers and direct support workers have the appropriate competencies to oversee or provide services and supports. By implementing many of the Task Force's recommendations, the state can help people with I/DD successfully transition from one life setting to another and live as independently as possible in the community.

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A copy of the full report, including the complete recommendations, is available on the North Carolina Institute of Medicine's website, <http://www.nciom.org>.



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