Introduction

Chapter 1

For most people, transitions from one period of life to another are challenging, complicated events. Moving from adolescence into adulthood, changing a living situation, or experiencing the death of a family member or caregiver is a difficult experience. However, people with intellectual and other developmental disabilities (I/DD)—especially those with more significant disabilities—may experience more difficulties than others during these transition periods.[a]

In the United States, approximately 1.5% of the population, or more than 4.7 million people, are estimated to have an I/DD.[1] In North Carolina it is estimated that more than 100,000 people have an I/DD.[2] Individuals with I/DD have a mental or physical impairment or a combination of mental and physical impairments that last throughout life and require a variety of long-term services and supports.[b] Which services and supports a person receives depends on his or her unique needs and the availability of natural supports (including family and community supports). In addition to regular medical and dental care, people with I/DD may need safe and affordable housing, home modifications, assistive technology, educational supports, accessible transportation, personal assistance in activities of daily living, vocational services, and assistance in developing friendships and relationships.[3]

In the United States, approximately 1.5% of the population, or more than 4.7 million people, are estimated to have an intellectual and/or other developmental disability (I/DD). In North Carolina, it is estimated that more than 100,000 people have an I/DD.

Services for individuals with I/DD in North Carolina are overseen by the North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS), Local Management Entities (LMEs), the Division of Medical Assistance (DMA), and the Division of Health Services Regulation (DHSR), depending on the type of service. Medicaid and non-Medicaid state funds are the largest sources of funding for non-educational services for people with I/DD. In addition, children and adolescents with I/DD receive public school-based services and supports, and people with I/DD may receive employment supports or help with independent living through the Division of Vocational Rehabilitation. People with I/DD often receive services and supports from different agencies and providers, leading to fragmentation of services. Coordination is critical to ensuring that the agencies, and the services provided, can better assist people with I/DD transition from one life setting to another.

As stated above, people with I/DD need coordinated services and supports from multiple organizations and agencies to help them through life transitions.

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[a] Throughout the report, we use the term people with I/DD to refer to people with intellectual and other developmental disabilities. Intellectual disability is the preferred term among people with I/DD, rather than mental retardation.

[b] The federal definition of an intellectual and other developmental disabilities (I/DD) is a severe, chronic disability which is attributable to a mental or physical impairment or a combination of mental and physical impairments; manifests before the age of 22; is likely to continue indefinitely; and reflects a person's need for a combination of special interdisciplinary or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated. The North Carolina definition of developmental disabilities is similar but includes people with traumatic brain injuries, regardless of the age at which the injury occurred. This definition is discussed more fully in Chapter 2.

Adolescents with I/DD who complete or age out of secondary school need connections to postsecondary schools, vocational rehabilitation, supported employment, day programming, or LMEs to ensure that they become active participants in the community. People with I/DD leaving state developmental centers or large private congregate residential settings to live in community-based settings need access to an array of services and supports appropriate to the intensity of their needs and their unique life goals. They need linkages to housing, medical, dental, habilitative, psychological, technological, and other services and supports to aid in the transition to community living. Aging adults with I/DD and those living with aging parents or other support providers need to be linked into a variety of different services and supports, including housing and medical care, so that they are able to receive needed services as their health or the health of their caregiver changes.

People with intellectual and other developmental disabilities need coordinated services and supports from multiple organizations and agencies to help them through life transitions.

Task Force on Transitions for People with Developmental Disabilities

The North Carolina General Assembly asked the North Carolina Institute of Medicine (NCIOM) to convene a task force to study transitions for persons with developmental disabilities from one life setting to another, including barriers to transition and best practices in successful transitions.[c] The Task Force 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, Division of Mental Health, Developmental Disabilities and Substance Abuse Services, North Carolina Department of Health and Humans Services. It included 40 additional Task Force and Steering Committee members.

In examining transitions for people with I/DD, the NCIOM was instructed to examine three topics:

1. The transition for adolescents leaving high school, including adolescents in foster care and those in other settings.
2. The transition from the developmental centers to other settings.
3. The transition for persons who live with aging parents.[c]

The authorizing legislation directed the NCIOM to seek the advice and consultation of state and national experts in developmental disabilities. The NCIOM was required to report back its findings and recommendations to the North Carolina General Assembly no later than March 1, 2009. The Task Force met a total of six times between October 2008 and March 2009. A complete list of topics and meeting agendas is included in Appendix A.

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[c] Section 10.15(s) of Session Law 2008-107

Report Structure

The report of the NCIOM's Task Force on Transitions for People with Developmental Disabilities includes seven chapters, beginning with this brief introduction. Chapter 2 provides an overview of I/DD. Chapter 2 also provides an overview of the developmental disability system, including services and supports offered through different agencies and the financing structure. Chapter 3 examines the transition for adolescents leaving high school and foster care. Schools play an important role in helping youth acquire the skills and knowledge needed to transition to secondary education, work, and community life. Chapter 4 addresses the transition for individuals moving from state developmental centers and large Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR) into community settings.[d] Nationwide, and in North Carolina, there has been a trend towards reducing the number of people with I/DD residing in large (more than 16 residents) state developmental centers and private ICFs-MR. Now, people with I/DD are much more likely to live in individual or small group settings (with six or fewer residents). The systems serving people with I/DD have had to change rapidly to accommodate the dramatic shift towards serving even those with the most significant disabilities in the community. Chapter 5 looks at transitions for aging adults with I/DD and those living with aging parents, family members, or other support providers. Individuals with I/DD who live with these aging caregivers need a variety of supports to help ensure a smooth transition when their parent or support provider is no longer able to offer services or support. Chapter 6 explores cross-cutting issues that are important for all three of the transitions identified by the North Carolina General Assembly. Chapter 7 includes a brief conclusion and a summary of the Task Force recommendations.

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[d] Intellectual disability is the preferred term when referring to mental retardation. However, Intermediate Care Facilities for Persons with Mental Retardation is statutory language.

References

1 Braddock D, Hemp R, Rizzolo MC. *The State of the States in Developmental Disabilities, 2008*. Seventh ed. Washington, DC: American Association on Intellectual and Developmental Disabilities; 2008.

2 Thompson S. Data for assessing the developmental disability services and supports system of North Carolina. Presented to: the North Carolina Institute of Medicine Task Force on Transitions for People with Developmental Disabilities; October 1, 2008; Morrisville, NC.

3 Shattuck PT, Parish SL. Financial burden in families of children with special health care needs: variability among states. *Pediatrics.* 2008;122(1):13-18.