



**People with intellectual and other developmental disabilities—especially those with more significant disabilities—may experience greater difficulties than others during life transition periods.**

**F**or 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 parent or caregiver is a difficult experience. However, people with intellectual and other developmental disabilities (I/DD)—especially those with more significant disabilities—may experience greater difficulties than others during these transition periods. An I/DD is a life-long condition and requires ongoing services. The services and supports that individuals with I/DD need can vary considerably, depending on the person, his or her unique needs, and the availability of natural supports (including family and/or community supports). The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) is the lead agency charged with overseeing services and supports provided to people with I/DD. However, many of the services and supports provided to people with I/DD are outside of the DMHDDSAS system. The complexity of the current developmental disability delivery system makes it difficult for many individuals with I/DD and their families to identify and obtain all needed services and supports. People with I/DD need coordinated services and supports from multiple organizations and agencies to help them through life transitions. Relative to others, people with I/DD may have fewer relationships to turn to for support during important life transitions.

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.<sup>a</sup> 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, Division of Mental Health, Developmental Disabilities and Substance Abuse Services, North Carolina Department of Health and Human Services. It included 40 additional Task Force and Steering Committee members, including legislators, DMHDDSAS staff, parents of individuals with I/DD, advocates, providers of services and supports to people with I/DD, representatives of local management entities, and other interested individuals. The Task Force met a total of six times between October 2008 and March 2009 to develop this final report for the North Carolina General Assembly.

The following chart lists the Task Force's recommendations in abbreviated form along with the agency or organizations charged with addressing the recommendation. While all 26 of the recommendations are important, the Task Force selected eight as priority recommendations. A full listing of the recommendations is included in the appropriate chapter as well as in Appendix B.

<sup>a</sup> Section 10.15(s) of Session Law 2008-107

	NCGA	DMHDDSAS	LME	Providers	Other public agencies	Others
<b>Secondary Transition</b>						
<p><b>Recommendation 3.1:</b> The State Board of Education (SBE) should examine existing school policies to improve the educational outcomes for children with intellectual and other developmental disabilities.</p>					✓ SBE	
<p><b>Recommendation 3.2:</b> The Department of Public Instruction (DPI) should add additional questions to the school outcome data collection survey for students with disabilities, to assess what students are doing after leaving schools and what skills could help them meaningfully engage in their communities. DPI should report the results to the Joint Legislative Oversight Committee for Mental Health, Developmental Disabilities, and Substance Abuse Services and the Joint Legislative Education Oversight Committee no later than February 2010.</p>	✓ LOC				✓ DPI	✓ IDD
<p><b>Recommendation 3.3:</b> The North Carolina General Assembly should appropriate \$6 million in recurring funds to the Department of Public Instruction to provide community-based instruction to students with intellectual and other developmental disabilities to help meet the life skills components of students' Individualized Education Program transition plans.</p>	✓ \$6m (R)				✓ DPI	
<p><b>Recommendation 3.4:</b> The North Carolina General Assembly should promote interagency coordination before a child transitions out of secondary schools and should help students and parents plan for transition.</p>	✓	✓	✓	✓	✓ DPI DVR NCCCS	✓ IDD Families
<p><b>Recommendation 3.5:</b> The Department of Public Instruction (DPI) should contract with an independent organization that has expertise on assistive technology (AT) to conduct a study to determine whether the AT needs of students are being met. The North Carolina General Assembly should appropriate \$60,000 in non-recurring funds to DPI for this study. DPI should report its findings and plans to the Joint Legislative Oversight Committee for Mental Health, Developmental Disabilities, and Substance Abuse Services and the Joint Legislative Education Oversight Committee no later than October 2010.</p>	✓ \$60k (NR) LOE				✓ DPI	✓ IDD Teachers School admin.

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<p><b>Recommendation 3.6: (PRIORITY RECOMMENDATION)</b>                      The North Carolina Community College System (NCCCS) should contract for an independent evaluation of educational and vocational programs available to people with intellectual and other developmental disabilities (I/DD) and identify best practices for providing meaningful postsecondary educational opportunities to people with I/DD in an integrated community setting. NCCCS should use the information from this study to develop a plan to provide more meaningful educational and vocational opportunities to people with I/DD. NCCCS should report its findings and plans to the Joint Legislative Oversight Committee on Mental Health, Developmental Disabilities, and Substance Abuse Services and the Joint Legislative Oversight Committee on Education no later than October 2010.</p>	✓ LOC LOE				✓ NCCCS	
<p><b>Recommendation 3.7:</b>                      The University of North Carolina System should expand inclusive postsecondary education programs for people with intellectual and other developmental disabilities. The North Carolina General Assembly should appropriate \$400,000 in SFY 2010 and SFY 2011 to the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) to expand Beyond Academics from a two-year to a four-year curriculum and \$60,000 in both years of the biennium to The University of North Carolina at Greensboro to complete the evaluation of Beyond Academics. DMHDDSAS and the Division of Medical Assistance should allocate eight Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities slots to students enrolled in Beyond Academics in both years of the biennium.</p>	✓ \$400k (R) \$60k (NR) (SFY2010 & SFY 2011)	✓			✓ UNC System Beyond Academics	
<p><b>Recommendation 3.8:</b>                      The University of North Carolina System and North Carolina Community College System should work together to expand the availability of postsecondary educational opportunities for students with intellectual and other developmental disabilities (I/DD), and should work with the Division of Mental Health, Developmental Disabilities and Substance Abuse Services and the Division of Medical Assistance to explore funding opportunities to support students with I/DD in postsecondary education.</p>		✓			✓ UNC System NCCCS DMA	

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<p><b>Recommendation 3.9:</b> The Division of Social Services should work with the Division of Mental Health, Developmental Disabilities and Substance Abuse Services to identify an assessment process to ensure children in foster care receive an appropriate assessment to determine if they have any intellectual and/or other developmental disabilities (I/DD) or mental health problems. Children who have been determined to have mental health problems or I/DD should be linked into the Local Management Entity system.</p>		✓	✓		✓ DSS	
<b>Transition to Integrated Community Settings</b>						
<p><b>Recommendation 4.1:</b> Each developmental center or private Intermediate Care Facility for Persons with Mental Retardation (ICF-MR) should have an admissions review committee that includes representatives of multiple Local Management Entities, the state or regional transitional coordinator, family members, and others as deemed appropriate to review any general admission placement before entry into the state developmental center or private ICF-MR. The committee should review the admission prior to placement to determine if the individual with intellectual and other developmental disabilities (I/DD) could be appropriately served in a community-integrated setting. The North Carolina General Assembly should provide the Division of Mental Health, Developmental Disabilities and Substance Abuse Services with the authority to use existing state funds in a more flexible fashion to support transitions and to avoid placements in state developmental centers or private ICFs-MR. Further, the state should implement policies to help community providers provide the necessary supports and services to successfully maintain the individual in the community and to prevent them from moving individuals with more significant I/DD or behavioral needs into state developmental centers or private ICFs-MR.</p>	✓	✓	✓	✓ DC ICF-MR	✓ Others	✓ Family rep.
<b>Transition from Aging Parents/Caregivers</b>						
<p><b>Recommendation 5.1:</b> Local Management Entities (LMEs) and the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should help families plan for the future so that the family's and individual's with intellectual and other developmental disabilities (I/DD) wishes are understood before a crisis occurs.</p>		✓	✓			✓ I/DD Families

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DMHDDSAS and LMEs should develop longer-term emergency housing and support options for people with I/DD who need emergency services because of the death or precipitous illness of a caregiver.						
<b>Recommendation 5.2:</b> Local Management Entities should work with appropriate community organizations to conduct outreach to identify families of individuals with intellectual and other developmental disabilities (I/DD) who are not currently connected to the I/DD system and ensure that older adults with I/DD have appropriate access to the range of services and supports offered by those organizations.			✓		✓ AAA	✓ Faith Home health Other
<b>Cross-Cutting Issues</b>						
<b>Recommendation 6.1: (PRIORITY RECOMMENDATION)</b> The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should work with Local Management Entities, the Division of Medical Assistance, Division of Vocational Rehabilitation, Department of Public Instruction, North Carolina Community College System, University of North Carolina System, individuals with intellectual and other developmental disabilities and their families, advocates, academics, community and institutional providers, and others to develop a statewide transition plan. The plan should identify the community services and supports and funding needed to support successful transitions. DMHDDSAS should report on progress to the Joint Legislative Oversight Committee on Mental Health, Developmental Disabilities, and Substance Abuse Services no later than October 2010.	✓ LOC	✓	✓	✓ DC ICFs-MR Others	✓ DMA DPI DVR NCCCS, UNC	✓ IDD Families Advocates Academics
<b>Recommendation 6.2: (PRIORITY RECOMMENDATION)</b> The North Carolina General Assembly should appropriate \$222,000 in recurring funds to the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) to hire three developmental disability transitions specialists and \$2,660,000 on a recurring basis to DMHDDSAS to distribute to Local Management Entities (LMEs) on a per capita basis to support developmental disability transition expertise at the local LMEs. Transition staff will have responsibility to develop systems change at the state and local levels to support successful transitions for people with intellectual and other developmental disabilities.	✓ \$2.8m (R)	✓	✓	✓ DC ICFS-MR Local Others	✓ DVR DPI NCCCS Others	✓ Families Others

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<p><b>Recommendation 6.3: (PRIORITY RECOMMENDATION)</b>                      The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should work with the Governor’s office to ensure that the needs of people with mental health, developmental disabilities, and substance abuse are incorporated into any plans for an electronic health records system developed in response to the American Recovery and Reinvestment Act. In addition, DMHDDSAS should create an active, computerized waiting list system to capture information on the numbers of adults and children who are waiting for services and the types of services needed. DMHDDSAS and Local Management Entities (LMEs) should identify other data needed for systems planning and use these data in statewide planning, needs projections, and quality improvement activities. The North Carolina General Assembly (NCGA) should appropriate \$72,765 in recurring funds to DMHDDSAS to support one new position to manage and analyze data and assist with waiting list coordination and management. NCGA should appropriate \$320,000 in non-recurring funds in SFY 2010, \$298,734 in recurring funds in SFY 2011 and \$3.1 million in non-recurring funds in SFY 2011, and \$2 million in recurring funds thereafter to DMHDDSAS to develop an electronic health record system.</p>	✓ \$320k (NR) \$73k (R) (SFY2010)  \$3.1m (NR) \$373k (R) (SFY2011)  \$2m (R) (SFY2012)  LOC	✓	✓	✓ DC ICFs-MR Others	✓ Gov.’s Office	
<p><b>Recommendation 6.4: (PRIORITY RECOMMENDATION)</b>                      The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should adopt a validated and reliable assessment instrument to determine relative intensity of support needs for individuals with intellectual and other developmental disabilities. The assessment should be used to assist in the development of the Person Centered Plan, for statewide and local planning purposes, and in determining an individual resource allocation. DMHDDSAS should develop a formula for a fair, equitable, and consistently applied allocation of resources that can be applied statewide. The North Carolina General Assembly should appropriate \$463,924 to DMHDDSAS to continue to test the Supports Intensity Scale™ (SIS) for these purposes.</p>	✓ \$464k (NR)	✓				
<p><b>Recommendation 6.5:</b>                      The Task Force supports the implementation of a consumer-directed budgeting option through the approved North Carolina Supports Waiver beginning in November 2009. The Division of Mental Health, Developmental Disabilities and Substance Abuse Services</p>		✓				✓ IDD Families

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should systematically move to expand consumer-directed budgeting to other people with intellectual and other developmental disabilities who have more significant needs.						
<b>Recommendation 6.6:</b> The Division of Mental Health, Developmental Disabilities and Substance Abuse Services should work with Local Management Entities to examine the need for flexible funding to support transitions.	✓	✓	✓			
<b>Recommendation 6.7: (PRIORITY RECOMMENDATION)</b> The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS), in collaboration with the Division of Medical Assistance (DMA) and other stakeholders, should establish clear accountability standards for case managers. The standards should be designed to improve outcomes for people served with intellectual and other developmental disabilities and should help to improve retention of qualified case management staff. DMHDDSAS should report its findings and recommendations to the Joint Legislative Oversight Committee on Mental Health, Developmental Disabilities, and Substance Abuse Services no later than October 2010. In addition, DMA should develop an approval process to authorize payments for up to 180 days of case management transition services to help develop and implement transition plans for people who are moving out of state developmental centers or private Intermediate Care Facilities for Persons with Mental Retardation.	✓ LOC	✓		✓ Case mgt. providers	✓ DMA	
<b>Recommendation 6.8:</b> The North Carolina General Assembly should appropriate \$9.4 million in recurring funds to the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) to fully fund existing and to double the availability of regional crisis interdisciplinary teams and crisis/respite beds for adults with intellectual and other developmental disabilities available as part of the Systemic, Therapeutic, Assessment, Respite and Treatment (START) model. In addition, DMHDDSAS should contract to do a gap analysis to determine the need for crisis services for children. DMHDDSAS should present the findings, recommendations, and any costs to the Joint Legislative Oversight Committee on Mental Health, Developmental Disabilities, and Substance Abuse Services no later than April 2010.	✓ \$9.4m (R) LOC	✓			✓ START	

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<p><b>Recommendation 6.9:</b>                      The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should work with the Department of Health and Human Services housing specialist, housing specialists in Local Management Entities, staff from the North Carolina Housing Finance Agency, and other appropriate groups to examine the availability and adequacy of permanent supportive housing, housing subsidies, and support services, and the barriers which prevent the development of additional housing options. The North Carolina General Assembly should appropriate \$73,765 in recurring funds in SFY 2010 and SFY 2011 to DMHDDSAS to support one position dedicated to housing. DMHDDSAS will report its findings and any recommendations to the Joint Legislative Oversight Committee on Mental Health, Developmental Disabilities, and Substance Abuse Services no later than January 2010.</p>	✓ \$74k (R) (SFY2010) \$74k (R) (SFY2011) LOC	✓	✓		✓ DHHS HTFA	
<p><b>Recommendation 6.10:</b>                      The Division of Mental Health, Developmental Disabilities and Substance Abuse Services should work with the Division of Health Service Regulation, Local Management Entities, parent advocacy groups, residential providers, and other appropriate individuals to develop a plan to promote shared living arrangements that promote greater self-direction and more inclusive housing.</p>		✓	✓	✓ Others	✓ DHSR	✓ Families Others
<p><b>Recommendation 6.11:</b>                      The Division of Mental Health, Developmental Disabilities and Substance Abuse Services, working with other agencies and providers, should identify or develop an assessment process for use in assistive living. The assessment should be conducted by independent assessors to identify people with intellectual and other developmental disabilities and to determine whether placement in an assistive living facility is the best option possible to meet the unique needs of the individual and not based solely on the person’s developmental disability.</p>	✓	✓	✓	✓ NF ALF	✓ DHHS DHSR DMA	
<p><b>Recommendation 6.12:</b>                      The North Carolina General Assembly should amend NCGS §108A-47.1 to allow State/County Special Assistance In-Home funds to be used to pay the same maximum payment rates as would be provided in licensed facilities to support otherwise eligible individuals in their own homes, alternative family living, or host families.</p>	✓					

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<p><b>Recommendation 6.13: (PRIORITY RECOMMENDATION)</b>                      The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should work with the Division of Vocational Rehabilitation and Local Management Entities (LMEs) to expand employment opportunities to more people with intellectual and other developmental disabilities. DMHDDSAS and LMEs should ensure that the funding available to support long-term vocational supports is available and used on a consistent basis throughout the state.</p>		✓	✓		✓ DVR	
<p><b>Recommendation 6.14:</b>                      The Area Health Education Centers (AHEC) program, health professional schools, and Division of Mental Health, Developmental Disabilities and Substance Abuse Services should work collaboratively with health professional associations, self-advocacy groups, parents, or parent advocacy groups to enhance the training provided to health professionals about providing coordinated health services for people with intellectual and other developmental disabilities (I/DD). AHEC should expand clinical and residency rotations in settings that routinely provide services to people with I/DD and should help continue and expand mini-fellowships in developmental medicine. The North Carolina General Assembly should appropriate \$150,000 on a recurring basis to AHEC to support these activities.</p>	✓ \$150k (R)	✓		✓ MD DDS Nurses Allied Health Others	✓ AHEC Health profession schools	✓ IDD Families Advocates Others
<p><b>Recommendation 6.15:</b>                      The Division of Medical Assistance (DMA) should examine existing utilization data and other data sources to determine whether Medicaid recipients with intellectual and other developmental disabilities (I/DD) can access medical, dental, therapy, psychological, or other behavioral services. If DMA determines that Medicaid recipients with I/DD, or a subset of these individuals, have unique or special barriers accessing medical, dental, therapy, psychological, or other behavioral services, then DMA should work with the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) and other provider groups to identify the barriers and options to improve access to care. In addition, North Carolina Community Care Inc. should work with DMA and DMHDDSAS to explore the possibility of creating a care management model designed to meet the special needs of people with I/DD.</p>		✓			✓ DMA CCNC	

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<p><b>Recommendation 6.16: (PRIORITY RECOMMENDATION)</b>                      The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should work with Local Management Entities, agencies that employ direct support personnel, the North Carolina Direct Care Workers Association, and other appropriate organizations to develop and implement a plan to improve the competencies and skills of direct support workers (DSWs). The plan should also include strategies to improve retention of DSWs. DMHDDSAS should report its findings and recommendations, including associated costs to implement the recommendations, to the Joint Legislative Oversight Committee on Mental Health, Developmental Disabilities, and Substance Abuse Services no later than October 2010.</p>	✓ LOC	✓	✓	✓ Others	✓ DCWA	✓

Note: The abbreviations included in the chart include: AAA (Area Agencies on Aging), AHEC (Area Health Education Centers) program, ALF (assisted living facility), CCNC (Community Care of North Carolina), DC (state developmental center), DCWA (North Carolina Direct Care Workers Association), DDS (Dentists), DHHS (Department of Health and Human Services), DHSR (Division of Health Service Regulation), DMA (Division of Medical Assistance), DPI (Department of Public Instruction), DSS (Division of Social Services), DSW (Direct Service Worker), DVR (Division of Vocational Rehabilitation), HTFA (Housing Trust Fund Agency), ICF-MR (private intermediate care facility for people with mental illness or other developmental disability), IDD (individual with intellectual and other developmental disability), LOC (Legislative Oversight Commission for Mental Health, Developmental Disabilities, and Substance Abuse Services), LOE (Legislative Oversight Commission on Education), MD (physicians), NCCCS (North Carolina Community College System), NF (nursing facility), SBE (State Board of Education), START (Systemic, Therapeutic, Assessment, Respite and Treatment)